A Guide for Hawai‘i’s Legislators, Organizations & Citizens

Aging Issues

2010
The Hawai’i Family Caregiver Coalition was formed to develop new partnerships at local and state levels to advance a coordinated approach to address the needs of Hawai’i’s family caregivers. As caregiving touches everyone, the mission of the Hawai’i Family Caregiver Coalition is to improve the quality of life of those who give and receive care by increasing community awareness of caregiver issues through continuing advocacy, education, and training.

Over the years, the Hawai’i Family Caregiver Coalition has supported our community by sponsoring the following projects:

- Holo Imua Kakou Legislative Reception
- Family Caregiver Awards Program – a joint venture with KHON2’s Elderhood Project
- Aging Issues Report
- Family Caregiver Awareness Day and Resource Fair
- Family Caregivers Speakers’ Bureau
- Family Caregiver’s Kit for Businesses

For more information, please contact Wes Lum at 808-343-2165 or at wesleylum@yahoo.com.

Organized in 1979, the Hawai’i Pacific Gerontological Society (HPGS) is a not-for-profit organization dedicated to improving the quality of life of Hawai’i’s older adults. HPGS promotes the understanding of the aging process, supportive services, and legislation that help people age with dignity and grace. It is the largest voluntary, multidisciplinary group in the State committed to dialogue and discussion, networking and information-sharing on issues and policies affecting older adults in Hawai’i.

If you are a professional or non-professional, actively retired or still employed, young or not so young, if you are engaged by the idea of creating a better Hawai’i for our elders, please accept this invitation to join the Hawai’i Pacific Gerontological Society now!

Please visit the Hawai’i Pacific Gerontological Society online at http://www.hpgs.org/ or mail your inquiry to: P.O. Box 3714, Honolulu, Hawai’i 96812.
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Mr. and Mrs. C. expressed fatigue and sadness regarding their current situation. Both individuals experience significant mobility limitations. Mr. C. cannot move about without a walker, and Mrs. C. cannot walk without a cane. Although the couple receives a limited number of homemaker services per month, they are waiting for Kupuna Care personal care services. With tears on her face, Mrs. C. described how she must bathe her husband in an outside area with a water hose because she has no assistance and cannot help her husband in and out of the bathtub. Mrs. C. continued on to describe how she assists her husband with many other basic life tasks as she struggles with her own limited mobility. Mrs. C. spoke of how she did her best to maintain their home, take care of her husband, and take care of herself, but yet her guilt is sometimes unbearable.

This couple has no immediate family in Hawai‘i. Family members moved to the mainland in order to find sufficient work. They don’t know how long they must wait for someone to assist them with basic tasks, such as personal hygiene.

This real-life story illustrates the need to improve Hawai‘i’s long-term care system. Aging Issues 2010 is the fifth annual publication that offers an overview of legislative issues dealing with aging, caregiving, and long-term care. It is a joint project of the Hawai‘i Family Caregiver Coalition (HFCC) and the Hawai‘i Pacific Gerontological Society (HPGS). In addition, several other organizations have contributed funds, which have made possible the publication of this report. Their support is gratefully acknowledged.

Each year, the Hawai‘i Legislature considers many bills on aging and related subjects, but it is often unclear how these bills relate to each other and to the major concerns of the state’s older and disabled populations. In past years, the Legislature has created new programs and provided enhanced funding for existing programs and projects. As Section 2 of the report indicates, Hawai‘i’s current financial situation calls for a radically different approach. This creates serious challenges for legislators, public agencies, advocates, and the public alike.

In good years or bad, public policy should be governed by broad principles, such as those found in Section 3 of this report. In addition to the principles described herein, we recommend that readers consult the reports of Hawai‘i’s Long Term Care Commission when these become available. When created in 2008, the Commission was charged with developing a comprehensive state plan based on broad policy decisions adopted by the Legislature.

The four previous editions of Aging Issues listed bills and resolutions that had survived hearings in their house of origin and had “crossed over” to the other house. These were bills that stood a reasonable chance of becoming law. The 2009 report described over 30 such bills and resolutions. The 2010 Aging Issues booklet is being written early in the session. The issues listed in Section 5 reflect selected measures supported by the Kupuna Caucus, the Joint Legislative Committee on Aging in Place, and senior advocacy organizations. Apart from the Kupuna Care program, they involve little or no financial appropriations.

Thousands of studies and reports have been written about the problems frail elders and persons with disabilities face in dealing with health, finances, and other issues. The statistics indicate that Hawai‘i, the nation, and the world face an aging tsunami for which we are ill prepared. Yet, this overwhelming mass of evidence has not significantly affected public policy at the local, state, or national levels. People are often motivated to act when they perceive that a problem may affect them personally. For this reason, Aging Issues this year includes personal stories from across the state which describes the difficulties any of us could experience when faced with aging or a disability. These are found primarily in Section 4, as well as in other locations throughout this report.
Hawaii, along with the rest of the nation and world, is experiencing a serious economic downturn which is reflected in dramatic reductions in revenues available for health and social programs. Hawaii is facing a 1.2 billion deficit through June 2011, based on current projections (Gov. Lingle, State of the State Message, 1/25/2010). This means that maintaining funds for current programs is threatened, and there are few, if any, resources for new endeavors. Therefore, most proposals being advanced this year have minimal or no funding requirements.

Recognizing the seriousness of the situation, senior advocate organizations (Hawaii Family Caregiver Coalition, AARP Hawaii, Policy Advisory Board for Elder Affairs, Kokua Council, Hawaii Alliance for Retired Americans) met in Fall 2009 and decided to unite for the 2010 Legislative Session around the priority of preserving Kupuna Care services for frail elder adults. The individuals receiving these services are in immediate need of assistance; and even then, most of these services have significant waitlists. As of September 30, 2009, 594 older adults were waitlisted statewide for Kupuna Care services. For example, there is over a four month wait to receive home delivered meals. Furthermore, the need for these services is growing and will continue to grow.

Consequently, during this session, senior advocacy organizations believe that in order for the state to meet its minimum obligations to preserve the well-being of citizens, the Rainy Day Fund should be preserved for its original purpose of providing health and human services, and that the Legislature should explore alternatives for raising additional revenue. We do not believe such a sizeable deficit can be closed solely by additional program cuts, since programs have already endured significant roll-backs.

Kupuna Care services have made my mother’s life so much safer and better. The Meals on Wheels program, which brings a hot lunch to her door, has literally saved her life. One day, Mom had started cooking and left the stove for what she thought would only be a minute. Forgetting she had the stove on, she went out into the yard. Luckily, I was able to defer what could have been a real tragedy.

The delivery driver of the meals makes it a point to make contact with mom everyday. He ensures that she’s safe, but more importantly, he provides that social contact she so enjoys daily. As for our family, we feel such relief knowing mom gets a hot nutritious meal on time. In truth, it has kept our sanity coordinating our hectic schedule with work and family. With her small appetite at her age, the meal sometimes provides both her lunch and dinner.

Kupuna Care also provides a helper to come in to mom’s little place and do a little bit of cleaning two hours every other week. Being frail, it’s extremely difficult for her to bend over to clean her bathroom and sweep and mop the floors. The homemaker service keeps her home clean and provides a healthy environment for her to live in.

Regarding Kupuna Care’s transportation services, it amazes me to see how caring the bus drivers are with the seniors. The drivers take the time to assist the seniors on and off the bus, watch that they reach the entrance to their destination, and sometimes even assist them to their door with their packages. Since they can no longer drive, transportation services provides a means for seniors to get to their medical appointments, attend activities at the senior centers, and do their shopping for necessities.

The Kupuna Care services have enhanced my mom’s health and well being, and have allowed her to live in her home near her family and friends, and remain in the community she has lived in all of her life. It is an essential program for all the kupuna of Hawaii.

— Bruce S.
The state administration and legislature currently face a genuine funding crisis that is likely to continue beyond this year. In the face of this crisis, we believe it is essential that funding and policy decisions respect fundamental principles. Sometimes, short-term savings by reducing programs can actually increase costs in the long run. We propose the following as fundamental policy principles:

**Fiscal Measures Should Spread the Burden Across the Entire Population.** In times of economic downturn, the easiest response is often to reduce public services to the most vulnerable citizens who depend upon these services for meeting their basic needs. We believe that such measures typically generate further social and health problems, and are lacking in fairness. We suggest that every effort be made to avoid this approach, and instead adopt measures that either reduce expenses or spread the burden across the entire population.

**Preserve the Safety Net of Home- and Community-Based Services.** Unpaid family caregivers provide approximately 80% of the care of disabled and frail elderly individuals. Patients cared for in their homes have higher life satisfaction and higher levels of functioning than those placed in institutional environments. The public interest is best served by maintaining those programs that provide services to frail and disabled persons in their homes and assist families in continuing to provide informal care. Reductions of such services would likely result in greater dependence on expensive institutional care.

**Create Policies and Programs to Support Home- and Community-Based Care.** A closely related principle is to create policies and programs that enable disabled and frail elderly to remain in their homes. Our long-term care system is still overly dependent upon institutional care. Family caregivers face daunting challenges in trying to balance caregiving with maintaining their own well-being, and in many cases, their need for paid employment. When resources become available, government should expand the infrastructure of home- and community-based services, such as developing single-access Aging and Disability Resource Centers for information and referral; creating wage replacement benefits for employed caregivers; providing resources for home modifications; offering financial assistance to family caregivers; and expanding respite services.

**Assure Consumer Choice and Quality Care.** A certain proportion of the disabled and frail elderly have circumstances or health conditions that require placement in a foster home, adult residential care home, or nursing facility. Patients often experience resistance to being removed from their familiar home environments, and families face concerns about selecting an appropriate care environment and being assured that their loved one will receive quality care. Several measures propose protections related to the quality of care and also provide ready access to information to assist them in making placement decisions.

**Develop Essential Public-Private Partnerships.** Traditionally, the aging network has drawn most heavily on federal and state resources. Many of these came into existence as a result of the federal Older Americans Act of 1965. Forty years later, it is abundantly clear that, even under good economic conditions, existing public programs cannot begin to meet the needs of today’s older population. These can be met only if and when the immense resources of the private sector are fully engaged in this effort. Legislators and public officials must make creation of working relationships with businesses, industry, and philanthropy a major priority.
Funding for home and community based services through the Kupuna Care program has remained static since 2002. With growing inflation, Kupuna Care services have become insufficient to meet the needs of Hawai'i’s frail elderly. The story of Mr. and Mrs. O describes the difficulties of maintaining a quality life with reduced Kupuna Care services.

Mr. O. receives a variety of Kupuna Care services. Because he is wheelchair-bound and has numerous deficiencies in the activities of daily living and the instrumental activities of daily living, he qualifies for personal care, homemaker, chore, home delivered meals, and transportation. His wife is a senior as well, and she serves as his primary caregiver.

Mrs. O. indicated that she is concerned for her own health, as she is taxed daily with providing full-time care for her husband. Mr. and Mrs. O. exemplify the folks for whom Kupuna Care services were initially designed—those who desire to live in their own homes rather than in institutions as they age in place.

Yet Mr. and Mrs. O. may lose service hours due to budget constraints. This year, because no additional Kupuna Care funding has been received by county area agencies on aging (AAA), funding is very limited. In order to serve all of those needing assistance, AAAs have reduced overall service hours.

Mrs. O. is willing to work diligently to keep her husband at home. We know, however, that caregivers often “pay” for increased efforts with their own health, and Mrs. O. is concerned about her own ability to maintain the stamina necessary to remain healthy.

B.G., their paid caregiver, also voiced concern regarding the number of folks that she knows who need help and are currently on waiting lists for services. “People need help, and we can’t help. There’s lots of people who need help and can’t get it,” she said.

B.G. also indicated that many providers are working two to three jobs and simply have no time to add additional kupuna to their schedules.

Respite care can be defined as the temporary physical, emotional, or social care of a dependent person in order to provide relief from caregiving to the primary care provider. Here, Sumi M. shares how respite, a Kupuna Care service, has really made a difference in their family’s life.

“In December of 1994, my husband Hank suffered a stroke, which left him paralyzed on his right side. Since then, he has lost the ability to walk and has remained in a wheelchair. I am his sole caregiver. We are both octogenarians, and we have no children.

Since 1995, I drove Hank to Kalakaua Gym in Kalihi three times every week, a stressful drive on the freeway during the morning rush hour. Then, in 2001, a Project Dana volunteer, Mike, came to our rescue, offering to take Hank to and from Kalakaua Gym on Fridays.

Mike has been a caring and faithful volunteer with whom Hank has developed a warm friendship. He occasionally clips articles and stories to share with Mike and looks forward to “Fridays with Mike.” I’m sure they have interesting conversations during their ride to and from the gym! I too eagerly look forward to Fridays, as it is the one time I feel totally free without worrying about Hank. It gives me time to do my own thing such as shopping, banking, or just visiting with friends.

Since last year, I have been taking a computer class, which has enabled me to contact friends around the world via e-mail. I truly get a psychological “lift” from not worrying about Hank and from being relieved of the stressful drive from Kahala to Kalihi.

Mike’s help has really been a blessing and a gift to Hank and to me, and we are grateful to Rose and Project Dana for providing this wonderful service.”

It’s not unusual for families to provide various levels of care to multiple family members. Janelle Y. shares here the experience of caring for her mother and grandmother while raising two boys and working for a social services agency.

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and other needs. I mostly help her with transportation to do her banking, shopping, picking up her medications, and occasionally providing transportation to her doctor’s appointments. I also do some Costco/Sam’s Club shopping for her.

In addition to working and caring for a young family (I have 2 boys, ages 5 and 7), caregiving for my mom and grandmother takes time out of my busy schedule. I find very little time to care for myself. I know I should find a de-stressing activity and/or physical activity for my health, but there does not seem to be a lot of time left, and I have little energy. I can totally empathize with other caregivers who ignore their own needs to see to their caregiving responsibilities.”

TRANSPORTATION SERVICES ARE AN ESSENTIAL COMPONENT OF A HEALTHY HOME- AND COMMUNITY-BASED SYSTEM. Emerence W. shares her story of how assistance with transportation has increased the quality of life for herself and her 88-year-old mother.

“My mother has multiple disabilities and medical problems, and I am also disabled. We subsist on Social Security and other entitlement programs, such as food stamps and Medicaid.

Since I do not drive, transportation has always been a constant worry for us. Before Project Dana, I would have to make multiple trips to the store on foot each week. I could only carry what would fit into my folding grocery cart, and just one or two bulky items would equal one trip. Another major concern was transportation to doctor’s appointments. It was a financial burden to always have to take a taxi.

Project Dana now takes me grocery shopping biweekly, which enables me to stock up on bulky and heavy items. Similarly, Project Dana provides us with reliable transportation to doctor’s appointments for my mother and relieves us of the exorbitant cost of taxi service. It also alleviates the worry of being late for an appointment and having to reschedule.”
When my mom suffered a heart attack approximately six years ago, I didn’t know where to turn. I helped out before and after work, which became very stressful and exhausting. I drove to and from Waikiki to Waipahu, where she lived with my brother (our father passed away 31 years ago). My brother provided limited help because of his work schedule.

My 88-year-old mother is diabetic (II), blind in one eye, has heart disease (had a bypass and has a stent), poor circulation in her legs (had a leg bypass), and her mobility is unsteady. However, her activities of daily living are fair, and her Korean stubbornness enables her to still live independently. She has some memory loss and is getting more fragile. She has a fixed income, and therefore cannot afford to pay for the homecare assistance which she requires.

I help my mother whenever I can, taking off from work to transport her to the doctor’s office, grocery shopping, house-cleaning, etc., but I do not meet all her daily needs. Finding and learning about community resources for the elderly was extremely frustrating. I searched the yellow pages, talked with friends, and made phone calls, which usually involved multiple calls before reaching an actual person to talk to.

On the bright side, after numerous phone inquiries, I found Child & Family Service (CFS), a nonprofit social service organization that offers assistance for the elderly, among others. Specifically, their respite and case management services provided much needed support and was a blessing for me. I was so impressed with CFS, their staff, and services, I became an employee myself and I hope to continue to assist others who may find themselves in my situation.

CFS programs are funded through the state’s Kupuna Care program and federal grants. The ‘Ohana Care Program provided my mother a respite worker who helped with light meal preparation, shopping, light chore services, etc. She received financial assistance to pay for these services until she was able to manage payments on her own. The Senior Case Management Program provided a case manager who made home visits to check on her status and give consultations. It was comforting for me to know that she was well taken care of during the hours that I could not be there for her. I believe the federal and state funding provided my mother services she would not otherwise have to live a healthy and independent life at home.

On the other hand, cutting federal and state funds and trimming or discontinuing services would deeply affect the elderly, children, and disabled. Decreasing funds and services would deny my mother’s enjoyment of a prolonged life at home and would certainly increase my stress level. In the future, it could possibly cause me to quit my job to care for her, as numerous others have done so already.

Currently, however, my mom no longer has a respite worker and is on a waitlist for chore services. Her caregiver respite services stopped because of her lack of finances. When she re-applied for services, there were no available workers in the Waipahu area. I hope my voice and message will be added to countless others to support funding for the above issues.

— Kathy M.

Kupuna Care. Enabling elders to remain at home with family caregiver and supportive services is essential in reducing expensive institutional care. Keeping loved ones at home is also preferred by families. Kupuna Care services are at the heart of national, statewide, and local efforts to rebalance long-term care towards home- and community-based care. The highest priority issue is to maintain Kupuna Care funding for the 2011 fiscal year, in part through using a portion of the Rainy Day Fund. legislative measure: SB819.

Community Services. Appropriates funds from the Rainy Day Fund for senior centers, the Kupuna Care program, the continued development of the Aging and Disability Resource Center, and respite services, among other health and human services. legislative measure: SB2469.

Assisting Grandparents Raising Grandchildren in Public Senior Housing. Requests housing agencies to make exemptions to allow eligible seniors who become the sole or primary caregiver for their grandchil- dren to be given sufficient time to find alternative housing. legislative measures: SB2473, SR22, SCR30.

Posting of Annual Inspections. Public internet posting of annual inspections of adult day health centers.

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ters, care homes, and foster care homes gives the public access to the same kind of information as is currently available for nursing homes. Residents, potential residents, and their caregivers should have information relevant to quality of care in making their placement decisions. Legislative measures: HB818, SB321, HB2471.

Silver Alert. A voluntary program, similar to Maile Amber Alert for children, would enlist law enforcement agencies in helping to locate missing elders with dementia or life-threatening physical problems. Legislative measures: HB2142, SB2097, SB2226.

Case Management Standards. Legislation is proposed to address quality-of-care and conflict-of-interest issues for case managers working with residents of adult foster homes. Legislative measures: HB2154 establishes a task force to undertake an assessment of case management issues as a basis for possibly requiring certification; HB2155 requires case management agencies and case managers to adhere to a professional code of conduct and establishes requirements for a code of conduct. SB2031 requires certification of case managers.

Fall Prevention Task Force. An estimated one-third of elderly in Hawai‘i fall each year. Preventable falls result in a significant number of injuries and deaths. The Task Force would encourage health care facilities, government, nonprofit agencies, and community organizations to collaborate in developing fall prevention programs and engaging in public education to reduce preventable falls. Legislative measures: SCR32, SR23.

Volunteer Career Mentoring Program for High School Students. Establishes a voluntary career mentoring program in the Department of Education to provide high school students with contact information for retirees who volunteer to share experience and knowledge about potential careers. Legislative measures: HB2143, SB 2096.

Pre-Need Funeral Trusts. Requires a 100% deposit for a pre-need funeral plan, plus the interest to be deposited in a trust. A cemetery or pre-need authority can deduct certain expenses, but requires annual statements of the disposition of the trust funds. Legislative Measures: HB2146, SB2285.

Long-Term Care Commission. Extends the sunset of the commission to the conclusion of the 2012 Legislative Session. Legislative Measures: HB2145, SB2286.

Home for Life Task Force. The Home for Life Task Force was created by Senate Concurrent Resolution 7 in the 2009 Session. Legislation is proposed to allow the Task Force to convene so as to fill vacancies and continue its work through 2010. Legislative measures: SCR31, SR24.

Deferred Elder Care Agenda
The Joint Legislative Committee on Aging in Place (Co-chairs: Rep. Marilyn Lee and Sen. Les Ihara) and the Kupuna Caucus (Co-chairs: Rep. Marilyn Lee and Sen. Suzanne-Chun Oakland) have been working over several years on a comprehensive set of measures to create an infrastructure of home- and community-based services which would enable Hawai‘i to re-balance long-term care from a heavy dependence on institutions to enabling individuals to age in place. These measures are critical in anticipating the future challenges of a rapidly growing elder population. Task forces, studies, and proposals have resulted from these efforts, but until there is an economic recovery, there are no state funds for their implementation. However, these measures should continue to have attention, and in some instances, securing private or federal funds may allow progress to continue. The measures include: aging and disability resource centers; the University of Hawai‘i Center on Aging; Sage PLUS staff on the Neighbor Islands; a cash and counseling model for the care of frail elders; new funding for a respite care directory; caregiver assistance and home modification tax credits; and a funding mechanism for wage replacement benefits for employed caregivers.
Public and Nonprofit Agencies

**Hawai‘i Aging and Disability Resource Center**
A one-stop source for information, assistance, and access to services and care for older adults, people with disabilities, and family caregivers.
Website: www.hawaiiadrc.org

**Executive Office on Aging**
Noemi Pendleton
Executive Director
Phone: (808) 586-0100
Fax: (808) 586-0185
Email: eoa@doh.hawaii.gov
Website: www4.hawaii.gov/eoa

**Kaua‘i Agency on Elderly Affairs**
Kealoha Takahashi
County Executive on Aging
Phone: (808) 241-4470
Fax: (808) 241-5113
Email: ktakahashi@kauai.gov
Website: www.kauai.gov/OCA/Elderly

**Maui County Office on Aging**
Deborah Arendale
County Executive on Aging
Maui: (808) 270-7774
Moloka‘i: (808) 553-5241
Lana‘i: (808) 565-7114
Fax: (808) 270-7935
Email: aging@co.mau.hi.us
Website: www.mauicounty.gov/departments/Housing/aging.htm

**Hawai‘i County Office of Aging**
Alan Parker
County Executive on Aging
Hilo: (808) 961-8600
Kona: (808) 327-3597
Fax: (808) 961-8603
Email: aparker@hcoahawaii.org
Website: www.hcoahawaii.org

**Elderly Affairs Division**
City and County of Honolulu
Elizabeth Bathea
County Executive on Aging
Phone: (808) 768-7708

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

**Hawai‘i Family Caregiver Coalition**
Harry Mattson, President
Phone: (808) 382-9483
Email: h.mattson@hawaii.rr.com

**Hawai‘i Pacific Gerontological Society**
Eldon Wegner, President
Phone: (808) 428-1654
Email: hpgs.hawaii@gmail.com
Website: www.hpgs.org

**Educational and Research Institutions**

**The University of Hawai‘i at Manoa Center on the Family**
Dr. Sylvia Yuen, Director
Phone: (808) 956-4132
Fax: (808) 956-4147
Email: syuen@hawaii.edu
Website: www.uhfamily.hawaii.edu

**Center on Aging**
Dr. Colette Browne
Interim Director
Phone: (808) 956-5001
Fax: (808) 956-9582
Email: cbrowne@hawaii.edu
Website: www.hawaii.edu/aging

**Ha Kupuna: National Resource Center for Native Hawaiian Elders**
Drs. Kathryn Braun, Colette Browne, & Noreen Mokuau
Co-Principal Investigators
Phone: (808) 956-6243
Fax: (808) 956-5964

**Public Policy Center**
Dr. Susan Chandler, Director
Phone: (808) 956-4237
Fax: (808) 956-0950
Email: chandler@hawaii.edu
Website: www.publicpolicycenter.hawaii.edu

**Kapi‘olani Community College**
Kupuna Education Center
Dr. Cullen T. Hayashida
Long-Term Care Development Coordinator
Phone: (808) 734-9108
Fax: (808) 734-9128
Email: cullen@hawaii.edu
Website: www.kupunaeducation.com

**Maui Community College**
Maui Community Care Corps
Rita Barreras, Project Director
Phone: (808) 264-0491
Email: rbarreras@hawaiiantel.net
Website: www.mauilongtermcare.org
I think that it’s time that I openly thank some good folks for some good things. My name is Roger. I’m elderly and have been living along on Social Security in a state-run housing project for about 10 years. I have a debilitating respiratory disease, and as my health worsened, so did my ability to take care of myself. Eventually, the simplest of chores became insurmountable tasks.

Then, about six years ago, I was fortunate enough to be put in contact with an agency designed to help the elderly, and I soon found my deteriorating quality of life dramatically improved in several areas.

I want to thank all you folks at the Agency on Elderly Affairs for arranging for me to receive a few precious hours a week of much needed help in making my apartment a cleaner, safer, and cheerier place to live. I also want to thank you for making it so much more convenient for me to utilize the bus transportation system to get to my doctor, the pharmacy, the grocery store, and all of the other places I need to get to. And finally, I want to thank you for making sure that I get a nourishing lunch, properly prepared and faithfully delivered to me five days a week. The good food and cheery smiles strengthen me in many ways.

I must also mention that, three years ago, respiratory failure put me in the hospital, where I lingered on life support for three weeks. Surprisingly to all, I rallied, and after a couple more weeks in recovery, I was able to return to my home again. In retrospect, I attribute much of my surviving the ordeal to the elderly care I had been receiving beforehand, and my impressive recovery to the care I’ve received.

— Roger D.
Section 6. (continued)

(Continued from previous page.)
- Angie Hoffman, MetLife
- Tony Lenzer, Hawai‘i Alliance for Retired Americans
- Wes Lum, Hawai‘i Family Caregiver Coalition
- David Marcouiller, MetLife
- Harry Mattson, Pacific Research and Planning Associates
- Gary A. Powell, The Caregiver Foundation of America
- Peter Reyes, Catholic Charities
- Eudie Schick, Policy Advisory Board for Elder Affairs
- Helen Wagner, Na Tutu, Grandparents Raising Grandchildren
- Eldon Wegner, Hawai‘i Pacific Gerontological Society

Report Production & Editorial Committee
- Tony Lenzer
- Wes Lum
- Eldon Wegner

Graphic Artist
- Jason Y. Kimura Communications

Members of the Joint Legislative Committee on Family Caregiving and Kupuna Caucus
The Hawai‘i Family Caregiver Coalition and the Hawai‘i Pacific Gerontological Society wishes to thank the Legislature’s Kupuna Caucus and Joint Legislative Committee on Aging in Place.

Joint Legislative Committee on Aging in Place
- Senator Les Ihara, Jr., Co-chair
- Representative Marilyn Lee Co-chair
- Senator Rosalyn Baker
- Senator Suzanne Chun-Oakland
- Senator Fred Hemmings
- Representative Karen Awana
- Representative Corinne Ching
- Representative Joey Manahan

Kupuna Caucus
