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## A Policy Analysis of the Kupuna Caregivers Act: Addressing the Needs of Working Caregivers in Hawaii

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Sarah Wackerbarth, PhD, Committee Chair

Dr. Corrine Williams, Director of Graduate Studies

**A Policy Analysis of the Kupuna Caregivers Act:  
Addressing the Needs of Working Caregivers in Hawaii**

**CAPSTONE PROJECT PAPER**

A paper submitted in partial fulfillment of the  
Requirements for the degree of  
Master of Public Health in the  
University of Kentucky College of Public Health

By

**Emily S. McCarthy**

Lexington, Kentucky

Final Examination:

Lexington, Kentucky, April 19, 2018

Capstone Committee:

**Sarah Wackerbarth, Ph.D.** (Chair)

**Richard Ingram, Dr.P.H.** (Committee Member)

**Ty Borders, Ph.D.** (Committee Member)

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**Emily McCarthy**

## **Executive Summary**

The primary purpose of this paper was to provide a policy analysis of the Kupuna Caregivers Act that was passed at the end of 2017 in Hawaii. This legislation provides a \$70 daily voucher that working caregivers can use to hire long-term care services for their elderly loved ones. This type of assistance allows caregivers to stay in the workplace, alleviates the stress of caregiving, and assists them in securing their own financial futures. The number of people over the age of 65 will double in size over the next forty years, presenting a variety of long-term care challenges in communities across the U.S. Higher rates of chronic disease present in our society today lead to increased health care costs, higher levels of disability, and a greater need for long-term care services. As these long-term care needs increase, seniors will rely on family caregivers to help them age in place. For Hawaii, the combination of an aging population and an ongoing labor shortage forced lawmakers to come up with a policy solution that could provide assistance to the increasing number of working caregivers, help keep them in the workplace, and maintain the same level of care for their elderly loved ones. Public health professionals must ensure that seniors and their caregivers have access to quality care, support networks, and financial assistance to ensure a quality of life that is fair for all citizens regardless of their socioeconomic status.

**Keywords: Caregiver, Kupuna Caregivers Act, Long-Term Care, H.B. 607, Hawaii**

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## Introduction

An aging population with a high rate of chronic diseases<sup>1</sup> is driving up demand for long-term care in the United States. Inevitably, the number of family caregivers will also grow to fulfill this demand. In contrast to previous generations, baby boomers are living longer and facing higher rates of chronic diseases like hypertension, obesity, coronary heart disease, arthritis, diabetes, stroke, cancer, and dementia.<sup>1</sup> Previous studies have shown that 25% of people with chronic conditions have one or more limitations performing the activities of daily life,<sup>2</sup> which fall under long-term care services that are typically not covered by health insurance.

To avoid the high costs of long-term care, seniors often rely on family members to serve as “family caregivers” to assist with their personal care. In this role, a family caregiver acts as an unpaid, informal caregiver to their loved ones. Sixty-one percent of adult caregivers of elderly or disabled family members are employed. These working caregivers often struggle to balance work, family and caregiving duties.<sup>3</sup> They also risk their financial futures, where studies have shown that caregivers lose between \$300,000 and \$650,000 through lost wages and lower Social Security benefits or pensions during their retirement years.<sup>4</sup>

Long-term care encompasses a range of services that provide help with personal care and more complex activities of daily life. Personal care includes bathing, dressing, eating, and using the toilet. Seniors with higher levels of disability need help with other daily tasks like housework, taking medication, preparing meals, managing money, and grocery shopping.<sup>5</sup> Due to the high rates of chronic disease among baby boomers, the

need for long-term-care services will become a critical need as they reach retirement age.

The state of Hawaii has one of the fastest growing elderly populations in the United States, with 17% of their population falling into the 65 and older category as of July 2016.<sup>6</sup> By 2040, approximately 24% of Hawaii's population will be 65 years and older.<sup>7</sup> As long-term care needs grew for their elderly citizens, or "kupuna" as they are referred to in Hawaii, political forces mobilized to support the growing number of caregivers as well. According to AARP, Hawaii currently has an estimated 154,000 caregivers, with this number expected to increase with the aging of the population.<sup>8</sup> In an effort to relieve caregiver strains and keep them in the workforce, Hawaii passed the Kupuna Caregivers Act in 2017. Primarily, this bill provides a voucher for working caregivers to use towards qualified long-term care services while they are serving as the primary caregiver for someone who is 60 years or older.

The purpose of this capstone was to provide a policy analysis of the Kupuna Caregivers Act and the potential impact on the lives of working caregivers, the healthcare system, and the labor market. This analysis examined the political factors that led to the passing of the legislation, possible solutions that were considered either nationally or at the state level in Hawaii and confront the trade-offs between the Kupuna Caregivers Act and these policy solutions. Finally, the Kupuna Caregivers Act was examined for cost, impact on employers, effect on caregiver stress, sustainability, and its ability to honor the idea of aging in place for seniors.



## METHODS

### *Policy Frameworks*

The following policy analysis relied primarily on the process described in Eugene Bardach's book, *A Practical Guide for Policy Analysis – The Eightfold Path to More Effective Problem Solving*.<sup>9</sup> The steps include: 1) Define the Problem; 2) Assemble Some Evidence; 3) Construct the Alternatives; 4) Select the Criteria; 5) Project the Outcomes; 6) Confront the Trade-Offs; 7) Decide; and 8) Tell Your Story. Steps one and two involved an extensive literature review to gather background information and the factors that led to the current demands on caregivers in Hawaii. Through this research, some alternative policies for step three were revealed that have either been suggested or tried in the U.S., Hawaii, or both. After reviewing the evidence, some basic policy evaluation criteria were established for step four based on the documented needs of caregivers, seniors and employers in Hawaii. Step five relies on predicting outcomes of the various policy solutions, which included financial calculations and examining previous outcomes of similar policies. Step six was completed by making a list of the possible positive outcomes and negative outcomes to determine what the trade-offs would be by choosing the Kupuna Caregivers Act over the other policies. Based on the previous steps, the decision to support the Kupuna Caregivers Act with some additional recommendations was made. Steps seven and eight from Bardach, "Decide" and "Tell Your Story," brings the policy analysis to a close by making final recommendations and conclusions about the Kupuna Caregivers Act and its relevance to public health.

To supplement the Bardach process, this policy analysis also reviewed aspects of the formal policymaking process laid out in Beaufort Longest's book, "Health Policymaking in the United States." Portions of the analysis focus on the key political factors that led to the passage of the Kupuna Caregivers Act and what future political forces may affect the long-term sustainability of the policy in Hawaii. To learn more about the political climate as this bill moved through the house, a review of committee reports and testimony by area businesses, public health agencies, and community members were performed through the website of the Hawaii legislature. Additionally, searches were performed to locate relevant news articles published in Hawaii about the progress of the Kupuna Caregivers Act leading up to the enactment of the bill.

### ***Literature Review Process***

In order to identify relevant information related to this policy analysis, a literature review was performed on Google's search engine and the National Library of Medicine database, using the following keywords or a combination of these keywords or phrases: caregiving; working caregiver; family caregiver; eldercare; caregiver burden; caregiving costs; economic impact; informal care; caregiver stress; caregiver strains; mental stress; physical stress; financial stress; long-term care; chronic disease; baby boomers; aging population; aging trends; aging in America; kupuna; kupuna caregivers act; Hawaii; Hawaiian families; family culture; employee productivity; lost wages; employers; absenteeism; Medicare; Medicaid; aging population. For the purposes of this paper, "caregivers" will refer to the primary provider of care for an elderly person or persons, which was the driving force in the development of the Kupuna Caregivers Act.

Information for inclusion was limited to scholarly articles, reports and other online materials published between 2000 and 2017 that focused on seniors, particularly focused on people 65 and older. Information from nationally recognized organizations like AARP, Centers for Medicare and Medicaid Services, the National Census Bureau and the National Caregivers Alliance was also utilized where appropriate. News articles from nationally recognized media outlets were included to locate information about the political climate leading up to the passage of the Kupuna Caregivers Act. Information about caregivers of children, the disabled, or younger adults was excluded unless the statistic was combined with one of these age groups. Editorial pieces, personal blogs, and social media were excluded.

## **RESULTS**

The results section includes two sections that map back to the steps in Bardach's Eightfold Path. The first section, "The Scope of the Problem," includes a definition of the problem (step one) and a summary of the evidence revealed through the literature review (step two). The second section, "Policy Solution," details the primary policy under analysis, the Kupuna Caregivers Act (step three).

### **The Scope of the Problem**

#### ***Retirement of Baby Boomers Increases Need for Long-Term Care***

The most significant contributor to the increase in the elderly population is the retirement of the baby boomer generation, who were born between 1946 and 1964.<sup>10</sup>

In Hawaii, the 65 years or older population increased from 8.0 percent in 1980 to 14.5 percent in 2010. By 2040, the segment will grow to 23.6 percent of the total population (see Table 1).<sup>7</sup> A large elderly population presents many challenges to the economy, due to their higher proportion of chronic diseases and the associated health care costs.

**Table 1: Share of Total Population by Age Group in Hawaii, 1980 to 2040**

Age Group	1980	1990	2000	2010	2020	2030	2040
0-14	23.3%	21.4%	20.2%	18.5%	18.5%	18.8%	18.5%
15-24	19.8%	14.8%	13.6%	13.3%	12.3%	12.1%	12.6%
25-34	18.7%	18.1%	14.1%	13.6%	13.4%	12.6%	12.5%
35-44	11.6%	16.2%	15.8%	12.9%	12.0%	12.1%	11.5%
45-54	9.7%	9.8%	14.2%	14.2%	11.6%	10.9%	11.1%
55-64	8.9%	8.5%	8.9%	13.0%	12.8%	10.6%	10.2%
65+	8.0%	11.2%	13.3%	14.5%	19.4%	23.0%	23.6%

*Source: 1) United States Census Bureau 1980 to 2010 and 2) Projections by Hawaii Department of Business, Economic Development and Tourism 2020 to 2040*

Baby boomers have higher rates of chronic diseases than previous generations, which requires more health care services and supports. Almost half of Americans live with a chronic condition, and nearly 80% of those aged 65 and older have at least one chronic condition. Hypertension, coronary heart disease, diabetes, arthritis, stroke, cancer, and dementia are common chronic conditions that often require years of ongoing care. Further, about 25% of people with chronic conditions have one or more limitations on activities of daily life. Chronic conditions results in more physician visits, higher rates of hospitalization, and greater difficulty with daily activities and personal care.<sup>2</sup>

To fulfill the long-term care needs of the elderly, family members are often called upon to serve as caregivers to their loved ones. The term “family caregiver” is often used to describe relatives, friends, or loved ones that provide unpaid help to another person who needs help with daily activities or personal care.<sup>10</sup> The majority of caregivers assist elderly loved ones with at least one activity of daily living such as getting dressed, bathing, eating or toilet use. Many also help them other activities of daily living such as housework, taking medication, preparing meals, managing money, and grocery shopping. Approximately 43.5 million adults have provided care for an adult or child in the last 12 months, with about 34.2 million providing care to adults 50 and older.<sup>11</sup>

### ***Financial, Mental and Occupational Strains on Caregivers***

Caregivers can experience a range of financial, mental, and occupational stresses while serving as the caregiver. A recent study estimated the estimated impact on lost wages and pension benefits to range from \$303,880 to \$659,139 during the retirement years.<sup>4</sup> Additionally, caregivers spend \$10,000 annually on average for household expenses, personal items, transportation, or paying for respite care.<sup>12</sup> Caregivers also spend time coordinating with various health care providers, community agencies, and businesses on behalf of care recipients. A recent AARP survey found that half of family caregivers perform medical tasks for the care recipients, often reporting that the fear of making mistakes or disappointing the care recipient causes additional stress.<sup>11</sup> In the workplace, caregivers have been known to reduce hours, leave their jobs, and show up

late for work due to caregiving duties. In many cases, caregivers jeopardize their financial futures to care for a loved one.<sup>12</sup>

***The High Cost of Long-Term Care***

Seniors often experience problems with access to care due to the rising costs and the lack of insurance coverage for long-term care services. A recent national survey estimated average annual costs for long-term care services, which showed Hawaii above the national average in all categories (see Table 2).

For most people over age 65, Social Security is their main source of income. As of June 2017, the average monthly Social Security benefit for retired workers was \$1,369 per month or \$16,428 annually.<sup>13</sup> Medicare, Medigap supplemental insurance, and most other private insurance plans do not cover long-term care. Medicare only covers skilled nursing care that is needed on a short-term basis recovering from an injury or medical procedure.<sup>14</sup> Elderly citizens often expend retirement funds paying for long-term care.

**Table 2: Average Annual Costs for Long-Term Care Services\***

	Hawaii	National Median
Home Health Aide	\$59,488	\$49,192
Adult Day Health Care	\$18,200	\$18,200
Assisted Living Facility	\$51,000	\$45,000
Nursing Home – Private	\$158,593	\$97,455
Nursing Home – Semi-Private	\$137,240	\$85,775

*\* Home Health Aide based on 44 hours per week, Adult Day Health Care based on 5 days per week, Assisted Living and Nursing Homes based on 12 months of care. Source: Genworth Cost of Care Survey, 2017*

Eventually seniors may qualify for Medicaid, which is the largest public payer of long-term care. Medicaid covers nursing home services, home health care services, and other personal care services for those that meet income and health care qualifications. But Medicaid benefits vary from state to state, and the coverage provided is not consistent for long-term care. Medicaid is primarily funded by federal and state tax revenues, so there is also no guarantee on the level of coverage for long-term care in the future.

### ***The Desire of Elderly to Age in Place***

Even if elderly populations could afford long-term care facilities, surveys have shown that seniors prefer to age in their home or the home of a loved one. An AARP survey revealed that 90% of people over age 65 want to stay in their homes as they grow old, and 80% believe they will stay in their current residence for their remaining years.<sup>15</sup> Caregivers often help senior with adapting their living space to plan for their future care needs. Living in a familiar place also ensures a sense of security and independence. New surroundings can cause seniors additional stress and uncertainty of the future. Maintaining independence boosts confidence and creates a sense of control during the aging process.<sup>16</sup>

### ***Shortage in the Labor Force and Financial Impact on the Economy***

As a significant number of people move into the 65 and older demographic, the U.S. is not replacing the working-age segment fast enough. Declines in immigration and

birth rates in recent years have exacerbated the problem.<sup>17</sup> Hawaii has seen a gradual drop in birth rates over the last ten years, and immigration reform threatens their large force of immigrant workers, which made up 21% of the workforce in 2015.<sup>18</sup> As the number of working-age adults declines, tax revenues that help pay for programs like Medicare, Medicaid, and Social Security also decrease and threaten the sustainability of these programs. Additionally, companies experience labor shortages and weaken the economy.<sup>19</sup> Hawaii reported a 2.7% unemployment rate as of July 2017. The state's Department of Labor and Industrial relations reported worker shortages across many industries.<sup>20</sup>

Nearly 61% of adults in the U.S. who are caring for elderly or disabled family members are employed,<sup>3</sup> which can negatively impact employers. As the demands of caregiving conflict with work, caregivers are forced to make work accommodations like reducing hours, taking leaves of absence, or leaving the workforce entirely.<sup>11</sup> A 2017 national survey reported that 14% of retirees left the workforce to care for an ill spouse or other family member.<sup>21</sup> Employers lose an estimated \$33.6 billion per year due to lost productivity of working caregivers. A recent study also showed that employers paid 8% more in health care costs for caregivers compared to other employees, potentially costing them an additional \$13.4 billion each year.<sup>4</sup>

This policy analysis examined the potential impact of the Kupuna Caregivers Act on the lives of working caregivers, care recipients, the healthcare system, and Hawaii's employers. The costs and benefits of the Kupuna Caregivers Act was compared with other policy alternatives that help pay for long-term care, support working caregivers,



support elderly wishes to age at home, help employers retain their employees or a combination of these.

### **Policy Solution**

#### ***House Bill 607 - The Kupuna Caregivers Act***

In July of 2017, the Hawaii legislature unanimously passed H.B. 607 to establish funding for caregiver support services to relieve some of the burdens of caregiving and to help keep more Hawaiian caregivers in the workforce. The bill authorized the Executive Office on Aging (part of the Hawaii Department of Health) to establish the Kupuna Caregivers Program and help caregivers locate long-term care services. Additionally, the bill provided further clarification on the eligible service and support options for the elderly that are provided by the Aging and Disability Resource Center (ADRC), which will also be the agency that implements the final program. Currently, \$600,000 in funding is appropriated to provide vouchers to long-term care service providers, which will help relieve some of the emotional, financial, and occupational stresses placed on caregivers. The funding will provide \$70 per day, payable to the service provider, for long-term care supports and services as outlined in the law. The ADRC plans to implement the program in 2018.

#### ***Eligibility Requirements and Provisions of H.B. 607***

Before implementation of the final caregiver support program, H.B. 607 defined the family caregiver and the qualified recipient to ensure the efficient use of long-term

care services by the target populations. In particular, this bill was designed for working caregivers of elderly adults that need help caring for loved ones with limitations related to a chronic condition. A family caregiver can be defined broadly as a spouse, adult child, other relative, partner, or friend who has a personal relationship with an older adult who provides a broad range of unpaid assistance for an older adult with a chronic or disabling condition. But to qualify for funds under the Kupuna Caregivers Act, caregivers must provide care to a qualified care recipient as defined by the law and also be employed at least 30 hours per week by one or more employers.<sup>8</sup> To qualify as a care recipient, the list of conditions was more extensive. Care recipients must be individuals who: 1) Are citizens of the United States or a qualified alien; 2) Are sixty years of age or older; 3) Are not covered by any comparable or government or private home or community-based care service, excluding Kupuna Care services; 4) Do not reside in a long-term care facility; 5) Have impairments of at least a) two activities of daily living, b) two instrumental activities of daily living, c) one activity of daily living and one instrumental activity of daily living OR a) substantive cognitive impairment requiring substantial supervision.<sup>8</sup>

Hawaii established the Kupuna Care program in 1999, which authorized the Executive Office of Aging to develop long-term care services to help frail and vulnerable Hawaiians over the age of sixty age in place. The program is operated through the various Aging and Disability Resource Center locations across Hawaii, which locates government-paid services for seniors, helps them locate long-term care service providers, and assists them in planning for their future care needs. Lawmakers decided

to utilize the same network of service providers in the implementation of the Kupuna Caregivers Act. H.B. 607 set a maximum amount of \$70 a day, payable to the service provider hired by the family caregiver. Caregivers do not receive any of the funds. The money is allocated to cover adult day care, transportation, chores, home-delivered meals, homemaker services, personal care, and respite care provided by a long-term care service provider.<sup>8</sup> Any expense over the amount of \$70 per day is the responsibility of the caregiver or care recipient.

### ***The Role of Politics***

Elderly citizens have fallen under different categories of social construction theory throughout history, which affects their political power and the balance of benefits and burdens that society bestows them. Under social construction theory, populations are categorized into the advantaged, the contenders, the dependents, and the deviants (see Figure 1). The level of power, benefits, and burdens varies across the different groups and can change over time depending on the political climate. Recently researchers analyzed the history of the changing social constructs of the elderly population, focusing on the baby boomer generation. The paper concluded that elderly persons could be categorized as “dependents” throughout most of the early 1900s, as they only made up a small segment of the population at the time and did not experience the level of social program and funding support that exists today. After World War II, the elderly population experienced notable improvements in their economic and social support systems

**Figure 1: Social Constructions and Politics, The Target Populations**

		Constructions	
		Positive	Negative
Power	Strong	<i>Advantaged</i>	<i>Contenders</i>
	Weak	<i>Dependents</i>	<i>Deviants</i>

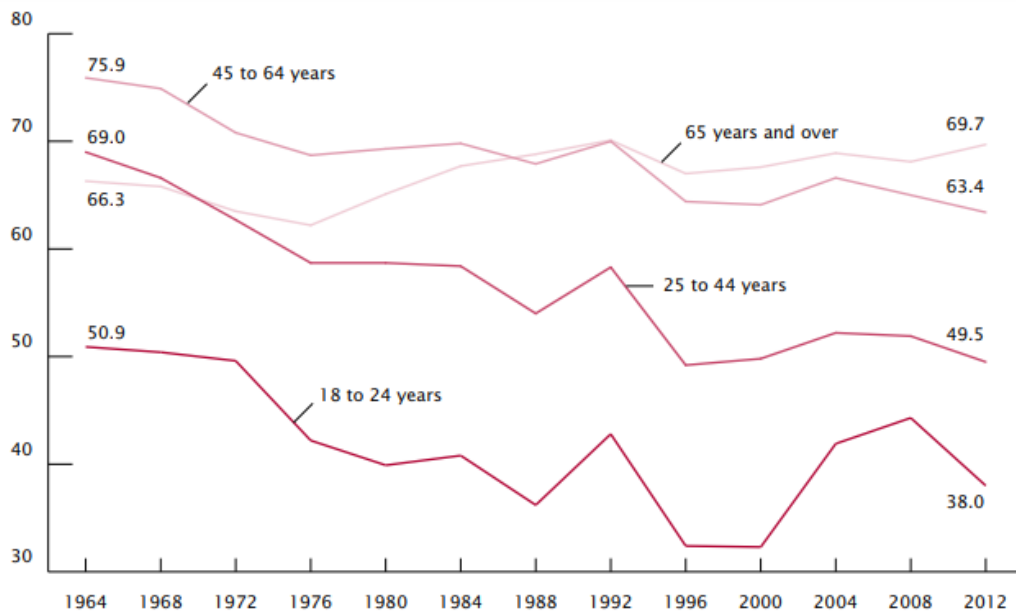
*Source: Schneider and Ingram, 1993*

that moved them into the “advantaged” category of the social constructions, most notably with the passage of the Social Security Amendment in 1965 when Medicare and Medicaid were created. Increases in Social Security benefits and private pensions also contributed to their improved financial security. Voting rates also began to increase in elderly populations, increasing their political presence and power. As these major policy changes were occurring, interest groups began increasing as well to fight for the rights of the elderly population.<sup>22</sup> The public at large continues to show strong support for the needs of our elderly population, but some are beginning to question the viability of social programs that elderly populations continue to benefit from. Some researchers project that more affluent elders will remain contenders and low-income elders will be forced into being dependents once again.<sup>22</sup> But when faced with the staggering

numbers of baby boomers nearing retirement age, political power may rely more on a large number of voters than income levels.

The United States Census Bureau has tracked the voter turnouts for all age groups in presidential elections from 1964 to 2012, revealing that people 65 and older have maintained a high voter turnout percentage through the years, second only to those age 45 to 64 (see Figure 2). During this time, 65% to 69% of people age 65 and older voted in the presidential elections.

**Figure 2: Presidential Election Voting Rates (Percent), 1964 to 2012**



Source: The United States Census Bureau, 2013

In the last few years, the elderly and their caregivers reached their window of opportunity in the policymaking process to develop a long-term care solution in Hawaii. The government had been lobbied by aging-related advocacy groups for years about the impending needs for long-term care as baby boomers reached retirement age.

Employers complained about worker shortages. Caregivers voiced their concerns about their long-term financial futures as they struggled to balance work and caregiving. Democratic Senator Rosalyn Baker led the charge, along with several other Democrats, started working on a long-term care solution to address the concerns of their constituents. Senate Bill 2478 was introduced in 2016 by Senator Baker, proposing a permanent 0.5% increase in the excise tax paid by businesses. However, this bill was designed like a long-term care insurance plan. The money collected would go into a trust fund, with benefits to be paid out to qualified individuals after the first five years. Qualified enrollees would be provided \$70 per day, 365 days of the year, for long-term care services.<sup>23</sup> This bill was also based on the premise of helping seniors “age in place,” and providing relief to their caregivers, as it would not pay for institutionalized care. The bill was deferred, as many large businesses and business advocate groups including the Chamber of Commerce opposed the increase in taxes, claiming that this would increase the cost of doing business in Hawaii, as well as increase the cost of goods and services to consumers and visitors to the islands.

The successful passage of the Kupuna Caregivers Act under H.B. 607 appears to have been achieved by strong support by aging-related interest groups who recognized the implications of an aging population on businesses, caregivers and the elderly themselves. Several organizations like the Executive Office of Aging, AARP, The Hawaii Family Caregiver Coalition and Caring Across Generations provided testimony in support of the bill. Caring Across Generations, a nonprofit advocacy group that works on policy initiatives supporting long-term care solutions for the elderly, created a campaign to

garner support for the bill. The website, [www.care4kupuna.com](http://www.care4kupuna.com), featured detailed information and updates about the bill, as well as a public service announcement that was advertised in Hawaii.<sup>24</sup> Caring Across Generations also organized events around the islands to inform Hawaiians on the benefits of providing support to working caregivers.

In 2017, H.B. 607 was introduced, with temporary funding of \$600,000 coming directly from the state's general funds. Since its passing in July 2017, the Kupuna Caregivers Act has received national press for its innovation and over 1,000 working caregivers have requested more information about the program. Hawaii is now looking to pass Senate Bill 2988 for \$3,400,000 in additional funding.<sup>25</sup> The new legislation would also establish additional tracking and reporting requirements for the Executive Office of Aging to collect information on the Kupuna Caregivers Program for inclusion in its annual report on elder programs. Applications are being accepted now, but the full impact of the program is yet to be determined.

## **INTERPRETATION**

The interpretation section contains three sections that cover Bardach's final steps in the eightfold process. The section titled "Policy Alternatives and Evaluation Criteria" presents several policy alternatives to the Kupuna Caregivers Act, as well as the evaluation criteria used to compare the selected policy options (Steps Three and Four). The second section, "Potential Impact of Choosing the Kupuna Caregivers Act," examines the goals of the legislation and the potential outcomes to be achieved once implemented (Steps Five and Six). And the final section, "Potential Barriers for the

Future,” summarizes some of the main barriers identified that must be addressed for the legislation to meet stakeholder expectations (step six).

### **Policy Alternatives and Evaluation Criteria**

Caregiver support is not a new concept to policymakers, but the importance of caregivers in the healthcare system is gaining traction in American politics. Recently, the Trump administration passed the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act that establishes a committee to develop ongoing strategies that will help recognize and support family caregivers. Currently, there is a shortage of long-term care providers in the U.S., which will be stretched even thinner as the elderly segment of the population grows across the country. Many experts have reported a looming shortage of long-term care workers in the U.S. to meet the demands of people with disabilities and older adults in the future.<sup>26-28</sup> Caregivers will be needed to fill these gaps in care for elderly citizens. In order to evaluate some alternative policy options that could address the needs of caregivers and the related labor shortage in Hawaii, five criteria will be used: 1) Cost; 2) Impact on caregiver stress; 3) Support of elderly desire to age in place; 4) Effect on employers; and 5) Sustainability of the policy.

One alternative is to utilize assisted living facilities so that caregivers are free to work full-time jobs while their loved one receives around-the-clock care by paid caregivers, but this is not an affordable option for most seniors living on Social Security income. The average cost of an assisted living facility in the U.S. is \$45,000 per year for a one-bedroom apartment. In Hawaii, the cost is even higher at \$51,000 per year.<sup>12</sup> With



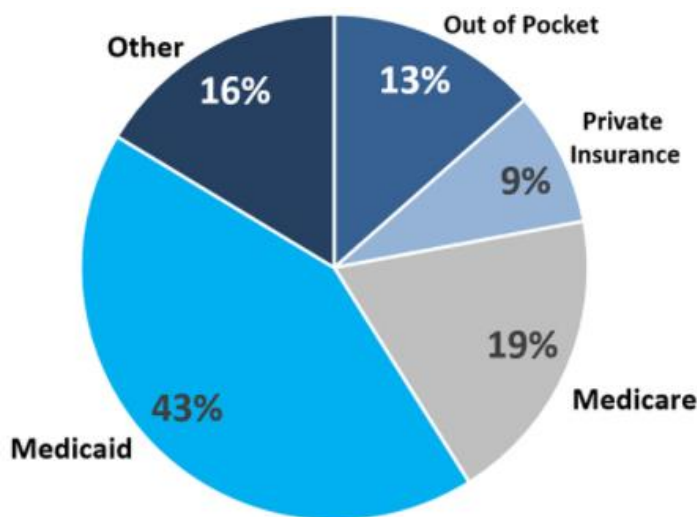
average social security benefits at \$16,428 per year,<sup>13</sup> there is a high likelihood that most elders cannot afford assisted living facilities without supplemental income from retirement savings or a pension, which will not be the case with a majority of baby boomers.<sup>10</sup> In addition, the elderly prefer to age in place as opposed to moving into a facility during their retirement years.

Another caregiving policy that is being explored in the Senate is a tax credit for qualified caregivers, under the Credit for Care Act of 2017. This bill would change the federal tax code to allow a tax credit of up to \$3,000 per year for working caregivers to help with the cost of long-term care services. Under the assumption that working caregivers spend around \$10,000 per year on out-of-pocket expenses for the care recipient,<sup>12</sup> the tax credit would only cover about a third of these costs. Caregivers would also have to wait until the next year to be reimbursed for their expenses, as well as maintain detailed documentation for the entire year. It is also unlikely that caregivers would budget this lump sum of money to use for long-term care services throughout the year. However, it would alleviate some of the financial and occupational burdens incurred by caregivers.

Medicaid and Medicare are two public insurance programs that could be expanded to pay for long-term care services. Medicaid is currently the largest payer of long-term care services, with Medicare being the second largest payer (see Figure 3). With the range of services needed, both programs would need to expand the scope of services included under their long-term care coverage. The Centers for Medicare and Medicaid Services reported that Medicaid paid for 43% of long-term care costs in 2015,

mainly for institutional facilities like nursing homes and home and community-based services such as assisted living, adult day care and home health aides. Medicare typically pay or short-term stays in rehabilitation centers or assisted living facilities, as required to recover from a surgery or other medical procedure in a hospital. With expanding insurance coverage, there is always the issue of moral hazard, where people tend to utilize more services than they need because the financial burden now falls on the insurer. The combination of rising health care costs, an aging population, and higher rates of chronic disease will make expanding coverage under Medicaid or Medicare nearly impossible to sustain in the long term for baby boomers.

**Figure 3: Payers of Long-Term Care Services in the U.S.**



*Source: Centers for Medicare and Medicaid Services, 2015*

Long-term care insurance has been a widely-discussed solution to address the care needs of aging populations and the burdens placed on caregivers, but it may not be a realistic solution in today's health care climate. Seniors on fixed incomes face higher

premiums that usually increase with age, which makes long-term care insurance out of reach for many.<sup>29</sup> In addition, longer life expectancies and the higher medical expenses associated with chronic conditions drives up the price of insurance. According to a study by the Center for Insurance and Policy Research, long-term care insurance premiums increased by 54% between 1995 and 2015.<sup>30</sup> Consequentially, long-term care insurance providers are becoming less inclined to offer long-term care insurance plans in the U.S.

Finally, employers could be part of the solution in terms of providing time off or flexible work schedules to employees who also serve as caregivers. Naturally, employers could face challenges to offering the same flexibility to all employees, risking lower productivity for the company as some employees would take advantage of additional time off even if they are not serving as caregivers. If caregivers could make up their missed work hours, this could be feasible in an office setting where work can be done outside normal business hours. However, this type of flexibility would be difficult to implement in service industries where they maintain structured business hours for customers.

### **Potential Impact of Choosing the Kupuna Caregivers Act**

Using the same criteria for evaluating the Kupuna Caregivers Act, it is the best option for Hawaii based on the state's need to keep caregivers in the workplace, honor the wishes of the elderly and relieve some of the financial and emotional stresses associated with caregiving. While still early in its implementation, some projections can be made about the potential impact of this policy in Hawaii. Based on the average costs

of similar long-term care services in Hawaii and the \$70 per day voucher available to caregivers for hiring long-term care service providers, a basic cost comparison was constructed (see Table 3). Nursing home care was not included in the cost comparison, as institutionalized care is not comparable to the personal care and assistance with activities of daily life that is common in a caregiver’s role. Additionally, the dollars spent for a home health aide were calculated for 20 hours per week, as this is the average number of hours that caregivers spend assisting the care recipient. Adult Day Health Care is calculated at their average daily cost (ranges from \$54 to \$95 per day), as most adult day centers charge a daily rate and do not allow hourly care. Assisted living facilities are not available by the hour, so the dollar amount represents the state’s average cost for 12 months of care, or full-time residency at the facility. Costs are projected out for one, five, and ten years. These costs are intended to represent total cost to society between the options, regardless of the payer.

**Table 3: Total Annual Costs of Kupuna Caregivers Act Voucher Compared to Similar Long-Term Care Services in Hawaii**

	One Year	Five Years	Ten Years
Voucher - \$70/day, 5 days/week	\$18,200	\$91,000	\$182,000
Home Health Aide - \$25/hour, 20 hours	\$26,000	\$130,000	\$260,000
Adult Day Health Care - \$75/day, 5 days/week	\$19,500	\$97,500	\$195,000
Assisted Living – Annually	\$51,000	\$255,000	\$510,000

*Source: Genworth Cost of Care Survey, 2017*

It is difficult to make exact predictions on how much money caregivers would use in a year due to variances in work schedules and the different levels of disability among the care recipients. For simplicity, this model proposes that caregivers would use the entire \$70 voucher once a day, 5 days a week to hire a service provider. In reality, some caregivers would only use the voucher a few days a week, while others might use the voucher seven days a week. However, the cost comparison above does show a clear cost savings when using funds to help pay for outside long-term care services as opposed to the government paying for comparable long-term services outright. Without the \$70 voucher provided by the Kupuna Caregivers Act to hire a service provider, caregivers are forced to spend their own money to pay for care or take time off work to provide this care themselves.

The expansion of the older population has raised concerns about the future labor supply in Hawaii and the potential impact on caregivers. As more people move into retirement, this will present challenges to Hawaii's economy, while simultaneously decreasing the productivity of existing workers who become caregivers for their elderly loved ones. While the Kupuna Caregivers Act will not fully address the labor shortage, it gives time back to caregivers to help them maintain employment and secure their own financial futures. In addition, the ability to take a break from caregiving can have a positive impact on the physical and mental health of caregivers.

## **Potential Barriers for the Future**

Although the Kupuna Caregivers Act addresses the need to keep working caregivers in the workplace as they care for their elderly loved ones, several obstacles stand in the way of its long-term success.

First, the amount of money needed to sustain this program is unknown. It is currently being funded out of general tax revenues, with no annual cap set on the amount each caregiver can spend to hire outside help. It may be difficult to predict how much will be spent each year, as the number of care recipients and working caregivers changes each year. Additionally, the amount each caregiver will use to hire outside providers will vary widely based on the flexibility of their employer and the disability level of their elderly loved one. As seniors age, the additional financial strain on Medicare and Medicaid in the state may also reduce the availability of funds for the Kupuna Caregivers Act.

Hawaii's long-term care system has steadily improved over the years, but certain gaps in care still exist. In the 2017 Long-Term Services and Support Scorecard published by AARP, Hawaii is ranked 7th overall across the 50 states, showing commitment to the needs of the elderly.<sup>31</sup> However, improvement is needed in the supply of health care workers to keep pace with the number of people that will soon be entering their retirement years. Hawaii ranks 40th overall in the number of home health aides and personal aides per 100 adults with limitations on their activities of daily life, where they report 13 per 100 adults, and the national average is 19 per 100 adults. If caregivers are to gain relief from their caregiving efforts, there must be an adequate supply of long-

term care workers to provide respite care. The long-term care workers must also be able to reach care recipients, which would be challenging in some of the remote areas in Hawaii. Approximately 110,000 people live in the rural areas of Hawaii,<sup>32</sup> some of which are located on small islands that lack access to long-term care services.

The cost of living in Hawaii is consistently the highest in the nation, presenting additional challenges to the low-income populations. The state also has one of the highest tax rates, ranking 48 of 50 states according to U.S. News and World Report.<sup>33</sup> The cost of home health aides, homemaker services, assisted living and nursing homes are also significantly higher than the national averages.<sup>12</sup> If the state wishes to maintain long-term care services that low-income seniors can afford, it may be necessary for the government to explore cost-reduction methods that ensure equal access for all seniors.

Finally, it is unclear how success will be measured for the Kupuna Caregivers Act. The amount of money spent and the number of caregivers utilizing the program will be simple to measure. However, stress levels and impact on the labor market will be difficult to measure without a detailed plan in place. Metrics should be put in place to measure the desired outcomes early in the implementation process. The cooperation of caregivers, care recipients, long-term care providers, and employers will be important to ensure that the perspectives of all stakeholders are represented.

## **LIMITATIONS**

Although this policy analysis presented a detailed analysis of the Kupuna Caregivers Act and its potential impact in Hawaii, there were some unavoidable

limitations. First, a majority of the background evidence found on PubMed or from national organizations is national data, not specific to Hawaii. In all cases, efforts were made to locate data for Hawaii. Secondly, since the Kupuna Caregivers Act is a new policy, it is difficult to predict what the uptake of this program will be in Hawaii and its future sustainability. Lastly, some assumptions were made about caregivers in Hawaii regarding how the proposed policy would affect their level of stress.

To conclude the steps in Bardach's Eightfold Path, steps seven and eight are addressed in the "Recommendations" and "Conclusion" sections below. Step seven, "Decide" will make final recommendations that serve to improve the chosen policy solution, the Kupuna Caregivers Act. Step eight, "Tell Your Story," summarizes the key points of the analysis and its relevance to public health.

## **RECOMMENDATIONS**

The intended goals of the Kupuna Caregivers Act are to reduce the burdens on working caregivers, keep caregivers in the workplace, and honor the wishes of the elderly citizens needing long-term care services in Hawaii. While this policy is a major step in addressing these issues, additional changes could be made to improve the long-term sustainability.

Although the annual costs of the program are unknown at this time, an annual cap per caregiver may be appropriate to control costs and ensure the efficient use of funding. Caregivers spend \$10,000 on average for out-of-pocket expenses related to



caregiving duties, but no data exists showing that working caregivers will need to hire outside services every day. While it may not be necessary to cover the entire \$10,000, the proposed amount of \$3,000 that the federal government is considering for a caregiver tax credit would provide some relief for caregivers.

Caregivers are called upon to help loved ones in a variety of ways that may not require professional assistance such as running errands, providing transportation, or paying bills. With the growing number of seniors in Hawaii, it may be beneficial to expand support networks in the community. Today's seniors are comfortable using computers, smart phones, and tablets. An established network of people that can communicate quickly to help each other with everyday activities or transportation could ease the burden placed on caregivers and provide companionship to those seniors living alone or in rural areas of the state. Although paid services like *Seniors Helping Seniors* currently exists, volunteer networks organized by community agencies or churches would be recommended to reduce costs. Senior Corps is an existing program that recruits seniors to volunteer through their *Senior Companions* program, currently assisting about 200 seniors in Hawaii with long-term care needs. Efficiencies could be gained by using this organization to recruit additional volunteers, as the number of elderly citizens needing assistance grows.

The labor market will continue to be a challenge in Hawaii, as birth rates have been declining, and working-age adults are set to retire in staggering numbers. Hawaii needs creative solutions that could attract young families to the state to build its current workforce and ensure a steady flow of people moving into the working-age population.

The high cost of living and housing are the biggest obstacles to attracting young families to the state. By offering more aggressive tax incentives to businesses and affordable housing options to young professionals who relocate to Hawaii, it could be possible to stimulate the economy and labor supply over time.

Finally, a comprehensive program evaluation for the Kupuna Caregivers Act should be developed in coordination with key stakeholders in Hawaii. Total cost, cost per caregiver, type and number of services provided, caregiver stress, job retention rates, impact on long-term service providers, and the effects on the elderly care recipients participating in the program would be important metrics to include in the evaluation of the program.

## **CONCLUSION**

The number of people over the age of 65 will double in size over the next forty years, presenting a variety of challenges in communities across the U.S. The higher rates of chronic disease present in our society today lead to increased health care costs, higher levels of disability, and the need for long-term care services. As these long-term care needs increase, seniors will rely on family caregivers to help them age in place. Caring for elderly loved ones can cause financial and emotional stress on caregivers as they struggle to balance work, family, and the daily responsibilities of caregiving. Low-income seniors and caregivers will face the heaviest burdens during this time, unless long-term strategies are put in place now. The combination of Hawaii's labor shortage and their aging population forced a policy solution that would support working

caregivers and help them stay in the workplace. Similar challenges will emerge in communities around the country as elderly populations increase, changing the balance of retirees and working-age adults.

Public health professionals must ensure that seniors and their caregivers have access to quality care, support networks, and perhaps financial assistance to ensure a quality of life that is fair for all citizens regardless of their socioeconomic conditions. Communities must begin assessing their ability to handle future long-term care needs for projected senior populations and create support systems that ease the burden on caregivers. Caregivers have become engrained in the health care system, providing an average of 20 hours per week in unpaid care for their loved ones and saving private- and publicly-funded insurance programs millions every year. We must find ways to strengthen this invaluable network of caregivers, as they will be vital in the meeting the impending demands of long-term care in the U.S.

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## **Biographical Sketch**

This capstone project was completed by Emily McCarthy. She earned her Bachelor of Arts degree from Culver-Stockton College in Canton, Missouri in May of 1997 with an emphasis in Communications and Public Relations. She graduated with her Master of Public Health degree from the University of Kentucky with a Population Health and Policy Management concentration in May of 2018. She completed a health policy internship with the Council of State Governments in 2017, publishing a national report on diabetes in the United States. She also served as a research assistant at the University of Kentucky to help complete an opioids needs assessment for the Lexington Fayette Urban County Government. Emily will be pursuing a public health career in Lexington, Kentucky following graduation.

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