

The background of the cover is a photograph of a tropical landscape at dusk. In the foreground, there is a lush green lawn with several tall palm trees. The sky is a mix of deep blue and orange, with scattered clouds. In the distance, there is a body of water and a range of mountains. The title 'Aging & Disability Issues 2023' is centered over a white horizontal band. The ampersand is a large, stylized orange symbol. The subtitle 'A Guide for Hawai'i's Legislators, Organizations & Citizens' is in a smaller, blue font below the title.

Aging & Disability Issues 2023

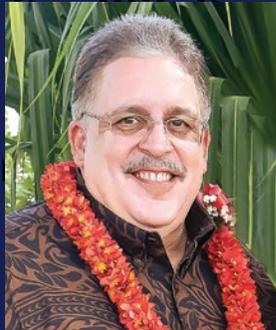
A Guide for Hawai'i's Legislators, Organizations & Citizens



Cover photo: Kualoa Regional Park, O'ahu

A Life Well Lived.

In Memory of...



Jerry Joseph Correa, Jr.

1964 – 2022

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Aging & Disability Issues 2023

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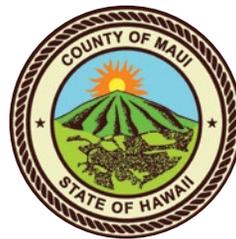
About the Hawai'i Family Caregiver Coalition,
the Maui County Office On Aging,
& the Hawai'i Pacific Gerontological Society



As caregiving touches everyone, the mission of the Hawai'i Family Caregiver Coalition (HFCC) is to improve the quality-of-life of those who give and receive care by increasing community awareness of caregiver issues through continuing advocacy, education, and training.

Over the years, the Hawai'i Family Caregiver Coalition has supported our community by sponsoring the annual Aging & Disability Issues report, Family Caregiver Awareness Day at the State Capitol, and the annual HFCC Members and Friends Luncheon.

For more information, please email Kathy Wyatt, President, at kwyatt01@aol.com or visit hfccoalition.org.



The Maui County Office on Aging (MCOA) takes the lead role in aging issues on behalf of older persons in Maui County. As the designated lead agency at the local level, MCOA promotes and protects the well-being of elderly individuals in Maui County.

For more information about MCOA or to request assistance, please call 808-270-7774. MCOA's mailing address is: Maui County Office on Aging, J. Walter Cameron Center, 95 Mahalani Street, Room 20, Wailuku, Hawai'i 96793.



hawaii pacific gerontological society

Organized in 1979, the Hawai'i Pacific Gerontological Society (HPGS) is a not-for-profit organization whose mission is "to increase awareness of and interest in the field of gerontology by providing networking and educational opportunities, as well as scholarships to Hawai'i's workforce or other interested parties to support the creation of needed policies and programs that will enhance the quality and age-friendly services to our kūpuna in Hawai'i."

If you are interested in pursuing this mission, you are invited to join HPGS by visiting at www.hpgs.org. You may also mail inquiries to P.O. Box 3714; Honolulu, Hawai'i 96812, or call Sherry Goya, HPGS Executive Director, at (808) 722-8487.

Introduction & Overview

By **Kathy Wyatt**, RN, MSN, MBA, LNHA, President, Hawai'i Family Caregiver Coalition; Member, Policy Advisory Board for Elder Affairs

This 2023 issue of the Aging & Disabilities Issues report is the 18th annual publication that offers an overview of legislative issues dealing with aging, disability, caregiving, and long-term care services and supports in Hawai'i. This report calls attention to the priority issues that deserve the 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), and the Maui County Office on Aging (MCOA). Their support is gratefully acknowledged.

This report has seven 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 2023.

Sections 2 through 5 describe the priority issues for the Legislature in the 2023 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. Also discussed are the specific bills that address the priority areas and their status at the time of writing this report.

Section 6, the Conclusion, provides a brief summary and a look ahead.

Section 7 contains a listing of information, education, and research resources relevant to aging and disability issues that may be helpful to those seeking additional information and education.

Additionally, personal stories from caregivers regarding the issues they face and the significance of public policies in en-

abling them to care for their loved ones can be found throughout the report. These stories demonstrate the emotional strains and rewards experienced by our struggling caregivers and describe the difficulties any of us could experience when faced with aging or disability. These stories provide a human face to legislative issues by illustrating how they are embodied in the very human experiences of individuals and families.

The Political Context of 2023

We have seen a slow and steady reawakening of our state from the COVID-19 pandemic over the past 12 months. Again, time passed both quickly and slowly. People returned to work, although some still worked from home. There has been a combination of virtual and in-person meetings. Care facilities opened their doors to visitors as the cases of COVID-19 diminished so loved ones could be visited by their families once again. There are still many cases of COVID-19 running through Hawai'i, and although the mask-wearing restrictions have all but disappeared in public, many choose to wear them, as well as keep a social distance in public places. Many of us have had COVID-19 more than once with varying levels of illness, even when vaccinated and boosted. Our beaches are wide open and visitors arrive in the thousands. Supplies continue to be an issue due to supply chain limitations, factories producing at slower rates, prices sky-rocketing, and bidding wars on food stuffs, building materials, and other essential items. But as witnessed during the height of the pandemic, the citizens of Hawai'i have continued their generosity to those experiencing hardship. Free vaccines are offered by several entities. Free test kits are distributed to any who need or want them.

According to a web article from A Place for Mom (aplaceformom.com, December 2, 2022), the number of unpaid family caregivers in the U.S. swelled from 43.5 million to over 53 million between 2015 and 2020, an increase of 9.5 million. AARP's 2019 Valuing the Invaluable report notes that caregivers provided approximately 34 billion hours of care valued at \$470 billion – more than total out-of-pocket spending on healthcare in the U.S. that year (\$366 bil-
(Continued on next page.)

lion), or all money spend on paid caregiving in 2016 (also \$366 billion). The report also notes that family caregivers spent an average of nearly \$7,000 on caregiving expenses, such as transportation and home modifications in 2016. Research has shown that family caregivers report higher rates of loneliness than their non-caregiving peers in mid-life and beyond.

Family caregiver support is firmly established as a national priority with the passing of the RAISE (Recognize, Assist, Include, Support, and Engage) Act. As required by this Act, the National Strategy to Support Family Caregivers was presented to the U.S. Congress in September 2022. The strategy illustrates actions — by federal and state governments, communities, employers, and others — to increase recognition and support for family caregivers. The National Academy for State Health Policy presented the National Strategy with the RAISE Act State Policy Roadmap for Family Caregivers. This roadmap starts with a public awareness and outreach program, much like the public awareness campaign introduced by the Alzheimer’s Association in **SB 163/HB 278**. Through the campaign, caregivers will know where to turn for information, for example. The Roadmap will assist the nation in strengthening its support and recognition of the critical role family caregivers play in our healthcare and long-term support systems. It also addresses the direct care workforce, which is a hot topic in our state and the nation. It directs actions to improve and streamline training and working conditions, develop career pathways, and much more.

Also on the federal front, the Older Americans Act (enacted in 1965) has been reauthorized and amended numerous times. In the 116th Congress, both the House and the Senate passed legislation to reauthorize the OAA for a five-year period. In 2020, President Trump signed the Supporting Older Americans Act of 2020, which authorizes appropriations through FY2024. This vital federal program serves every community in the country. It connects older adults and their caregivers to services that help them age with health, dignity, and independence in their homes and communities. The OAA funds critical services that keep older

adults healthy and independent – services like meals, job training, senior centers, caregiver support, transportation, health promotion, benefits enrollment, and more.

The 4th quarter 2022 Statistical and Economic Report by the Hawai‘i Department of Business, Economic Development, and Tourism (DBEDT) predicts that while Hawai‘i’s economic growth rate, as measured by the percentage change in real gross domestic product (GDP), will increase by 2.6 percent in 2022 over the previous year, economic growth is expected to slow to 1.7 percent due to the expected global economic downturn. In 2024 and 2025, Hawai‘i’s economic growth is expected to return to normal growth levels at about 2%.

According to the most recent economic projections (November 2022) by the top 50 economic forecasting organizations published in Blue Chip Economic Indicators, U.S. economic growth is expected to be at 1.8% in 2022 and only 0.2% in 2023. Though the U.S. economy is likely to enter into a recession in the early part of 2023, the impact on Hawai‘i is likely to be small due to the following reasons:

- Tourism recovery remains strong.
- Labor market conditions continue to improve.
- State tax collections continue to rise.
- Construction activity and home sales are declining.

The economic turmoil caused by the COVID-19 pandemic energized initiatives to diversify the state’s economy. Priorities included investments in agriculture and information technology. However, investments in critical services for our rapidly aging population and those with disabilities are also priorities. The efforts of the Legislature’s Kupuna Caucus are and will be vital. The Kupuna Caucus is convened by Senator Sharon Moriwaki and co-convened by Representative Troy Hashimoto. Their leadership will be instrumental in our efforts. Now more than ever, aging and disability advocates must be steadfast in ensuring that elected officials at all levels of government are committed to our elders and those with disabilities.



Keeping Kūpuna Healthy

THREE SERVICES KEEP THE ELDERLY HEALTHY & ACTIVE

By Sarah Yuan, PhD

Legislative Committee Member,
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About seven baby boomers are turning 65 every minute in the U.S. Our local population is aging rapidly and living longer than any other state. By 2030, when all baby boomers are 65 or older, Hawai‘i’s older adult population is projected to increase to 23%, or nearly 369,000. As our state’s demographic makeup changes, so are how we care for our kūpuna. A wide range of services has been developed to keep older people healthy, active, and safe, and support them to live in their own homes and community regardless of their ability level. Many of these service programs were initiated by federal and state agencies, while others evolved through local private and public partnerships. Much of the funding for these programs comes from federal and state governments, although in Hawai‘i, county governments also provide funding.

- Kupuna Care/Kupuna Caregivers
- Aging and Disability Resource Centers

Kupuna Care Program & Kupuna Caregivers

Hawai‘i’s Kupuna Care (KC) program was established in 1999 to provide long-term services and supports (LTSS) to adults age 60 and over with disabilities such as cognitive impairment or lack of access to comparable services. The program aims to enable older adults to remain in their homes and communities, delaying premature placement to expensive residential care facilities. In 2017, a new Kupuna Caregivers (KCG) program was established to focus on supporting working caregivers. The KCG helps make LTSS for kūpuna more affordable and provides the help caregivers so desperately need. It en-



ables caregivers to continue earning their retirement benefits, helps businesses retain experienced workers, and provides peace of mind to the caregiver that their loved one is being cared for while they work. In 2022, KCG was incorporated into the KC program to improve administrative efficiency.

KC/KCG is administered by the state’s Executive Office on Aging (EOA) through the Area Agency on Aging (AAA) in each county, with program services provided by non-profit and for-profit organizations. The program offers nine core services: adult day care, assisted transportation, attendant care, case management, chores, home-delivered meals, homemaker, personal care, and transportation.

In FY22, as the state began to lift COVID-19 restrictions, more older adults were able to participate in adult day care (+46%), assisted transportation (+58%), and transportation (+8%) services. There were increases in the number of service units for chores (+30%) and homemaker (+3%), although the number of participants was similar to last year. The utilization of other KC services, such as personal care, home-delivered meals, and case

management, continued to drop. This was likely due to the availability of family caregivers because of unemployment or under-employment, similar services available from other funding sources (e.g., federal stimulus and CARES Act funding), and the hampered capacity of the service delivery system. EOA served more than 7,800 older adults through KC and the federally-funded LTSS in FY22.

In FY23, Kupuna Care received \$9.5 million in EOA’s base budget, which included a \$2.65 million non-recurring fund. In the 2023 legislative session, **HB 1486 HD 1** proposed to appropriate \$1.88 million to Kupuna Care in FY24, which will restore the funding to the pre-pandemic level.

Aging and Disability Resource Centers (ADRC)

Older adults and people with disabilities and their families are often unprepared when the sudden onset of a severe health condition or sudden decline in function occurs. Once faced with the need for long-term services and supports (LTSS), families find navigating care systems challeng-

(Continued on next page.)

ing. Aging and Disability Resource Centers (ADRCs) are designed to simplify the process of obtaining information and accessing services. ADRCs also reduce the fragmentation of care systems, recognizing that the care needs of older adults and people with disabilities are often similar. Through a single coordinated system, a county's ADRC can ensure access to high-quality care and person-centered services, optimize choice and independence, encourage personal responsibility, and provide support so individuals and their families can make informed decisions about LTSS.

Hawai'i's ADRCs are administered by the state's Executive Office on Aging (EOA) and implemented by the counties' Area Agencies on Aging (AAAs). It started in 2006 when the EOA received a federal grant to pilot the system and was subsequently supported by funding from several federal grants and Hawai'i's State Legislature. Since 2016, the ADRC system has been fully implemented statewide, with customized operation by each AAA while adhering to a standard set of functional criteria across counties. The system offers a full range of information on long-term support programs and benefits; conducts the assessment of individuals' needs for services to maintain independent living in the community; and is a single entry point for Kupuna Care and Older Americans Act (OAA) services.

In FY22, the ADRCs received approximately 26,000 contacts through phone calls, emails, and walk-ins. It was less than 60% of the past annual figures mainly because other temporary community resources became available to help address food security and COVID concerns during the pandemic. However, the demand for LTSS assessments increased by almost 60% in FY22. The ADRCs conducted nearly 4,500 assessments and authorized services for individuals who needed community-based long-term care. This upward trend is expected to continue as the state's aging population grows. If the governor's biennium budget (**HB 300** and **SB 354**) is approved by the Legislature, it will provide \$3.1 million for ADRCs in FY24.



Pearl City Community Church, November 2022

Healthy Aging Partnership Program

By Michiyo Tomioka, PhD

The Hawai'i Healthy Aging Partnership (HHAP) was established in 2003 to improve the health status of older adults by empowering residents to make healthy decisions and engage in healthier lifestyles. HHAP was nationally recognized in 2013 and received the Network on Multicultural Aging (NOMA) Award for Excellence in Multicultural Aging from the American Society on Aging. They have received support from multiple funding streams, including state and county budgets and grants. HHAP is a public-private partnership with largely public funding of private providers who offer the programs to the public. HHAP offers two evidence-based health promotion and disease prevention programs—Better Choice, Better Health and Enhance®Fitness—for the multicultural population in Hawai'i. The Partnership has continuously evaluated the outcomes of the programs.

Better Choices, Better Health (BCBH) – Ke Ola Pono, also known nationwide as Stanford's Chronic Disease Self-Management Education, is a six-week, evidence-based self-management program where individuals with a chronic or ongoing medical condition(s) learn how to manage their health better and improve their quality-of-life. The workshop does not replace professional medical treatments; instead, it complements and supports them. Participants learn to manage their health conditions and interact with their health-

care providers. HHAP offers BCBH via in-person, phone, virtual (synchronous), online (asynchronous), and in-person with limited capacity formats. Over the years, the BCBH has served a total of 3,178 participants. Six-months after completing the program, participants reported doing more exercise (increased from 50 minutes to 66 minutes in stretch/strengthening exercises, and from 106 minutes to 133 minutes in aerobic exercise. They had less adverse symptoms (reduced pain, 23%; fatigue 22%; shortness of breath 32%; and stress 13%). Participants also experienced a 15% decrease in ER visits. HHAP's cost analysis estimated a net savings of \$656 in health-care spending per participant.

Enhance®Fitness is an evidence-based group exercise that combines cardiovascular and balance exercises, strength training, and stretching to prevent functional decline in older adults. Classes are interactive and consist of one-hour sessions conducted three times a week by certified fitness-specialized trainers. Enhance®Fitness improves participants' cardiovascular fitness, strength, flexibility, and balance, and motivates regular attendance by creating a fun and friendly exercise environment that nurtures relationships. The HHAP offers the program via in-person and virtual formats and has served 1,756 older adults since its inception. Many kūpuna returning to the Enhance®Fitness site enjoyed spending time with their classmates. On average, participants reported improved lower-body strength (20%), upper-body strength (19%), and transferability (13%). A nation-

CAREGIVER STORY

Our Caregiving Journey

By Kathy Sakamoto

Our caregiver journey began in 2011 when dad passed away from liver cancer. Dad noticed mom's memory issues when she would forget the pot on the stove and burn a hole in the pot. After a two-month wait, dad was able to go to mom's first geriatric doctor visit before he passed away. An MRI scan revealed that mom had experienced mini strokes, and she was diagnosed with vascular dementia.

Together, a sibling and I provided the care that mom needed. I took time off from work to attend the Alzheimer's Association seven-part series of workshops to learn about dementia and the progression of the disease. As care became increasingly difficult, I took early retirement in 2013.

My sibling became ill and could no longer care for mom. I began a daily commute between the Windward side and town to provide care for mom in May 2020. My husband and I welcomed our first grandchild a few months later.

Per the geriatrician's advice, we started mom at an adult day care after being on a waitlist. Beginning with two days of care, we slowly increased the number of days at day care thanks to help from the City and County Elderly Affairs Division Kupuna Care Program. The timing could not have been better, as we were blessed with two more grandbabies born during this pandemic. Beginning in 2023, I will be caring for a newborn granddaughter as well as my 92-year-old mother—opposite extremes of the caregiver spectrum.

As mom's needs increased, her geriatrician enlisted the aid of a hospital-based social worker to help our family cope with her worsening dementia and frequent falls. The service that was most beneficial for me was the social worker's referral to myPersonas. The myPersonas health guide scheduled regular phone calls to discuss anything regarding mom's care and other



stressors in my life. Their listening ear and unconditional support was invaluable, as well as having someone in my corner walking along with me. The myPersonas contract through mom's provider ended in December 2022. I reached out to the state's largest health insurance provider to request providing myPersonas services to its members. With individuals being isolated during the pandemic, having an unbiased health guide's support is sorely needed. Hopefully, other caregivers will have access to early Alzheimer's education and ongoing support during their caregiver journey.

al Enhance®Fitness study estimated a net healthcare saving of \$945 per participant.

During the pandemic, HHAP had to close all Enhance®Fitness sites and cancel BCBH workshops and training, as they were all in-person. The HHAP surveyed Enhance®Fitness participants on COVID-19 impacts and found that nearly all participants were negatively impacted by the pandemic, and their health status had declined. The findings also showed that the kūpuna lacked access to safe and effective health promotion activities. To overcome the challenges caused by the pandemic, HHAP started to offer the programs online, virtually, or by phone. Preliminary evaluation findings showed that, during the pandemic, both BCBH and Enhance®Fitness remained effective in all outcome measures. The HHAP partners

also gained skills and experience in offering the programs in alternative formats. Since mid-2022, HHAP gradually resumed the in-person format to help more kūpuna stay healthy and socially connected.

Legislative proposal: Despite the proven achievement in increasing quality-of-life and reducing health care costs, HHAP continues to struggle to obtain funding from the state. Legislation has been sporadic in its support of the HHAP and has not provided resources to allow the programs to expand. The Legislature has not passed any appropriation for HHAP for three years since the 2020 legislative session.

The lack of funding inhibits HHAP from bringing the two programs back to full capacity and reaching more kūpuna and their caregivers to keep them healthy in the community. HHAP is in a critical sit-

uation. Without these programs, more kūpuna will access emergency and acute health services due to falls and chronic diseases. While Hawai'i continues to be the state with the longest life expectancy, the state needs to invest in helping our kūpuna maintain good health and age in place. With the urging of senior advocacy groups, the Legislature has introduced three bills in the 2023 session to fund the Hawai'i Healthy Aging Partnership.

The three Healthy Aging Partnership-related bills are **SB 1419**, **HB 872**, and **SB 853**, requesting \$550,000 for FY24. This appropriation is urgently needed for HHAP to keep the statewide coordinator, evaluator, trainers, and instructors. These personnel play critical roles in sustaining HHAP and its impactful evidence-based programs.

Retirement Years

AN AGE-FRIENDLY HAWAII

Eldercare Workforce Planning for 2030 & Beyond

By Kendi Ho, Christy Nishita, PhD,
Cullen Hayashida, PhD,
& Caroline Cadirao

The U.S. is continuing to experience a dramatic global population shift, where for the first time, the number of older adults match and will eventually exceed the younger generation of millennials. In Hawai'i's Generational Economy, 2021 projections show 25.3% of Hawai'i's population will be 65 and older by 2060 (Mason and Abrigo, 2020). Older adults in Hawai'i will need more intensive and focused attention as Hawai'i outpaces U.S. longevity rates. In 2018, Hawai'i's life expectancy from birth was 82.3 years versus 78.7 years for the U.S.

At the same time, the general fertility rate has been declining for decades (CDC, 2022), which has consequential repercussions for eldercare. Fewer children are being born who can later serve as family caregivers, and therefore, there is an even greater need for a qualified workforce. This confluence of demographic factors will result in ever growing numbers of elders and their advocates seeking acute, long-term, and home-based care. Hawai'i needs bold, innovative, and sustainable planning to meet the workforce needs of older adults within the continuum of care and across all industry sectors. Hawai'i should also assure the continued health and engagement of active agers to marshal this growing human resource and moderate the demand for long-term care services.

Workforce Needs to Support Aging Well In Hawai'i

Workforce development is sorely needed in two broad categories: (a) in the continuum of care and (b) in the emerging employment areas that support active aging. The Healthcare Association of Hawai'i's workforce initiative report (2022) identified 3,873 non-physician clinical



job vacancies in their hospitals, skilled nursing facilities, assisted living, home health, and hospice care. Home health had the leading percentage of vacancies with 39% of total openings.

A number of organizations in Hawai'i have already created workgroups or task forces around the topic of workforce development in the healthcare industry, reflecting an awareness of the need to effectively recruit and retain direct care workers, community health workers, nurses, physicians, geriatric specialists, and others to reinforce and expand Hawai'i's current system of care. Examples of organizations with workforce development working groups already in existence include the Hawai'i Pacific Gerontological Society (HPGS), Kupuna Collective, Hawaii Healthcare Workforce Advisory Board, Hui Pohala, National Conference of State Legislatures (Hawai'i is a member), Hawaii Health Workforce Summit, and the CDC BOLD Hawaii Workforce Development Workgroup. The magnitude and scope of the problem is so great that an "all hands on deck" response is warranted, especially as the COVID-19 pandemic worsened an already critical healthcare workforce shortage that long predated the pandemic.

A new workforce development center focused on aging concerns could advance task force recommendations and fill the gap in current workforce development goals, and

actively plan and implement training initiatives to meet the needs of older adults.

Proposed Legislation

Legislative bill **HB 652/SB 902** requests funds in the amount of \$1 million for the establishment of a Caregiver Workforce Support and Development Center (CWS-DC) within the Executive Office on Aging. It aligns well with the former Kupuna Education Center's dedicated mission and vision of addressing the well-being of older adults in Hawai'i through family caregiver education, foundational home care paraprofessional training, and active aging strategies. The CWSDC would complement existing workforce and professional development for community-based home care; spearhead innovative ideas to support active aging by articulating career pathways in future career pathways to support aging well; and build capacity for improved health outcomes for older adults and families.

Although initiatives and training programs exist to promote workforce development in healthcare (e.g., Healthcare Association of Hawaii, Kapi'olani Community College's Certified Nurse Aide Training), this CWSDC fills critical workforce gaps and develops a niche by focusing on (a) addressing gaps in community-based care, (b) preparing trainees to specifically work with our kūpuna, and (c) focusing on active aging strategies.

Gap in the Caregiving Pathway: Institutional Care vs. Home Care

Current workforce development programs in the healthcare sector, such as the health industry’s partnership in Good Jobs Hawai‘i, focuses mainly on clinical or institutional careers that require professional licensures, such as the nursing career ladder from Certified Nursing Assistant (CNA) and Licensed Professional Nurses (LPN) to Registered Nurses (RN). Because clinical care receives insurance reimbursements, work requirements are standardized with a living wage.

On the other hand, community-based care is provided by both formal and informal caregivers. Formal caregivers — nursing assistants, personal care assistants and companion aides — are paraprofessionals who are essential to support care in activities of daily living, such as showering or cooking. The lack of homecare workers is well-documented due to the intensity of the work, low wages, lack of standardized training requirements, and lack of respect. Given the need for better coordination of paraprofessional care of older adults, the bulk of the coordination often falls under the informal care of a family or community member. Additionally, there is also the need to complement this with family caregiver training.

Clearly, a sustained effort is needed to assess, plan, and cultivate the quality of in-home care through continued education, training, and professional development of paraprofessionals and family caregivers. Community colleges like Windward Community College have an established CNA-LPN-RN career ladder, but pathways are needed to support paraprofessionals in becoming a CNA.

Care for Kūpuna: Changing Mindsets

Ageism is a concerning issue in the healthcare field; it impacts perceptions that older adults are not worth additional assessments or treatments, and leaves older patients feeling unheard and undervalued (Span, 2018). Students training for a health profession may get only a few hours of training on aging topics and usually only see older adults in facilities who are frail or have dementia.

	CATEGORY	EXAMPLES
PRIMARY	Non-Med Caring	Direct care workers, non-medical home care, adult day care
	Equipment	Assistive technology, universal design
	Information	Elder-friendly programs, DVDs, books, software
	Leisure	Active aging tourism, senior tourist activities, exercise clubs
	Finance	Pension products, reverse mortgages, asset management
	Housing & Facilities	Smart homes, care homes, ALF, universal designs
	Alternative Medicine	Anti-aging medicine, Hawai‘i brand of aging & wellness
	Farming	Gardening, self-sufficient farming
SECONDARY	Non-Med Caring	Direct care workers, non-medical home care, adult day care
	Equipment	Assistive technology, universal design
	Information	Elder-friendly programs, DVDs, books, software
	Leisure	Active aging tourism, senior tourist activities, exercise clubs
	Finance	Pension products, reverse mortgages, asset management
	Housing & Facilities	Smart homes, care homes, ALF, universal designs

Figure 1: Active Aging Industries Are Emerging. (Adapted source: Takeo Ogawa, Asian Aging Business Center, Fukuoka, Japan, 2009)

A handful of medical schools in the U.S. have included healthy and active older adults in the classroom to share their interests and passions to show that they have value and can live full lives (Span, 2018). Intergenerational contact has demonstrated benefits for both old and young, and is particularly effective in reducing ageist stereotypes (Burnes et. al., 2019). This awareness and exposure to aging issues also needs to occur at younger ages, and high school students exploring possible healthcare careers are a critical target.

The Center on Aging (COA) at the University of Hawai‘i has focused on developing an eldercare curricula that focuses on changing mindsets on aging, building appreciation for the role of older adults in our society, and understanding the impact of the social and built environment in promoting health. Through intergenerational activities, empathy challenges, and age-friendly neighborhood audits, students learn empathy, communication strategies, and ensure students approach care for our kūpuna in the right way. COA strives to reframe aging from a strengths-based approach in its training

of both high school and university students in preparation for future careers.

These approaches are innovative and needed, especially in our local context with isolated populations that do not lend themselves to specialty training and care. There is a need to build capacity within the community to engage all students and trainees in aging issues as a part of their health career training and empower youth to be better caregivers to family and neighbors.

Active Aging: Tapping Hawai‘i’s Growing Human Resource

Workforce development needs in aging careers could be sustained by a dedicated center that is not limited to clinical workforce requirements. Moreover, active aging could become key to maintaining health outcomes as well as become an unexplored area of industry. Figure 1 above provides a sampling of the types of programs and services targeting older adults that can become a source of new employment opportunities for young people as Hawai‘i’s population continues to grow old. Additionally, there are many new examples of programs to engage old-

(Continued on next page.)



er adults — paid or unpaid — to continue remaining healthy, engaged, and continuously contributing. Those efforts need to be explored, developed, and promoted.

A Multi-Pronged Strategy Needed

The solution to the eldercare staffing shortage is complex and requires a diverse set of strategies to support ongoing recruitment and retention. In addition to the approaches noted above, other solutions may include the initiation or continuation of rural health training programs, more attractive medical reimbursement rates, favorable tax incentives for healthcare providers, and scholarships for students interested in pursuing careers in healthcare. Across all strategies, it is imperative that eldercare workers see aging from a strengths-based lens, approach care with empathy, and are skilled at communication, particularly in interacting with those with dementia. At the same time, Hawai'i can re-examine its policies and approaches to keep older adults in the workforce and offer opportunities for continued, active engagement, and empowerment of kūpuna in our communities.

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Prescription Drug Prices

By Craig Gima

AARP Communications Director

The AARP asked Hawai'i residents to share how the high prices of prescription drugs affect their lives.

Hawai'i resident Gary told us he's "hoping not to have to make a choice between my medication and food." Lisa, another resident, said: "I exercise, eat right, and take care of my health as much as possible, but most of my monthly social security payments go towards drugs and medical costs."

We listened and lobbied hard in Congress so big powerful drug companies would include provisions to lower the cost of medicines in the Inflation Reduction Act that became law last year.

Kūpuna should see the impact of the changes starting this year and continuing over the next several years, with the biggest savings coming in 2025 and 2026.

Three provisions took effect this year for Medicare beneficiaries.

- Vaccines recommended by the Centers for Disease Control and Prevention's Advisory Committee on Immunization Practices are now free to Medicare beneficiaries. The vaccine for shingles, a two-shot regimen that used to cost hundreds of dollars, is now available at no cost.
- Copays for a 30-day supply of any covered insulin under Medicare Part D is now capped at \$35.
- Drug companies that increase the prices of their products faster than inflation

must pay the higher-than-inflation amount back to the government. For example, if inflation were 5%, and a drug price increased by 6%, the drug company would have to pay the 1% difference for all Medicare sales of that drug back to the government.

Next year, once Medicare beneficiaries spend \$7,050 in out-of-pocket costs in Part D, they will enter "catastrophic coverage" and will not be responsible for additional drug costs. Currently, beneficiaries still must pay 5% of the cost after reaching catastrophic coverage. In addition, Part D premium increases will be capped at 6% a year through 2029. Eligibility for Medicare's Extra Help program will increase from 135% to 150% of the federal poverty level (roughly \$20,000 for a single person or \$27,000 for a couple in 2022). The Extra Help program helps pay some or all out-of-pocket costs for those who are eligible.

In 2025, The maximum amount people with Medicare will have to pay out of pocket for their prescription drugs will be capped at \$2,000 a year and Part D members will have the option of spreading the cost of drugs over the entire year to lessen the impact of a big drug bill at one time.

The biggest impact should be seen in 2026 when Medicare will negotiate prices for up to 10 drugs; up to 15 drugs in 2027 and 2028; and 20 drugs in 2029 and beyond.

The provisions in the Inflation Reduction Act were negotiated and hard fought. Compromises had to be made, but AARP is committed to fighting any efforts by big drug companies to scale back the law and will continue to fight on the state and federal level for further efforts to reduce the price of necessary medications, including expanding price reductions beyond Medicare. Americans should not be paying the highest drug prices in the world and should not have to choose between paying for food and rent and the medicines they need to stay alive and healthy.

(Continued on next page 12.)

CAREGIVER STORIES

A Sandwich Generation Caregiver

Submitted by Gimme A Break

Aja Higa, Gimme A Break's 2022 Caregiver of the Year 2022, received the most "likes," "loves," and "cares" during the non-profit's Facebook award contest throughout National Caregiver Month in November. Her prize package included a Tahitian pearl set with necklace, earrings, and a bracelet/ring combo, a gift basket, a trophy, and a tiara presented to her by Mrs. America United States and Mrs. Hawai'i of 2021. The recognition and appreciation is for all Aja does as a caregiver!

Aja grew up around caregiving. She was there as her mother Kathy cared for her

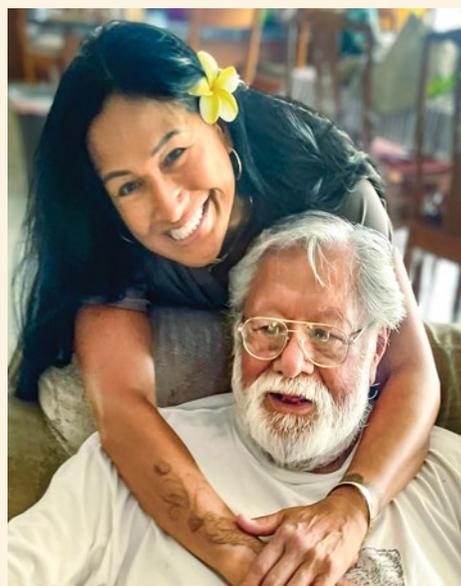


great grandmother till the day she passed. In 2007, Aja suddenly lost her father and grandmother just months apart. She had to quit her job, as her grandfather now needed care after he suffered an infection in his spine. Aja took online classes to learn how to care for him correctly. She is also a mother raising a young boy. Although she struggles, Aja always tries her best and her mom and family are so proud of her. She has been such a tremendous caregiver for her family.

Aja is a "sandwich generation" caregiver, a phrase becoming more and more prevalent coming out of the COVID-19 pandemic. The sandwich generation refers to a gen-

eration of young to middle-aged adults who are "sandwiched" between caring for their aging parents while also raising their own children. As baby boomers retire at a rate of 10,000 per day, the sandwich generation continues to grow.

Sixty-five percent of caregivers lose their jobs, their relationships, and even their own personal freedoms, yet never lose their heart for caring. Aja knows how family is so important and anything can happen. She is such an amazing person who is so full of love, nurturing, and patience. Aja is a well-deserving winner of the Gimme A Break Caregiver of the Year award.



A Guardian of Heritage

Submitted by Gimme A Break

Ipolani Pang-Kee is a native Hawaiian lomilomi practitioner. She has been a licensed massage therapist for 20 years. She gives tremendously, but her heritage and training gives her the energy to carry on.

Ipolani's training in massage therapy started at a young age while taking care of her dad. His training was old school, strict and hands-on with getting rid of muscle tension and "knots" in his back and shoulders. With his guidance and training, she mastered myofascial trigger point, deep tissue, acupressure, and back walking therapy—hands-free balancing with no ceiling bar or wall for balance.

Through Ipolani's caregiving for her dad, she learned how to pass and renew her energy. This journey he paved the way for was for her to continue in strength, technique, and chi energy—he had upgraded her to first class with a sprinkle of chi energy magic. As for lomilomi, it is her birthright. "This is who

I am. I am Hawaiian. It's in my DNA, it's in my koko, my bloodline, it's in my soul, my spirit and mana," says Ipolani. "Lomilomi is life—this is my kuleana." She feels blessed to have a life filled with island roots, Hawaiian culture, local traditions, and a lifetime of experiences in traditional Lomilomi. A caregiver at heart, Ipolani's passion is helping people; she loves what she does and is honored to represent her family lineage of kahuna healers.

As caregivers, we may give so much of ourselves and our time to others. Ipolani's story helps us remember what we get back and the importance of "ohana, and our family heritage. Caregivers are the guardians of history and tradition that continues to be passed on.

Can You Hear Us Now? A Story Worth Hearing

By Rick Tabor

Have you ever imagined what it would be like to be hearing impaired? Living without sound. What if you discovered many hearing impaired cannot afford hearing aids?

One in three people between the ages of 65 and 74 experience hearing loss, and about half of seniors over 75 do. Around 40 million Americans including children and adults, approximately 16% of the population, suffer from hearing loss severe enough to affect their communication abilities. In the United States, at least two children out of 1,000 births have hearing-related disorders. In the state of Hawai'i, approximately three per 1,000 children are born annually with permanent hearing loss.



HMSA insurance spokespersons say hearing aids are covered if an employer or individual purchases the right insurance. Cost factors are the common barrier. Kaiser offers a hearing aid plan. The basic Medicaid & Medicare Original Plan does not cover hearing or eye coverage. Consumers must purchase the correct Medicare Advantage (managed care) plan and meet certain conditions and criteria to qualify for hearing aid coverage. Those plans have a copay and only cover a percentage of the cost. The consumer covers the remaining balance. The average cost of hearing aids ranges from \$1,000 to \$4,000 per ear. Many in Hawai'i are not able to afford plans with hearing aid coverage.

In July 2023, the FDA approved over-the-counter (OTC) hearing aids for persons



with mild to moderate hearing issues. Concerns have delayed the start of these sales until October 7, 2023. Cheaper hearing aids may not equate to better or safe solutions. Most understand the importance of a qualified hearing specialist assessing a person's hearing loss, matching the conditions to the proper hearing aids, fitting the hearing aids, and follow up services. OTC hearing aids are unmonitored. Anyone can buy a sound amplification device. Our ears are sensitive and once damaged, there is no recovery, so professional advice should be considered.

Most of us take our hearing for granted. Hearing loss is gradual. We may find ourselves straining to hear in a noisy place. Our partners may say, "You're not listening to me." The average person does nothing until it's going, going, gone! And then it's too late to listen. The irreversible effects have arrived. Let's not do that. Let's hold our health insurance companies accountable for the coverage we think we're paying for. Hearing should not be considered "cosmetic." The isolation that comes with the silence of not hearing can lead to mental and physical health issues. Research has linked hearing loss to dementia-related issues. The resulting medical costs far outweigh the cost of appropriate hearing aids.

A recent review found 16 states have Medicaid coverage for hearing aids. Those states have implemented similar hearing aid bills to the one Hawai'i pre-

viously attempted to pass, which would have required Medicaid/Medicare and insurance plans to help with hearing aid costs. It also asked for \$1,500 per hearing aid every 36 months. The Deaf-Blind Task Force reintroduced these measures in hearing aid bills **HB 935, SB 606** in the 2023 legislative session. We may see a rule change soon. It would be worthwhile to give testimony in favor of these bills if you are interested and want to help. Those who are unable to pay for hearing aids would be grateful for those who care enough to ask for affordable hearing coverage for everyone.

Standardization of Medicaid Coding & Reimbursement

By Kathy Wyatt, RN, President of Hawai'i Family Caregiver Coalition, President of Adult Day Centers Hawai'i, Member of the Policy Advisory Board for Elder Affairs

Title XIX of the Social Security Act is a federal and state entitlement program that pays for medical assistance for certain individuals and families with low incomes and resources. This program, known as Medicaid, became law in 1965 as a cooperative venture jointly funded by the federal and state governments to assist states in furnishing medical assistance to eligible needy persons. Medicaid is the largest source of funding for medical and health-related services for America's financially disadvantaged.

Within broad national guidelines established by federal statutes, regulations, and policies, each state establishes its own eligibility standards; determines the type, amount, duration, and scope of services; sets the rate of payment for services; and administers its own program. Medicaid policies for eligibility, services, and payment are complex and vary considerably, even among states of similar size or geographic proximity. Additionally, state legislatures may change Medicaid eligibility, services, and/or reimbursement at any time.

Because each state makes its own Medicaid guidelines, it begs the question as to why there is no standardization in the Hawai'i Medicaid system. Of the five managed care organizations that are contracted with Med-QUEST, the Medicaid program, each one makes their own rules. One company may say a client is eligible, while another company says they don't qualify. Each company employs their own case managers that do the assessments to decide whether someone is eligible. Those case managers can make arbitrary decisions on the levels a client may qualify for. There is no consistency on assessment levels, and then each company reimburses at arbitrary rates. If the state of Hawai'i sets the eligibility requirements and reimbursement, then why is there no consistency among the contracted Med-QUEST companies? Why can one company set a reimbursement rate while another com-

pany sets a different reimbursement rate? The finances are all coming out of one pot at the state level, aren't they?

SB 889 was introduced by Senator Sharon Moriwaki. This bill would standardize the Medicaid program so all the contracted companies work from the same rules. It would standardize reimbursement rates at a sustainable level for providers while caring for kūpuna and other Medicaid recipients.

SB 1474/HB 1341, introduced by Representative John Mizuno, would appropriate full funding of Medicaid Home and Community-Based Services, including estimated payment increases. There has not been a cost of living increase for providers for over seven years.

Passage of these bills is needed. As a community-based service, adult day care is a vital rung in the long-term care ladder. It is the most economical service for kūpuna who want to age in place but need supervision, socialization, and mind and body stimulation while their caregivers are at work or running errands. There are 27 adult day care centers in Hawai'i across all counties. Many of them can't accept Medicaid recipients in need of service due to poor reimbursement from Medicaid. It is impossible to sustain a business if the reimbursement rate is almost half the average cost for attendance in an adult day care facility. Adult day care facilities want to serve kūpuna in

need, but are unable to without adequate reimbursement. Some do accept kūpuna on Medicaid, but the number must be limited due to the reimbursement rate, leaving many without service.

Conclusion

Each state establishes its own eligibility standards; determines the type, amount, duration, and scope of services; sets the rate of payment for services; and administers its own program. However, there no standardization in Hawai'i's Medicaid program. It clear that Medicaid guidelines are set by the state, yet are not consistent. The issues surrounding Med-QUEST can be remedied if the Legislature standardizes assessment criteria and reimbursement rates. Support for **SB 889** and **SB 1474** is asked on behalf of kūpuna who are Medicaid recipients and providers who would care for these kūpuna.

Kūpuna Collective: Collaboration & Innovation for Aging Impact

By Christy Nishita, PhD, & Lindsey Ilagan, Co-Coordinators, Kūpuna Collective

The Kūpuna Collective emerged out of a statewide need to bring community-based organizations and other local service providers together in rapid and efficient response to urgent problems faced by Hawai'i's older adults during the COVID-19 pandemic. As in the rest of the nation, many kūpuna in Hawai'i experienced increased social isolation and food insecurity due to the closure of congregate meal sites, limits on their social support networks, and the fear of going to the grocery store and other retail outlets to purchase food. Left unaddressed, these problems could have resulted in devastating outcomes escalated by new and existing healthcare issues.

In March 2020, the City & County of Honolulu Elderly Affairs Division (EAD) recognized the need for an "all-hands-on-board" approach and initiated a call to action by organizing a core team that included AARP Hawai'i, the Harry and Jeanette Weinberg Foundation, Age-Friendly Honolulu, and the University of Hawai'i Center on Aging. The Kūpuna Food Se-

(Continued on next page.)



curity Coalition (KFSC), as it became known, quickly extended to include over 40 nonprofit, government, private, and community organizations. The KFSC had a substantial impact on reducing food insecurity among older adults in the City and County of Honolulu. Raising over \$6 million in public and philanthropic dollars, the KFSC leveraged its diverse funding to support collaborative projects and expand service capacity like never before. Drawing on their shared mission to meet the critical needs of older adults in their communities, service providers reached across organizational and sectoral lines to coordinate an island-wide response.

Within six months, the KFSC delivered 1.2 million meals and 30,000 wrap-around health and social services to kūpuna in need. This was possible by mobilizing existing resources effectively, maximizing community assets, and leveraging a collective impact approach.

Impacting Lives

A kupuna served by the Salvation Army, one of the KFSC’s valuable service providers, commented: “During this virus, I ran out of money for food. The Salvation Army came to my rescue. They gave me a food box that tasted so good. They called and followed up with me to see how I [was] doing and if I needed food...Their follow-through was wonderful.”

Providing services to kūpuna also created opportunities for lasting friendships. Our Kūpuna, a non-profit organization, partnered low-income, vulnerable kūpuna with volunteers who were screened,



THE KŪPUNA COLLECTIVE

Vision

All generations in Hawai‘i thrive in a vibrant age-empowered society that maximizes the health, independence, and engagement of kūpuna.

Mission

The Kūpuna Collective brings together a collaborative network of partners who elevate critical issues, mobilize community assets, and drive innovative solutions that support and empower kūpuna in Hawai‘i.

Values

- **Equity** – We strive to ensure kūpuna have equitable access to resources and services that support their health and wellbeing.
- **Collaboration** – We leverage our strengths to work better together.
- **Inclusion** – We honor the vast range of strengths and abilities of the kūpuna we serve.
- **Upstream** – We focus our work on the intersecting social drivers of health that impact older adults’ ability to make healthy choices and live independently.
- **Respect** – We aim to change mindsets on aging, empower kūpuna as valuable members of society, and combat ageism.

vetted, and authorized to shop on behalf of kūpuna using their Supplemental Nutrition Assistance Program (SNAP) benefits. In one example, a kupuna with chronic illness living on Hawai‘i Island was paired with a family who volunteered to shop for her. A valuable friendship was formed: “They brought me flowers on Mother’s Day. Since I lost my daughter 12 years ago, that meant a lot. The [volunteers] are wonderful angels.”

Building an Infrastructure: The Kūpuna Collective

Building upon the momentum generated by the community response to the COVID-19 pandemic, the Hawai‘i Public Health Institute (HIPHI) and the Univer-

sity of Hawai‘i Center on Aging (CoA) seized the opportunity to partner and strategize on a more permanent structure — the Kūpuna Collective.

HIPHI is a 501(c)(3) non-profit organization that provides the backbone support for the Kūpuna Collective, including co-convening meetings, fostering collaborations, providing fiscal intermediary services, and amplifying community voices. The CoA serves as its co-coordinator, including strategizing directions, integrating and training students in the Kūpuna Collective’s efforts, providing data analytics, and documenting collective impact. The EAD serves as an advisor, bringing support and expertise in delivering home and community-based services. At the heart of the Kūpuna Collective is its members, more than 270 individuals statewide representing a range of diverse organizations leading the good work to support and empower kūpuna in every county. Regular convenings, both virtually and in-person, allow members to raise critical issues, mobilize resources, and drive innovative solutions by working together.

The Kūpuna Collective continues to build broad, cross-sector partnerships statewide to leverage funds and respond nimbly to critical issues and needs among kūpuna. It strives to uplift its members using four strategies:

CAREGIVER STORIES

Submitted by Gimme A Break



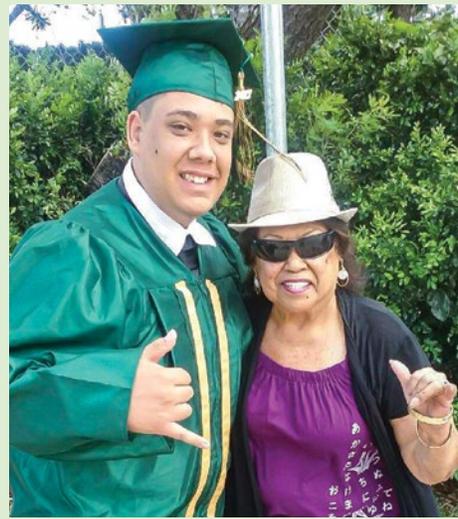
Caregiving for My Bestest Friend

At 22 years old, Tevin Reiger is at the threshold of his life. Very intelligent, a talented singer and performer, he always has a big warm smile for everyone he meets. You would never know he was the primary caregiver for his grandmother and his “papa” since he was a sophomore in high school. Tevin’s grandmother passed away in January 2023.

“She’s my mom, because she’s the one who raised me,” Tevin said with warmth and re-

spect about his grandmother. Their relationship brought her an elevated quality-of-life as she aged. Tevin often took her out to get all the special treats she loved.

Tevin never saw his relationship as caregiving or as a burden because he considered her his best friend. “We were the bestest of friends,” Tevin said. “We told each other everything and we did almost everything together.” Tevin always stood at his grandmother’s side, and she will always remain in his heart.



1. Support collaboration and networking among kupuna-serving agencies and organizations;
2. Build capacity and provide technical assistance through training and workforce development;
3. Incubate new kupuna programs and ideas; and
4. Improve, scale, and sustain our work for long-lasting change.

Current Program & Policy Efforts

Currently, the Kūpuna Collective is championing several initiatives that stem from lessons learned from the pandemic. First, the Collective works with its partners to develop and sustain integrated, person-centered services, including the expansion of food security programs tied with the provision of wraparound support. Second, the Collective continues to incubate programs and support partners in developing age-friendly and

dementia-friendly projects to combat social isolation and build more inclusive, age-empowered communities. This includes increasing equitable access to benefits and services, bridging the digital divide, and improving community conditions that support healthy aging.

Drawing on the strength of its members, the Collective has the potential to influence policy change. Collective members and the EAD participated in roundtable meetings with Representative Ed Case and Senator Mazie Hirono to highlight critical needs and opportunities to better serve kūpuna. Moving forward, the Collective intends to strengthen its advocacy role by amplifying the voices of kūpuna and service providers in diverse communities statewide.

What began as a coordinated effort to provide nourishment to Hawai‘i’s older adults during a pandemic has grown into a broader mission to nourish relationships, leverage respective strengths in the com-

Always Learning to Be Better!

Gina-Marie Tampon has worked as a caregiver since 2018, at first with a local company that supported and encouraged her to learn and



grow. With this encouragement, she decided to get her CNA certificate, as well as a patient care technician certificate. In time, Gina joined another company that offered her even more learning and growth opportunities. She has always loved learning and constantly embraces ways to better herself in the healthcare field.

Being a caregiver can be challenging, but for Gina it is very much worth it because, as she says, “I always give it my all and be the best I can be for my clients and residents. When I see them smile or laugh and they say ‘thank you,’ that really warms my heart and they’re the ones who make me want to work even harder and push forward for them—they are my family!”

The kūpuna are the ones who keep Gina on her toes, challenging her every day to be better. “They make me want to fight for them every single day,” she says. “They make me feel that I have a purpose in life, which is to serve them and to keep going and never give up. They make me realize life is very precious and to never take life for granted, and to always be happy even when times get rough. They make me who I am today.”

It was this amazing attitude that won Gina the Honorable Mention at the 2021 Gimme A Break Caregiver of the Year Award Facebook contest. It’s impossible to not be proud of Gina and all her accomplishments.

munity, and deliver results-oriented solutions to a wide range of needs on behalf of Hawai‘i’s kūpuna and their supporters.

Visit the Kūpuna Collective at www.hiphi.org/kupuna to learn more about the valuable partners and work of the Collective.

Aid to Caregivers

Paid Family Leave

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

Why Paid Family Leave? Demographic data help to identify the problem in Hawai'i. Forty percent of Hawai'i's workforce provides care for older parents, and family caregivers provide 70% of all care for frail elderly persons. Furthermore, unpaid leave under the federal Family and Medical Leave Act is inaccessible for 69% of Hawai'i residents.¹

In November of 2019, the Hawai'i State Legislature released a legislatively-mandated report on the viability of creating a paid family leave program in Hawai'i. A revised version of the report was released in December of 2019.² The report has helped to inform legislators' proposals in the 2023 legislative session.

HB 166 and **SB 1051** propose establishing a paid family leave program for state and county employees and authorizing a qualifying employee to take up to 12 weeks of paid leave for the birth or placement of a child or to care for a family member who has a serious health condition. **HB 235** proposes requiring certain employers to provide a minimum amount of paid sick leave to employees to be used to care for themselves or a family member who is ill or needs medical care.



HB 236 and **SB 360** propose requiring the Department of Labor and Industrial Relations to establish and administer a family leave insurance program, providing family leave insurance benefits and extends the period of family leave to 16 weeks for businesses that employ one or more employees who meet the hourly qualifications, and eliminating the previous threshold of 100 employees for employers to be subject to the family leave law. **HB 490** proposes providing employed individuals with up to eight weeks of paid family leave during the first year after the birth of the individual's child, adoption of a child by the individual, or placement of a child with the individual through foster care, and eight weeks of paid family leave to care for the individual's family member having a serious health condition during any benefit year paid through an employer-based private insurance program currently used to provide for temporary disability benefits. **HB 491** proposes establishing within the Department of Business, Economic Development, and Tourism a leave grant program to help small businesses offer their paid family leave and sick leave. **HB 1409** proposes extending, under certain conditions, the family leave period for up

to eight weeks for employees who are unable to perform their employment duties due to the birth of a child who is required to stay in a neonatal intensive care unit. **SB 342** proposes requiring employers to provide a minimum amount of paid sick leave to employees to be used to care for themselves or a family member who is ill or needs medical care and supplemental paid sick leave to employees under certain public health emergency conditions.

We strongly encourage the Legislature and the Governor to pass a strong paid family leave law. Employees need subsidized time off to care for a newborn, newly adopted or foster child, or an ill or disabled family member. Paid family leave guarantees that employees can cover the basic costs of living while providing care to family members when they need it most.

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Hope & Momentum: Alzheimer's Public Health Awareness Campaign

By Ron Shimabuku, Director Public Policy and Advocacy, Alzheimer's Association

Alzheimer's disease is a public health crisis. According to data from the Alzheimer's Association, in Hawai'i, approximately 29,000 individuals age 65 and older live with the disease, and nearly 70,000 provide care for them. By 2025, the number of individuals with Alzheimer's is projected to increase by 20.7%. Additionally, many are experiencing subjective cognitive decline — one of the earliest warning signs of future dementia. Results from the 2020 Behavioral Risk Factor Surveillance System found that in Hawai'i, 6.7% of those age 45 and older report experiencing confusion or memory loss occurring more often or worsening. More than two-thirds have not talked to their healthcare professional about it.

Aligned with the 2013 National Plan to Address Alzheimer's Disease, the Hawai'i 2025: State Plan on Alzheimer's Disease & Related Dementias was established to improve treatment and services for those living with Alzheimer's disease and related dementias (ADRD), and their families. A goal contained within the plan focuses on public awareness and engagement. The strategy is to educate the community on general knowledge and understanding of ADRD through various dementia-related topics. This would include, but is not limited to, reducing stigma, early diagnosis, risk factors, warning signs, brain health, behavioral changes, advance care planning, and caregiver supports.

In 2020, the Executive Office on Aging, the lead state government agency tasked to coordinate a system-wide network of aging and caregiver support services, received the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Program award from the Centers for Disease Control and Prevention (CDC). The award focuses on health systems promoting risk reduction, early diagnosis, prevention, and management of co-morbid conditions, and avoiding hospitalizations. Awardees have been tasked to establish statewide demen-

tia-focused coalitions and update ADRD plans accordingly. In 2023, the CDC announced a new round of BOLD funding to implement data-driven strategies and activities rooted in existing infrastructure. Awardees are also expected to increase general ADRD awareness with the public, providers, and other professionals.

In 2023, the Alzheimer's Association is focusing on educating the community to take preventative measures when experiencing symptoms of dementia. It has put forth a proposal to the Hawai'i State Legislature requesting an appropriation to implement a public health campaign to educate our communities on the early signs of cognitive impairment, the value of early detection and diagnosis, and discuss changes in memory and thinking with healthcare professionals.

health awareness campaign supplemented by federal and state funding. Consideration has also been given to the timing of the BOLD award and state fiscal biennium. It is my hope that with the combination of federal and state resources, and agreement by all stakeholders involved in this campaign, it will yield promising results to end the fight against Alzheimer's disease and related dementias.

Caregiver Education

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

Providing care for a loved one can be challenging, especially for someone with Alzheimer's disease or other dementias. Family caregivers frequently begin their caregiving journey with no experience and little or no training, and can



New FDA-approved Alzheimer's disease therapies are here, and more are on the horizon, which may allow people more time to participate in daily activities, remain independent, and decide on the future of their health. These treatments are beneficial at the early onset of the disease; therefore, early detection and diagnosis are critical.

The Alzheimer's Association has provided recommendations to the Executive Office on Aging and the State Legislature on effectively implementing this public

be understandably overwhelmed by their new responsibilities. They don't know what to expect as their loved one's dementia progresses, so they don't know what questions to ask to prepare themselves for what lies ahead. With no experience and no education, the caregiver will experience stress, uncertainty, fear, frustration, and a myriad of other emotions. One of the most effective ways to help ensure the highest quality of care for those with dementia is through caregiver education. Learning about the disease and knowing what to expect can

(Continued on next page.)



help caregivers feel more in control and better able to cope and plan ahead.

The Alzheimer's Association is sponsoring a bill to educate the public through a public awareness campaign. The bill is **SB 163**, Relating to Health. Supporting **SB 163** would benefit current caregivers, future caregivers, and health care providers. Arming them with knowledge about Alzheimer's disease will prepare everyone on how to recognize symptoms, what to do with that recognition, and what resources are out there for them.

A caregiver once said that she was exhausted taking care of a family member who had dementia and was very frustrated. It seemed that it was a continuous battle to get their loved one to do anything. After she went through a caregiver educational session, she learned that arguing with someone with dementia is pointless and just causes stress for them and for the caregiver. She learned so many coping skills and life got a lot easier. Armed with the resources needed to continue to provide safe, effective care for their loved ones, and the knowledge that there is help in the community to assist them, caregivers can be successful in their caregiving

journey, and their loved ones can remain at home and in their communities.

Current statistics issued by the Alzheimer's Association show that 29,000 people age 65 and older are living with Alzheimer's in Hawai'i. For people age 45 and older, 8.5% have subjective cognitive decline. There are 51,000 family caregivers caring for someone with Alzheimer's, so they bear the brunt of the disease in Hawai'i. These caregivers provide 81 million hours of unpaid care at a value of \$1.6 billion. The cost of Alzheimer's disease to the state Medicaid program is \$240 million, and just imagine what it would cost the state without the contribution of family caregivers!

There are many organizations that offer quality caregiver education that caregivers should know about. Educational sessions have continued to be offered to family caregivers at no cost to the caregiver throughout the pandemic via Zoom and other virtual venues. Hale Hau'oli Hawai'i, the Alzheimer's Association, The Caregiver Foundation, the Hawai'i Parkinson Association, and AARP all offer online training. Hale Hau'oli Hawai'i and AARP collaborated to provide weekly one-hour sessions in November 2021 to caregivers on all islands.

Hale Hau'oli Hawai'i, non-profit organization, offers educational workshops and caregiver support groups, as well as acts as a resource hub for educational opportunities with other organizations. Previous Hale Hau'oli Hawai'i educational workshops were recorded and are available on their website at www.halehauolihawaii.org, where caregivers can go to refresh their memories any time they are feeling stressed.

The Caregiver Foundation provides seniors, disabled adults, and their caregivers training on caregiving, aging, and financial management. The organization also offers island-wide caregiving support with educational components. Many resources can be found on their website at www.thecaregiverfoundation.org.

The Alzheimer's Association – Aloha Chapter offers a wide variety of programs and services, including educational programs for caregivers, community groups, and professions, as well as online caregiving training. The Aloha Chapter also offers caregiver support groups that include educational components. Their website is www.alz.org/hawaii.

The Hawai'i Parkinson Association has annual symposiums where a leading specialist on the disease answers patient and caregiver questions. Caregiver support with educational components is also offered. Their website, www.parkinsonshawaii.org, provides education and caregiver support group locations.



AARP offers caregiver education programs and online training and education for both new and experienced caregivers. Educational topics can be found on their website at www.aarp.org.

Another excellent resource for family caregivers is the Senior Information and Assistance Handbook, a publication of the Elderly Affairs Division, Department of Community Services, City and County of Honolulu, which is updated periodically.

The old saying “being forewarned is to be forearmed” makes sense in providing the public with information about Alzheimer’s disease and related dementias. Receiving education and training for caregiving, learning practical caregiving approaches, and using local caregiving resources are important strategies.

Our goal is to reach as many people as possible to share invaluable information that can make their lives and the lives of their loved ones better and easier. Caregiver education also leads to improved health outcomes, not only for kūpuna, but also for their caregivers. Your support of **SB 163** would be of immeasurable benefit to caregivers and the many who suffer from Alzheimer’s disease or related dementias.



The CARE Act

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

Having a loved one go into the hospital and return home is a stressful time for family caregivers. A law passed in 2016 requires hospitals to make the transition in and out of hospitals easier. On June 16, 2016, then Governor David Ige

signed Act 69 of 2016 — the Caregiver Advise, Record, Enable (CARE) Act — which requires hospitals to adopt and maintain written discharge policies consistent with recent updates to federal regulations to support families by enabling patients in inpatient hospitals to designate a caregiver prior to discharge or transfer from the facility. The CARE Act makes it easier for family caregivers and patients to work with the hospital for the best possible outcome.

The law empowers caregivers and hospitals to form a partnership for the best possible care and makes it clear that family caregivers are part of the patient care team. The Act provides three supports for family caregivers when a patient goes into the hospital and as they transition home:

- Identification – A patient has the opportunity to designate a family caregiver on the medical record when admitted to the hospital.
- Notification – The family caregiver is notified if their loved one is to be discharged home or transferred to another facility.
- Instruction – Hospitals must offer family caregivers instruction on the medical tasks they will need to perform at home.

Family caregivers are unsung heroes — they deliver for their loved ones every day. The CARE Act recognizes and helps family caregivers in the taxing care transition from hospital to home.

CAREGIVER STORY

Submitted by Gimme A Break

A Caregiver's Smile

Roseline, “Rosie” Alipio-Young is a mother, daughter, and wife—and a caregiver who has never lost her smile and infectious laugh throughout her caregiving. “Caring for my husband has been a challenge for us both,” she says. “Especially since he lost his leg, getting up and down the stairs to our place is a struggle. [But] he’s the love of my life and I would do anything for him!”

When her husband lost his leg, Rosie became the rock that held her family together. After years of caregiving, she continued to gather strength by attending support sessions with Gimme A Break to keep her wellness balance, to survive and hold her marriage together. Rosie and husband Daron



both volunteer at the Gimme A break “safe” space in Windward Mall. An amazing pair, they have a strong faith and love for each other, living an amazing life. Visit them there and hear more about their journey.

CAREGIVER STORY

How I Formed My All-Star Caregiving Team

By S. Sanae Tokumura

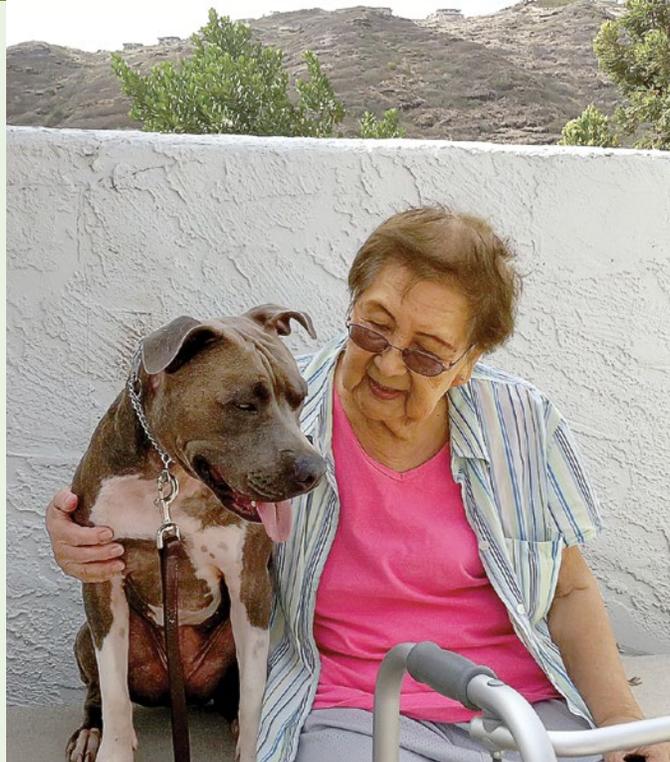
In late September 2011, my mom mentioned on the phone “bleeding ulcers.” Mom lost dad unexpectedly when I was seven and lived alone after I left for college. I had been going back and forth from O’ahu to Kaua’i since I was in college to clean the house, wash the car, and gradually began food shopping, and then cooking and freezing food much like she had done for me not too many years prior.

On October 1, on a visit right after that phone call, I found out mom was hiding her pain and fear. A typical member of our greatest generation, mom was stoic and determined not to be a burden. When she picked me up at the airport, her car had a big dent. When we arrived home, I saw that the end of the concrete wall that fenced her wide driveway and yard was broken at the exact height as the dent. There was an abundance of instant food in the pantry from Longs Drugs and no fresh veggies or fruits in the fridge.

Her primary care doc in Lihue released medical records to us and I found out they had been treating her post-menopausal bleeding with antibiotics for weeks. The next day, I dragged her to O’ahu for a visit to her geriatrician, who had completed a baseline a few years prior. For what we both thought would be a visit of a few days, mom packed an alarm clock, nothing else. The role reversal began when I packed a small suitcase for her on that last visit home.

She ended up never returning there to live.

Enter husband Craig, MVP team member. Position: Center. He rebounded and slammed everything in sight. These many years later, he still remembers the day mom came to live with us, and even the time of day he picked us up at the airport, because life was never the same for any of us.



First week at our home; mom only spoke to Balo

“Almost 10 years passed this way, but mom gradually lost the ability to care for herself. I began bathing her, then brushing her teeth.”

Recruit #2: Dr. Jessica Barry. Position: Point Guard. We visited Dr. Barry practically the day after that. She immediately referred us to the right specialist. It was cancer. Very shortly after some tests ordered that day, mom, at age 85, was told by Dr. Barry that she could no longer live alone — and of course could no longer drive. She also was diagnosed with vascular dementia.

When mom could no longer speak for herself, I felt a huge burden to be her advocate. That anxiety led to actively seeking information and an intentional movement toward resources. Finding help was not easy. Information wasn’t plainly available. I hit the jackpot when I discovered the Alzheimer’s Association. I soon joined a free,

information-packed seven-week class and learned about mom’s and our situation.

Recruit #3 Mom’s attorney. Position: guard. Armed with basic information for our stage of the game, mom and I took care of legal matters with the family attorney. With proper documents, I could navigate and execute all matters for her as her trustee in finance (insurance, banking) and health.

Then I took some days off and flew back to Kaua’i right before Christmas 2011. With the help of family and

friends, we cleared out my entire childhood home, with me crying almost the entire time.

I shipped all of mom’s important pieces of furniture to O’ahu, which would make her feel more comfortable at our house, according to my team. Her sofa, her bed, her dining set, TV, knitting paraphernalia, her ikebana vase collection, and books. I checked every scrap of paper in countless files and drawers after finding cash tucked away between the pages of old phone books stacked beneath a kitchen counter. A 40-yard roll-off dumpster bin sat in the driveway, which was soon filled with a mountain of things, and I gave away bags and bags of household supplies. I napped in three-hour increments. I laugh at myself now, remembering how I thought that an eight-day stint was hard!

Meanwhile, mom at the time was completely able to care for personal needs and Craig was holding down the fort at home. Later, in the aftermath of her surgery, chemo, and radiation, I nursed her and we still managed to keep our business running.

Recruits #4 and #5: Day care and day health programs. Position: Forwards. What helped



Mom at day care

us most at the time was the invaluable adult day care program at Mo'ili'ili Community Center, and then when mom needed more assistance, Arcadia's Adult Day Health Program at Central Union Church. Mom's quality-of-life and joyful friendships blossomed during this time.

Almost 10 years passed this way, but mom gradually lost the ability to care for herself. I began bathing her, then brushing her teeth. One day I was in a public bathroom with her and she couldn't figure out which way to get out of the stall. So I was in the stall with her from then. It was like that.

Then the awful day came when I had to introduce my beautiful, proud mother to pull-up diapers. I remember thinking that I would be intimately involved with every single BM she ever would have for the rest of her life. Then I began feeding her. It gradually took more than an hour to feed her one meal. She appreciated good cooking.

Recruit #6, Jody Mishan. Position: Guard
Meanwhile, Craig and I attended more classes on caregiving to keep sharp and current. Jody Mishan, who coordinated many of those classes, taught me to keep asking questions and not to give up. Don't wait to be invited. Make your way. I learned that I was not a prisoner of any system or process. I used to be such an obedient person. No

longer. I spoke up for my mom, who scribbled things on notepaper so she wouldn't forget, so she would be able to ask me the next time I came into her room. I admired my brilliant mother throughout my life, but never more than watching her bravely endure and maintain her dignity as much as she possibly could during those days.

Recruit #7, Kathy Wyatt, RN, MSN, MBA, LNHA. Position: Power Forward. The day came when I thought I would lose my mind with sadness, defeat, and despair as mom continued to decline, especially after she stopped attending her day health program because of COVID. A steep downward spiral began until my mother couldn't transfer her weight anymore. The care responsibilities by then were total, and heart-stopping near falls, slips, and slides began occurring. I joined Kathy Wyatt's Hale Hau'oli Hawai'i Caregiver Support Group.

Eventually mom had to be moved to a facility. We went through huge bumps in this road, both in finding a suitable place and in my emotions. Trusting some stranger with the health and safety of my mom was unthinkable.

At one place that seemed too good to be true, we realized within minutes after mom moved in that we were in trouble. The operator's caregiving skills for a person in my mom's condition was not truthfully report-

ed. I sat in the next room and cried, because I didn't want mom to be afraid, and I simply didn't know what to do. I was horrified that we had to leave mom there overnight as our team rushed to find a safer harbor. We were going to bring her back home the next day if we weren't able to move her to an appropriate setting. Paperwork and COVID stretched out our waiting to three days. I may have slept about two hours through that whole horrible mess.

It's a jungle out there when seeking a good, qualified care home operator. A good placement counselor is a must. And during visits to places that seem appropriate, don't believe everything you're told by the agency. Use your own eyes and head, and go with your gut. Are there signs of disrepair, is it too hot, too cold, noisy? How many people are helping? Ask the hard questions. In mom's case, she is completely unable to defend herself verbally or physically, and she would not be able to tell us what was happening to her. Imagine her being at the mercy of an unqualified caregiver. It was and still is my responsibility to protect her.

Recruit #8, Maunalani Nursing and Rehabilitation Center, Position: Guard. Today, after making some serious and financially ruinous errors, mom is safely in the care of a wonderful facility. I certainly continue to speak up, and they respond immediately, doing their very best to support all of us.



Mom's last Christmas at our home in 2020 before moving to a care home

Disability Issues

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

Issues exist that affect both people with disabilities and older adults. Members of the Hawai'i Family Caregiver Coalition join forces to address these issues. Additionally, issues that affect only older adults or only people with disabilities also exist. The Coalition advocates for these two individual populations as well. This section describes legislative measures being discussed in the 2023 Legislature that might not be addressed in other sections of this report.

Service Animals

The regulation, or lack thereof, of service and other emotional, comfort, and support animals continues to be a major problem for many in the community. The proliferation of fake service animals by individuals wishing to access environments that prohibit the presence of pets is well documented. Act 217 of 2018 established a civil penalty for knowingly misrepresenting an animal as a service animal and conformed Hawai'i law with the definition of "service animal" under the Americans with Disabilities Act of 1990. In 2023, bills have been introduced to offer more clarity to the service animal/assistance animal/emotional support animal issue. **HB 871** and **SB 612** propose requiring that a disclaimer be provided by sellers or providers of emotional support animals, or certificates, identifications, tags, vests, leashes, and harnesses for emotional support animals stating that the animal is not a service animal.

Community Living

Several bills have been introduced to improve the lives of people with disabilities.

HB 218, introduced by Representative Gregg Takayama, and **SB 608**, introduced by Senators Joy San Buenaventura and Karl Rhoads, propose requiring pharmacies to provide accessible prescription drug label information to individuals who have difficulty seeing or reading prescription drug container labels and



inform the public that prescription drug label information is available in alternate accessible formats for individuals who have difficulty seeing or reading prescription drug container labels.

HB 415 and **SB 101** make an appropriation to the Department of Health to implement the recommendations of the statewide mobility management task force, established pursuant to Act 214, Session Laws of Hawai'i 2013. Tasked by the 2013 Hawai'i State Legislature, the Department of Health's Executive Office on Aging convened the statewide task force to address the mobility needs of Hawai'i's kūpuna and people with disabilities.¹

HB 870 and **SB 614** propose requiring the Department of Human Services to establish a neighbor islands Blind and Visually Impaired Service Pilot Program that provides training and other services to blind or visually impaired individuals residing on the neighbor islands.

HB 916 increases the monthly needs allowance for individuals residing in long-term care facilities from \$50 to \$75 and requires certain long-term care facility operators to pay for generic toiletries, linens, meals, and snacks.

HB 933 and **SB 611** propose requiring the Public Utilities Commission to use

universal service fund moneys to provide free telecommunications access to certain information for individuals with print disabilities.

HB 1413 proposes requiring that the Legislature ensure that state facilities, businesses, and recreational facilities meet certain accessibility requirements and be in compliance with the federal Americans with Disabilities Act of 1990, as amended.

The casual observer might think that the worst consequence of poor dental health would be lost teeth. However, some studies have linked common oral problems to illnesses, including heart disease, stroke, diabetes, premature birth, osteoporosis, and even Alzheimer's disease. In most cases, the strength and exact nature of the link is unclear, but they suggest that dental health is important for preserving overall health.² **HB 1197** appropriates funds to the Department of Human Services (DHS) to restore basic adult dental benefits to Medicaid enrollees and requires DHS to obtain the maximum federal matching funds available for this expenditure.

Individuals who are deaf or hard of hearing at any age face many challenges in receiving information conveyed in an auditory manner. Hearing impairment can impose a social and economic burden

on individuals and families. In adults, hearing impairment often makes it difficult to obtain, perform, and maintain employment. It also makes it difficult to respond to warnings or hear doorbells and alarms, and to understand and follow a physician's advice and directions. Hearing impairment can lead to depression, withdrawal, or isolation, as it can be difficult to converse with friends and family, leading to frustration or embarrassment.³ **HB 818** and **SB 609** propose requiring health insurance policies and contracts to provide coverage for the cost of hearing aids at a minimum of \$1,500 per hearing aid for each hearing-impaired ear every 36 months. **HB 935** and **SB 606** propose exempting from the general excise tax gross receipts received from the sale of hearing aids.

HB 1145, introduced by Representative Lauren Matsumoto, and **SB 389** require

any expenses incurred in developing and administering the Hawai'i ABE savings program and establishes a position within the Department of Health's State Council on Developmental Disabilities to support the Hawai'i ABE savings program. The Achieving a Better Life Experience Act of 2014⁴ allows states to create tax-advantaged savings programs for eligible people with disabilities (designated beneficiaries). Funds from these 529A ABE accounts can help designated beneficiaries pay for qualified disability expenses. Distributions from ABE accounts are tax-free if used for qualified disability expenses. ABE accounts allow people with qualifying disabilities to save money without losing their state and federal benefits. Money saved in ABE accounts does not count against asset limits in some federal programs (e.g., Supplemental Security Income (SSI) and Medicaid.)⁵

SB 672, introduced by Senators Joy San Buenaventura and Angus McKelvey, eliminates language that subjects the use of the Hawai'i ABE Savings Program Trust Fund to the discretion of the Director of Finance, expressly allows the Hawai'i ABE Savings Program Trust Fund to be used to provide incentive payments to Hawai'i public school ABE account owners, and establishes one full-time equivalent permanent position to provide statewide outreach, advocacy, and relationship management for the Hawai'i ABE Savings Program.

Health, Education & Human Services

Several bills also have been introduced to advance programs and services to improve the health, education, and welfare of people with disabilities.

SB 318 proposes establishing the Fetal Alcohol Spectrum Disorders Task Force within the Department of Health and requiring a report to the Legislature. **HB 897** and **SB 713** propose establishing a task force to review policy issues and opportunities relating to the navigation, access, and coverage of Medicaid services by individuals with autism or fetal alcohol spectrum disorder and to make a recommendation on whether a waiver or other approval from the Centers for Medicare and Medicaid Services is necessary to ensure accessibility of certain services for individuals with autism or fetal alcohol spectrum disorder. **HB 900** and **SB 714** propose establishing the fetal alcohol spectrum disorders special fund to be administered by the Department of Human Services and which shall consist of federal funds and interest earned on those funds; establishing a temporary fetal alcohol spectrum disorders task force within the Department of Health for administrative purposes; and, requiring a report to the legislature.

HB 388 proposes adopting the National Instructional Materials Accessibility Standard and requiring the Department of Education to obtain instructional materials in accessible formats for eligible students. Similarly, **SB 607**, introduced by Senators San Buenaventura and Rhoads,

(Continued on next page.)



all places of public accommodation and state buildings constructed after December 31, 2023 to provide universal changing accommodations that are equally accessible to men and women.

HB 1263 authorizes the Director of Finance to use funds deposited into the Hawai'i ABE (Achieving a Better Life Experience) savings program trust fund for

SB 384 authorizes each county to adopt ordinances to enforce the design, construction, and signage requirements of the federal Americans with Disabilities Act of 1990, as amended; part III of chapter 291, Hawai'i Revised Statutes; and any administrative rules adopted under that part, including the establishment of penalties for failure to comply with the ordinance.

proposes adopting the National Instructional Materials Accessibility Standard to a) provide instructional materials to eligible students in a timely manner and requires the Department of Education (DOE) to coordinate with the National Instructional Materials Access Center; b) authorize the DOE to assist non-public elementary and secondary school and alternative educational programs in obtaining accessible instructional materials; and c) require all elementary schools, secondary schools, and alternative educational programs to provide eligible students with accessible instructional materials,



assistive technology devices, and assistive technology services at the same time print instructional materials are provided to other students.

HB 830 and **SB 605** proposes requiring the Department of Education to meet with Hawai'i School for the Deaf and Blind stakeholders and members of the Hawai'i deaf community regarding the development of a plan to transition the Hawai'i School for the Deaf and Blind to a conversion charter school.

SB 755 requires the State Council on Developmental Disabilities to submit a report focused on the health disparities experienced by individuals with developmental or intellectual disabilities in the state to the Legislature prior to the convening of the regular session of 2025.

HB 1451 proposes authorizing advanced practice registered nurses (APRNs) to certify whether a person is totally disabled under the income tax code; adding

APRNs as primary providers in advance mental health care directives; and, authorizing APRNs to make capacity determinations for purposes of advance mental health care directives.

SB 1473, introduced by Senator Jarrett Keohokalole, requires a) the Department of Health and the Department of Human Services to develop and adopt rules, policies, and plan amendments necessary to ensure that the state Medicaid program covers medically-needed services, including applied behavior analysis services for individuals age 21 and older with neurodevelopmental disorders, including autism spectrum disorder; and b) the Department of Health and Department of Human Services to apply for any necessary approvals from the Centers for Medicare and Medicaid Services to amend the state Medicaid plan to provide reimbursements for medically-needed services, including applied behavior analysis services, for individuals age 21 and older with neurodevelopmental disorders, including autism spectrum disorder.

Information Technology Accessibility

As society, including government programs and services, becomes increasingly digital, persons with disabilities are at risk of being left behind. Many could be forced out of fully participating in their communities and in state programs and services. Implementation of new digital technologies and procedures must be consistent and ensure that these technologies are accessible to individuals with disabilities.

HB 1222 and **SB 613** proposes requiring each house of the Legislature to establish by its rules, procedures that enable the Legislature to use remote testimony at legislative committee hearings; enable

the public to present oral testimony at legislative committee hearings through remote testimony; and accommodate persons with disabilities through remote testimony.

Recognition and Awareness

HB 834 and **SB 610** propose recognizing American Sign Language as a fully developed, autonomous, natural language with its own grammar, syntax, vocabulary, and cultural heritage.

HB 899 and **SB 715** propose designating the month of September as “Fetal Alcohol Spectrum Disorder Awareness Month” to promote public awareness of the risks of alcohol consumption during pregnancy.

More than 66,000 working-age persons with disabilities reside in the state of Hawai'i. Almost 40 percent of these residents are currently employed. **HB 794** proposes designating the month of October as “Disability Awareness Month: Employment, Enrichment, and Inclusion” in recognition of the employment challenges and successes of persons with disabilities in our state.

We strongly encourage our lawmakers to pass legislation promoting the inclusion, involvement, and independence of our persons with disabilities. Let us ensure these individuals and their families have access to the services and supports they need to grow, develop, and participate in our island communities.

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Conclusion

COMING OUT OF HARD TIMES & FACING A BRIGHTER FUTURE

By **Kathy Wyatt**, President, Hawai'i Family Caregiver Coalition, & President of Hale Hau'oli Hawai'i

The Legislative Process

Sections 2 through 5 of this publication have illustrated the kinds of aging and disability issues legislators face each and every year. At the beginning of each legislative session, a great number of bills are presented 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. Advocates must be prepared at the very beginning of a legislative session to respond rapidly to identify and support favorable legislation and to testify rationally and robustly in opposition to legislation deemed harmful to kūpuna or persons with disabilities.

Advocates must take advantage of opportunities for incremental change and then build upon these. Press for whatever incremental advances are politically possible at any given time.

Advocacy

Effective, successful advocacy is comprised of six key elements:

- 1. Teamwork.** As an individual, an advocate needs to join organizations that are effective in creating change aligned with the individual's goals and welcoming of the individual's contributions, no matter how great or limited those contributions might be. Similarly, stakeholder agencies



and organizations need to ally, collaborate, and partner to effect change. Advocacy is a joint venture. Find allies and work with them. The potential for success is much greater when several organizations and people are on your side. Ensure that you and your allies have the same message. The collective voices of multiple groups can be the fundamental and vital difference in demonstrating the critical mass demanding change. Avoid completely dismissing an organization which might disagree with some items on your legislative agenda. If the organization is in favor of any of your issues, then it as ally. The relationship you build may benefit your future advocacy efforts. Additionally, representatives of the organization might be inclined to hear your rationale on issues where your positions differ.

- 2. Relationships with legislators and their staff.** Nurture relationships. Personal, face-to-face contact or personal phone contact with key legislators and their legislative staff to educate them about important issues is the difference between success and failure. Make your voice heard. Say mahalo. Remember that our legislators and their staff are

busy during the legislative session and that their time is limited and valuable.

- 3. Testimony.** Demonstrate broad support for bills being heard with a substantial number of clear, concise, compelling, and convincing written testimonies and attendance at legislative committee hearings, either in person or virtually.
- 4. Statistics.** Know and use the facts. Increasingly, the need for services and the effectiveness of programs must be demonstrated clearly via solid scientific evidence and reliable data.
- 5. Personal stories.** Personal stories can matter as much as statistics. Dramatic stories spark change effectively and can be a great source of clout for advocates. Presenting real life stories of actual people and putting faces on kūpuna or persons with disabilities is the most powerful method to influence legislators and have them seriously deliberate the consequences of their actions. The effectiveness of personal stories is amplified if the person telling the story is a constituent or is someone the legislator personally knows.

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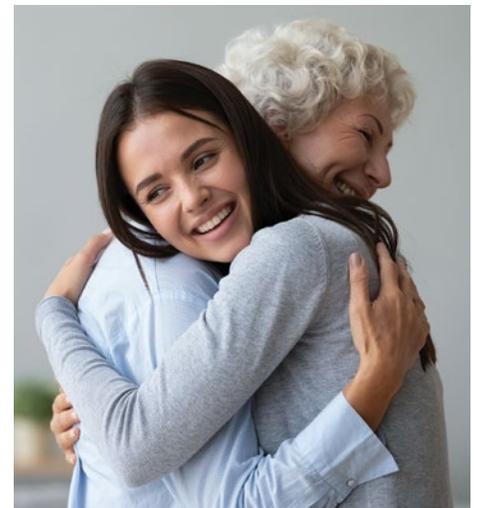


6. Incremental change. Advocates must take advantage of opportunities for incremental change and then build upon these. Press for whatever incremental advances are politically possible at any given time. Never give up. Continue to push. Exercise strategic patience. Prepare for the eventuality when the window of opportunity that change agents have been cultivating arises.

A Silver Tsunami, with its many thousands of additional elders and unprecedented numbers of the very old, arrived in the 1990s. This tsunami has not yet peaked. Thirty percent of Hawai‘i’s total population, (approximately 475,000 individuals) will be 60 years or older by the year 2035. The fastest growing segment of the population are those who are 85 and older. They are the ones who will have the larger number of chronic

conditions because these accumulate over time and with age. These kūpuna are at risk to have the highest rates of Alzheimer’s disease and other dementias, and to have the highest care needs. Fewer caregivers will be available. Tremendous stress will be placed on the care system. The majority of the care that the “oldest old” currently receive outside of institutional settings is informal care from family.

The state and federal governments have taken significant leaps with the establishment of the Kūpuna Caregivers Program and the RAISE Family Caregiver Advisory Council in the recent past. However, even if all the legislation described in this report were enacted, it would not meet all the needs of Hawai‘i’s next generation of elders and persons with disabilities. We must continue to think five to 10 years ahead, and beyond.



The Challenges

We must strongly consider and robustly address five challenges:

- 1.** How do we create cohesive, comprehensive, coordinated, efficient, pur-



posefully-built, wide networks and systems of support for caregivers and their care recipients, ones that will meet the needs of all our island populations, especially in rural areas which are often inadequately and poorly served?

2. How many professionals and paraprofessionals are required to meet the care needs of our kūpuna and disabled?
3. How will we develop (i.e. recruit, educate, continuously educate, and retain) the necessary numbers of professionals and paraprofessionals, as well as provide appropriate training for family caregivers.
4. Given the limitations of both state and federal government ability to finance programs and services, how can government develop more extensive and effective partnerships with

the private, for-profit sector to meet colossal and enormous future needs?

5. We recognize that older adults play a key role in building strong, resilient communities. Community members learn from the successes, failures, joys, and difficulties of kūpuna. How can we encourage kūpuna to connect and engage with the community to support and inspire others?

We are called to:

- Intensify our work to overcome the challenges of the Silver Tsunami;
- Advance, enact, and (when prudent) adjust policies and programs that work not just for the present, but for a future where never have so many lived so long; and
- Develop strategies and implement systems that promote and support the

health, safety, and independence of our aged, disabled, and family caregivers.

Last year, the COVID-19 pandemic threatened the policies and programs that protect the welfare of our kūpuna and persons with disabilities. Going forward, regardless of whatever crisis is at hand, their health and wellbeing must always be secured as a continuing facet of a just society.



Information, & Education & Research Resources

Public & Nonprofit Agencies

Hawai'i Aging and Disability Resource Center

The Hawai'i Aging and Disability Resource Center (ADRC) helps older adults, individuals with disabilities, and family caregivers find options for long-term supports and services available to them in the state of Hawai'i. The ADRC is a highly visible and trusted source where people of all incomes and ages can turn for information. ADRC staff will help determine if you are eligible for government paid programs, assist you in finding providers you may pay for yourself, and work with you to develop an individual plan for meeting your future long-term care needs. The assistance is paid for by the state and counties at no cost to you.

Phone: (808) 643-ADRC (808-643-2372)
TTY Line: 643-0889
Email: adrc@doh.hawaii.gov
Website: hawaiiadrc.org

Executive Office on Aging

The Executive Office on Aging (EOA) is the designated lead agency in the coordination of a statewide system of aging and caregiver support services in the state of Hawai'i, as authorized by federal and state laws.

The federal Older Americans Act establishes an Aging Network and provides federal funding for elderly support services, nutrition services, preventive health services, elder rights protection, and family caregiver support services. Chapter 349 of the Hawai'i Revised Statutes established the Executive Office on Aging as the focal point for all matters relating to older adults' needs and the coordination and development of caregiver support services within the state of Hawai'i.

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925 Dillingham, Suite 200
Honolulu, Hawai'i 96817

Information and Assistance Senior Helpline: (808) 768-7700
Website: www.elderlyaffairs.com/site/1/home.aspx

Hawai'i County Office of Aging (HCOA)

Kahi Malama, A Place of Caring
William Horace Farr,
County Executive on Aging
Website: www.hcoahawaii.org

Aging and Disability Resource Center
1055 Kino'ole Street, Suite 101
Hilo, Hawai'i 96720-3872

Phone (808) 961-8626
Kona: (808) 323-4392

Kaua'i Agency on Elderly Affairs

Kealoha Takahashi,
County Executive on Aging

Pi'ikoi Building
4444 Rice Street, Suite 330
Lihue, Kaua'i, Hawai'i 96766

Phone: (808) 241-4470
Email: elderlyaffairs@kauai.gov
RSVP (volunteer program): rsvp@kauai.gov
Website: www.kauai.gov/Elderly

Maui County Office on Aging (MCOA)

Rowena Dagdag-Andaya,
County Executive on Aging

95 Mahalani Street, Room 20
Wailuku, Hawai'i 96793
Phone: (808) 270-7774

Email: mcoa.adrc@mauicounty.gov
Website: www.mauicountyadrc.org
Moloka'i: (808) 553-5241
Lana'i: (808) 565-6818

AARP Hawai'i
Keali'i Lopez, State Director
1001 Bishop Street, Suite 625
Honolulu, Hawai'i 96813

Toll-Free: 866-295-7282
Email: hiaarp@aarp.org
Website: states.aarp.org/hawaii

CareSift

CareSift takes a personalized approach to match seniors with care providers at no cost to families. Founded by health-care professionals and social workers, CareSift navigates the system to provide different care options and an extra source of support. CareSift works one-on-one with both caregivers and seniors to ensure a seamless process.

Phone: (808) 400-9992
Email: info@caresift.com
Website: caresift.com

Disability and Communication Access Board

Kirby Shaw, Executive Director
1010 Richards Street, Room 118
Honolulu, Hawai'i 96813

Main Office Phone:
(808) 586-8121 (Voice)
(808) 586-8162 (TTY)
(808) 586-8129 (Fax)
Email: dcab@doh.hawaii.gov
Website: <https://health.hawaii.gov/dcab/>

Call DCAB toll free from your county:
Hawai'i County 974-4000, ext. 6-8121#
Kaua'i County 274-3141, ext. 6-8121#
Maui County 984-2400, ext. 6-8121#
Moloka'i & Lana'i 1-800-468-4644, ext. 6-8121#

Gimme A Break

Gimme A Break is a non-profit 501(c)3 organization whose mission is to care for caregivers by giving an emotional and physical break as well as resources for continued well-being.

Phone: (808) 754-3787
Email: info@gab808.com
Website: gab808.com

Hawai'i Family Caregiver Coalition

Kathy Wyatt, President
Email: kwyatt01@aol.com
Website: hfccoalition.org



Hawai'i Pacific Gerontological Society

P.O. Box 3714
Honolulu, Hawai'i 96812

Sherry Goya, HPGS Executive Director
Phone: (808) 722-8487
Email: sgoyallc@aol.com
Website: hpgs.org

Medicare Nursing Home Compare

A nursing home is a place for people who cannot be cared for at home and need 24-hour nursing care. Nursing Home Compare has detailed information about every Medicare and Medicaid-certified nursing home in the country.

Website: www.medicare.gov/nursinghomecompare/search.html

National Alliance for Caregiving

Established in 1996, NAC is dedicated to improving quality of life for friend and family caregivers and those in their care by advancing research, advocacy, and innovation.

1730 Rhode Island Avenue, NW, Ste. 812
Washington, DC 20036

Phone: (202) 918-1013
Email: info@caregiving.org
Website: www.caregiving.org

Project Dana

Project Dana is a Faith In Action program that provides a variety of services to the frail elderly and disabled to ensure their wellbeing, independence, and dignity in an environment of their choice. Support comes from a corps of trained volunteers guided by the principle of "Dana," which combines selfless giving and compassion without desire for recognition or reward.

Project Dana recruits and trains volunteers across the state to assist the frail and elderly with:

- Friendly visits
- Respite services
- Transportation to medical appointments, grocery shopping, and religious services
- Telephone visits
- Minor home repairs, light housekeeping
- Home safety assessment/education
- Family caregiver support

Volunteers are sensitive to diverse cultures and traditions. They receive initial and continual training and education from the project and are managed by trained volunteer coordinators from partner congregations.

Cyndi Osajima, Executive Director
902 University Avenue
Honolulu, Hawai'i 96826

Phone: (808) 945-3736
Email: info@projectdana.org
Website: www.projectdana.org

St. Francis Healthcare System

Phone: (808) 547-6500
Email: info@stfrancishawaii.org
Website: www.stfrancishawaii.org
Educational & Research Institutions

Educational & Research Institutions

The University of Hawai'i at Mānoa

Center on Disability Studies

University of Hawai'i at Mānoa
1410 Lower Campus Road, 171F
Honolulu, Hawai'i 96822

Phone: (808) 956-5850
Email: [cgsinfo@hawaii.edu](mailto:cdsinfo@hawaii.edu)
Website: cgs.coe.hawaii.edu

Center on Aging University of Hawai'i at Mānoa

Myron B. Thompson School of Social Work & Public Health
Christy Nishita, PhD, Interim Director

Gartley Hall
2430 Campus Road
Honolulu, Hawai'i 96822

Email: uhcoa@hawaii.edu
Website: www.hawaii.edu/aging

Center on the Family

University of Hawai'i at Mānoa
2515 Campus Road, Miller Hall 103
Honolulu, Hawai'i 96822

Phone: (808) 956-4132
E-mail: cof@hawaii.edu
Website: uhfamily.hawaii.edu

Elder Law Center

University of Hawai'i at Mānoa
William S. Richardson School of Law
Professor James H. Pietsch,
Director/Attorney

2515 Dole Street, Room 201
Honolulu, Hawai'i 96822
Phone: (808) 956-6544
Web: www.hawaii.edu/uhelp/index.html

Hā Kūpuna

National Resource Center for Native Hawaiian Elders
University of Hawai'i at Mānoa
Myron B. Thompson School of Social Work & Public Health
Kathryn Braun, DrPH,
Principal Investigator and Director
Rachel Burrage, PhD, Co-Investigator
Yanyan Wu, PhD, Researcher
Yeonjung (Jane) Lee, PhD, Researcher
Shelley Muneoka, MSW,
Project Coordinator

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

Phone: 808-956-7009
Email: hakupuna@hawaii.edu
Website: manoa.hawaii.edu/hakupuna

Public Policy Center

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

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

Phone: (808) 956-4237
Email: ppcsec@hawaii.edu
Web: publicpolicycenter.manoa.hawaii.edu



Aging & Disability Issues 2023

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