Long-Term Care Reform in Hawaii: Report of the Hawaii Long-Term Care Commission

Appendices to the Final Report

Hawaii Long-Term Care Commission
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Appendix B: First Report of the State Long-Term Care Commission to the Hawaii State Legislature (2011)
FIRST REPORT OF THE STATE LONG TERM CARE COMMISSION TO THE HAWAII STATE LEGISLATURE PURSUANT TO ACT 224, SESSION LAWS OF HAWAII 2008, AS AMENDED.

THIS REPORT, together with its attached appendices, is submitted in partial fulfillment of Act 224, Session Laws of Hawaii 2008, as amended. Act 224 created a long term care commission to conduct a comprehensive assessment of Hawaii’s long term care system and to recommend changes.

A commission of 15 voting and 5 non-voting ex officio members was constituted as required by the Act. The commission decided to divide its work into two phases over the course of two years. The goal of the first phase was to conduct research about Hawaii’s long-term care system and, fundamentally, to “identify problems with current long term care capacity, programs and services” to the 2011 Legislature. Act 224, SLH 2008, §4. The second phase of work, to be conducted in 2011, addresses public and private financing options and will “develop a five-year comprehensive long term care plan” that promotes “a full continuum of institutional and community-based services, including benchmarks to evaluate accomplishments for each year.” The commission’s recommendations will be presented to the 2012 Legislature.

The commission engaged RTI International of Research Triangle Park, N.C., to be its research consultant after a nationally-posted request for proposals. Joshua Wiener, Ph.D., Distinguished Fellow and Director of the Aging, Disability and Long-Term Care Program for RTI, leads RTI’s relationship with the commission. This project is also a research undertaking of the Social Science Public Policy Center, University of Hawai‘i at Manoa, for which Professor David Nixon, Ph.D. serves as principal investigator.

The work of the commission has been financed entirely from non-state government resources.

Stuart Ho, Chairman
Appointed Commissioners

**Dr. Patricia Blanchette**
Professor, Geriatric Medicine, John A. Burns School of Medicine, UH

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Executive Administrator, Hawaii State Council on Developmental Disabilities

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Chief Executive Officer, Hale Makua

**Russell Okata**
former Director, Hawaii Government Employees Association

**Linda J. Posto, LUTCF, LTCP**
Financial Advisor

**Chuck Sted**
President and CEO, Hawaii Pacific Health

**Eldon Wegner**
Professor Emeritus, Department of Sociology, UH Manoa

**Gerard Russo** (deceased, seat vacant)
Associate Professor, Department of Economics, UH Manoa

Ex-Officio Commissioners

**Director, Department of Commerce and Consumer Affairs**
Department designee: Martha Im

**Director, Department of Health**
Department designee: Keith Ridley

**Director, Department of Human Services**
Department designee: Patty Johnson

**Director, Department of Labor and Industrial Relations**
Department designee: Audrey Hidano

**Director, Department of Taxation**
Department designee: Mark Yee
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Executive Summary

Act 224 (SLH 2008, as amended by Act 24 SLH 2010) created the Long Term Care Commission and charged it with conducting a comprehensive assessment of the long-term care system. The Commission was to present recommendations to improve accessibility, efficiency and effectiveness of the system for Hawaii's families. The Commission is further charged with considering measures to protect the state from unsustainable cost growth of Medicaid, and to explore public and private sector approaches to accomplish these goals.

During Phase 1 of its work, the Commission conducted research about the long-term care system in Hawaii. It selected 7 policy reforms from among a list of 13 options drawn from experts and the experiences in other states.

Selected for Phase 2 Scrutiny
✓ Education and Awareness Campaign
✓ Kupuna Care Expansion
✓ CarePlus
✓ Long Term Care Insurance Partnerships
✓ Long Term Care Insurance Tax Incentives
✓ Synchronize Hawaii’s Regulation of Long-term Care Insurance with National Standards
✓ Unification of Long-term Care System

Examined and Not Selected
✗ Expand Medicaid eligibility
✗ Add Personal Care as an Optional Service for Medicaid
✗ Marketing Campaign for the CLASS Act
✗ State Wrap-Around Program for CLASS Act
✗ Increase the Supply of Nursing Home Beds
✗ Income Tax Incentives/Rewards for Family Caregivers

Phase 2 of the Commission’s work, to be conducted during the remainder of 2011, will
further examine the viability, cost effectiveness, and administration of the 7 selected options.

In summary, the Long Term Care Commission finds that:

1. More than 1 in 10 of Hawaii’s population either experiences a disability or provides care for someone who does. While the focus of the Commission has been primarily on the disabled elderly, we note that the burdens and benefits of long-term care touch both the young and old alike.

2. A large majority of Hawaii’s people lack sufficient funds or have only a limited ability to pay for nursing home or at-home care.

3. The number of the state’s disabled and the number of those who provide caregiving services to them will rise as Hawaii’s population ages.

4. The likely social and demographic consequences of the increased need for long-term care will include increased demands on caregivers, increased need for long-term care capacity, and higher government expenditures.

5. A good long-term care system for Hawaii would assure its people access to high-quality, cost-effective care that is provided, whenever possible, in homes and communities, and, if possible, in the disabled person’s choice of setting.

6. The bar to realizing these goals is money, or the lack of it. The Commission believes that the most promising source of long-term care financing is public and/or private long-term care insurance.

7. Deciding on the form of such insurance is the work of Phase 2 of the Commission.

8. The state’s management of long-term care is fragmented. One consequence of fragmented management is that you don’t see the kind of information that a unified management (or policy-maker) would demand and disseminate.

Background

Hawaii is home to the fastest aging population in the U.S.

The simple fact that Hawaii’s population is aging at a faster rate than the national average means that the state and its families face substantial challenges in the coming two decades. The baby boom generation, usually defined as those born between 1946 and 1964, is an unusually large segment of the population, and they began reaching retirement age in 2011. The share of Hawaii’s population who are 65 or over is projected to increase by 50% in just the next nine years. The share of Hawaii’s population over 85 years old is projected to increase by two thirds in the same time frame. Already, between 5 and 7 percent of Hawaii’s population 18 years of age or older have physical or mental health problems that require long-term care (Public Opinion Survey, at 11). Another 5 percent of the population reports that they provide caregiving services.

Rapid growth in Hawaii’s older population will put enormous pressure on families, on existing nursing and adult care facilities, and on the state budget. The urgency of the situation is evident in the high costs of professional care. One year in a nursing home costs $133,000, on average. A year in an assisted living facility costs $51,000, on average. Most people prefer to age in their homes, and home health aides cost $22 per hour, on average. Most people are unaware of and unprepared for these
expenses, even though over 69% of the population will require some form of long-term care at some time in their life, based on national estimates.

As a result of the high costs in Hawaii, the state Medicaid program spends over $500 million annually on long-term care services for fewer than 9,000 people over the age of 65. The state’s share of those Medicaid costs exceeds $250 million. Imagine if that population increases by 50% in just the next nine years or doubles by 2030.

As the older population grows, a much higher portion of Hawaii’s families will face the financial and logistical responsibilities of caring for a loved one. The Commission’s survey of the public suggests that 62 percent of the adult population cannot afford to pay any of the costs of nursing home care, and another 32 percent say they can afford less than half the cost (Ibid at 16).

Even though Medicaid costs are split with the federal government, the state’s share could balloon, as the population ages. Many more of Hawaii’s elders will need care and many fewer family members will be available to provide care.

Sources of Funding

Our survey suggests that Hawaii’s people have not set aside sufficient savings to deal with long-term care risks. It is not surprising, therefore, that investment by long-term care providers has been low, their places largely taken up by the volunteer
friends and relatives of the disabled elderly at the cost of the caretakers' own
ccontributions to the state's productivity.

So, what should be the source of new financing in Hawaii's long-term care
system?

• The federal and state governments are unlikely sources of new money in the current
fiscal environment.
• Medicare, contrary to widespread belief, provides very limited long-term care benefits.
• Medicaid (i.e., Quest Expanded Access) is a program confined to aiding the poor.
• Most Hawaii households, our surveys suggest, have not saved enough or insured
themselves against disability.
• The Commission believes that the most promising source of long-term care
financing is public and/or private long-term care insurance.

Reform Goals

As the 2008 Hawaii legislature noted: “Over the years, a number of initiatives
have been undertaken to begin the needed transformation of the services and programs
that support seniors and persons with disabilities in Hawaii.... However, the State of
Hawaii has not taken a comprehensive look at needed systems reforms, nor developed a
solid plan about how to prepare for the future service needs of these rapidly expanding,
vulnerable populations.” (Act 224, Session Laws of Hawaii 2008, as amended)

Even aside from costs, Hawaii’s current long-term care system is a confusing,
frustrating bureaucratic jumble of eligibility rules and regulations across many state and
county agencies and private facilities. Hawaii is blessed with a culture that honors its
elders, so that unpaid family members provide much more assistance than is typical in the rest of the U.S., but when family care is not enough, Hawaii’s residents need to be able to quickly and easily access services.

A good long-term care system for Hawaii would assure its people access to high-quality cost-effective care that is provided, whenever possible, in homes and communities and in the disabled person’s choice of setting, as much as possible. This proposition incorporates the “goals of reform” expressed in the “Options” report prepared by the Commission’s consultant, RTI International (Options for Hawaii, at 2), and conforms to the goals of Hawaii’s Med-Quest Division. The specific reform goals the Commission adopted to guide its deliberations are as follows:

• Increase public awareness of long-term care through education
• Treat the risk of needing long-term care as a normal life (health) risk.
• Make the long-term care system more responsive to consumers.
• Change the balance of institutional and home and community-based care.
• Design an effective and affordable system, both to the individual and government.
• Protect against catastrophic out-of-pocket costs.
• Prevent dependence on welfare in the form of Medicaid.
• Improve access to long-term care services.
• Ensure that long-term care reforms do not increase inequality.

Hawaii is facing some urgent challenges on long-term care, but they can be addressed with appropriate and effective public policy adjustments. Facing these challenges will require shared responsibility including local and state government,
families, employers, private agencies, and civic organizations. The proposals which are under consideration all assume a public-private partnership in meeting the challenge of long-term care, although they differ in the role of government and mode of public assistance.

The Long Term Care Commission is charged with a comprehensive assessment of the long-term care system, and recommendations to improve accessibility, efficiency and effectiveness of the system for Hawaii’s families. The Commission is further charged with making recommendations to protect the state from unsustainable cost growth of Medicaid, and was directed to explore public and private sector approaches to accomplish these goals.

**Commission’s Approach**

The Commission is charged in Act 224 with five primary tasks:

1. **Identify Problems with the Current System**

At this stage in its assessment, the Commission finds three main barriers to the reform goals the Commission has subscribed to:

   (a) Lack of Money, whether in the form of government assistance or programs or in the hands of the disabled individual. The Commission, after considering the most likely sources of financing long-term care, believes that the most promising
source of financing is public and/or private long-term care insurance. The Commission plans to focus much of its attention on this financing vehicle during 2011.

(b) Lack of Unified Management. The state government's fragmented management of long-term care, is currently parceled out among several executive departments and agencies. One consequence of the state's management-by-silo style is that questions that might be asked by a single-system manager are not asked, and data that should be shared with everyone involved in the long-term care effort are not shared. The Commission will address this issue during 2011.

(c) Lack of an Informed Public. Neither the public nor public policy-makers yet view risks that end up requiring long-term care as normal health risks. If the public did, they would insure against such risks just as they insure against risks to their general health or home, and the state government would manage long-term care as a single problem, and not as a group of unrelated issues. The Commission believes that educating the public to the risks that old age disability poses to their health and financial security should be a high state priority.

(2) Develop a Five Year Plan that will ensure a continuum of Care and that will Establish Benchmarks to Allow Assessment of How Well Hawaii Achieves Its Goals

As part of its work plan, the Commission will develop a five year
implementation plan, to include recommended benchmarks for assessment of the implementation and operation of its proposals. The Commission anticipates that the lion’s share of the work on this item will occur during Phase 2, scheduled for completion by the end of 2011.

(3) Recommend an Array of Public and Private Financing Approaches to Meeting Hawaii’s Goals

Consistent with Act 224, the preliminary report from the Long Term Care Commission identifies “preliminary proposed system reforms,” and the reforms focus most of their attention on public and private financing of long-term care. The preliminary options selected by the Commission will be further scrutinized and evaluated during 2011.

(4) Monitor Federal Regulations and Make Appropriate Recommendations in Response to Important Changes

At the time that Hawaii passed Act 224, the possibility of a major overhaul of the nation’s health insurance industry was only a vague possibility. Now that the Patient Protection and Affordable Care Act (PPACA) has been signed into law, there are important realities for Hawaii to anticipate. The Commission has already devoted considerable attention to one federal program contained in PPACA: the Community Living Assistance Services and Supports (CLASS) Act. The CLASS Act creates a
voluntary government-sponsored long-term care insurance program available to working people and students.

While it is a significant innovation, the Commission judges that the CLASS Act will not serve as an adequate solution to Hawaii’s long-term care challenges for two inter-related reasons:

(a) the program cannot be subsidized by federal tax dollars. Just like any other private long-term care insurance, CLASS insurance benefits must be paid for with premiums from policy-holders;

(b) the program is voluntary, and therefore policies are likely to be purchased by people with high current risk of needing long-term care.

Because of these two factors, many analysts expect that premiums for the CLASS Act policies will need to be set relatively high to pay for the relatively expensive risk pool that chooses to buy into the program. Such a scenario is self-reinforcing, and might result in very high premiums and very low participation rates. The best estimates available suggested that monthly premiums for CLASS Act long-term care insurance might cost about $120 per month. But one study suggested that if participation rates were very low, the insurance might cost $280 per month or more - making the policies unaffordable for virtually everyone.

In 2010, the Commission gathered information specifically engineered to assess
the likelihood that CLASS will be successful in Hawaii. As detailed in the “survey report” (Appendix G), a representative statewide survey was conducted to determine whether people would be interested or willing to pay premiums in the vicinity of costs being discussed in Washington ($120 a month). As the following chart indicates, there is no evidence that anything more than a small fraction of the population in Hawaii would purchase CLASS Act long-term care insurance, at those costs.

“How Much Would You be Willing to Pay to Enroll in the CLASS Act?”
[Data for Employed Respondents]
(source: figure 27 of RTI Survey Report, at 32)
As a result, the Commission concluded that the CLASS Act was unlikely to address more than a very small part of the long-term care financing problem. While CLASS will become part of the long-term care landscape, beginning in 2014, it seems unlikely to significantly alter that landscape.

Aside from the CLASS Act, there are other federal initiatives which are already impacting the situation in Hawaii. For example, the Executive Office on Aging currently has several Federally funded initiatives, including development of Aging and Disability Resource Centers in each county, the Community Living Program, and the Person-centered Hospital Discharge Planning Initiative. In addition DHS, has several federal programs - the biggest being Quest Expanded Access - which are re-balancing the long-term care towards home and community-based services. The Commission's perspective and recommendations need to take into account this context.

(5) Collaborate with Stakeholders in Educating the Public

The Commission’s research in 2010 convinced us that the public needs significantly better education about long-term care services and financial planning. One of the policy options to be explored in 2011 is an explicit public education campaign, and one of the other policy options - creation of “Long Term Care Partnerships” also features public education as an important component.
Preliminary Proposals

Long-term care is a multifaceted problem, and there are many potential public policy approaches to improving the long-term care system. Based on the Commission’s deliberations and the findings of the opinion studies, RTI presented a report containing a large menu of policy options for the Commission’s consideration. The report provided an assessment of the advantages and disadvantages of each option and cited the available empirical evidence regarding the viability and effectiveness of each strategy. The Commission met on February 2 and 3, 2011 to review the RTI “options report”, with an eye to narrowing the number of options down to those that they judged the most promising or worthy of further scrutiny in 2011.

The Commission met over two full days in February 2011. Each option of the RTI report was discussed for clarification and debate. The final selected options below are recommendations to be further studied in Phase 2 for financial costs and viability, cost-effectiveness, and administration. The following options were discussed, and those prioritized for in-depth scrutiny in 2011 are indicated in the table.

Policy Options Selected for Phase 2 Scrutiny

✓ Education and Awareness Campaign
   Most stakeholders interviewed by the Commission expressed frustration with
the lack of knowledge by government officials and the public about long-term care issues. Bold initiatives are not possible if policymakers and the public are unaware of the issues and realities. The Commission agrees and will propose a public awareness campaign.

✓ Kupuna Care Expansion

Kupuna Care serves as a small state-funded program for Hawaii residents who need limited home and community-based services, but do not yet qualify for Medicaid. The program has a waiting list. The Commission may propose a Kupuna Care expansion as a way to support family caregivers and to postpone or reduce reliance on more expensive residential care options and Medicaid claims.

✓ CarePlus

A small but mandatory state-run long-term care insurance program was proposed in 2003, as a way to ensure that every working resident in Hawaii carried at least a minimal level of long-term care insurance. The program passed the legislature but was vetoed by the Governor. The Commission will investigate further whether this program could serve as a complement to several other long-term care insurance reforms it will consider in 2011.

✓ Long Term Care Insurance Partnerships

Partnership programs encourage purchase of private long term care insurance, in return for asset protection for the purchasers. Under authority of the 2005 Deficit Reduction Act, 43 states have enacted the necessary statutes to allow the marketing and sale of such insurance, and the Commission will investigate whether Hawaii should join their ranks.

✓ Long Term Care Insurance Tax Incentives

Most states provide some kind of state income tax deduction or credit for long-term care insurance premiums. The Commission recognizes that such incentives could be offered for either private or public long-term care insurance. It will investigate in 2011 the level of subsidy that might be necessary to encourage widespread purchase of long-term care insurance.

✓ Synchronize Hawaii’s Regulation of Long-term Care Insurance with Model Regulations of the National Association of Insurance Commissioners (NAIC)
As part of its efforts to encourage long-term care insurance, the Commission will review current Hawaii regulations of such products, to ensure that insurance products marketed and sold bring value to Hawaii consumers. NAIC continually updates its model regulations, and the Commission will conduct a comparison.

**Unification of Long-term Care System**

There is consensus among the long-term care stakeholders we interviewed that “there is no real long-term care system;” every component was designed for a different purpose and the components do not work together (*Stakeholder Interviews at 14*). Forms and procedures for institutional placement or service delivery are multiple and inconsistent. The state’s management of long-term care regulation and services is fragmented.

The fragmentation of long-term care in Hawaii is rooted in the multiple funding streams and the bureaucratic division of responsibility for different populations and health conditions. The Department of Health regulates most, but not all, residential care facilities, but most of the funds that pay for patient care in the same facilities are administered by the Department of Human Services (which also regulates 850 community care foster family homes). Another agency playing an increasingly important role in long-term care, the Aging and Disability Resource Centers (ADRC), receives its federal funding through the Executive Office on Aging, and must coordinate its activities with county Area Agencies on Aging (AAA) of each county. Finally, the office of the Insurance Commissioner (of the Department of Commerce and Consumer Affairs) regulates the activities of private long-term care insurance carriers.

One consequence of fragmented management is the absence of key information that a unified management would demand or disseminate. Numbers are the language of management. Hawaii’s long-term care system probably generates fewer numbers than a manager-in-chief would desire. “Stakeholders” dealing with long-term care programs, for example, are able to describe their frustrations and problems, but few of them were able to quantify them, a fundamental requisite when formulating policies or measuring their effectiveness (*see, generally, “Stakeholder Interviews”*). As another example, the most fundamental threshold question posed by this project—how many individuals in Hawaii have two or more “activities of daily living” deficits for 90 days or more—could not be accurately answered. The Commission had to settle for an extrapolated estimate (*see
Overview of Long Term Care, at 2). There is also the problem of useful information gathered by one long-term care silo not being disseminated among other silos. For example, prior to the introduction in 2009 of Quest Expanded Access, 60 percent of Med-Quest enrollees received care in nursing facilities; the remaining 40 percent received care at home. With the introduction of managed care today—just two years later—only 40 percent of Quest Expanded Access enrollees receive care in nursing facilities; the remaining 60 percent receive their care at home (Minutes of Commission meetings, February 2-3, 2011). The data describing this abrupt turn-around and the lessons it offered might have been of value to managers of other long-term care silos seeking similar results, but there was no direction that the information be shared and with whom.

The Commission may offer recommendations to unify and rationalize the system, to improve the ability to access needed services.

Policy Options Considered and Rejected

✗ Expand Medicaid Eligibility

Medicaid serves as the provider of last resort for people who have expended all their resources, but still need long-term care. The state could expand its eligibility standards, to reach a broader segment of the population and lessen the level of poverty to which seniors must sink themselves to obtain Medicaid payments. The Commission felt this option runs contrary to its charge to shield the state budget from growing Medicaid costs.

✗ Add Personal Care as an Optional Service for Medicaid Recipients at Home

Personal care services are available in the optional menu for non-institutionalized Medicaid recipients in many states, but not in Hawaii. The lack of such optional services in their homes might encourage more people to seek institutional care and drive up state Medicaid costs. The Commission felt that this dynamic is more limited in Hawaii, because the state does provide chore services for non-institutionalized Medicaid recipients. Adding personal care as an optional service would, in view of the
Commission, increase Medicaid direct costs while failing to provide much shield from
people seeking out institutional care.

✔ Marketing Campaign for the CLASS Act

The federal CLASS Act will establish a national long-term care insurance
program that is voluntary. The Commission engaged in substantial investigation of the
likely success of this product. We find that few people will purchase this kind of long-
term care insurance because the premiums will be very high, and premiums will be high
because very few people will purchase it. Because Hawaii is a small state, a state-run
marketing effort to encourage purchase of CLASS insurance will have no discernable
impact on premiums that are set nationally and is not likely to have major success.

✘ State Wrap-Around Program for CLASS Act

Some states have begun discussion of supplementary programs and benefits for
those who purchase CLASS Act long-term care insurance. The Commission felt that the
state is unlikely to be able to assemble a package of supplements to make CLASS Act
long-term care insurance an attractive product for very many people in Hawaii.

✘ Income Tax Incentives/Rewards for Family Caregivers

Family caregivers certainly face very significant emotional and financial strains,
and the Commission finds that references to tax incentives for family caregivers are
widely popular in Hawaii. But the level of tax credits typically considered in recent
legislative bills are paltry sums, relative to the financial burdens borne by family
caregivers. The public benefits of concentrating state tax dollars on family caregivers is
not evident, in the view of the Commission.

✘ Increase the Supply of Nursing Home Beds

Nursing home beds have been in short supply with large waitlists for years in
Hawaii. But the Commission’s investigation finds that, perhaps because of the success
of the QExA experiment, the demand for nursing home beds has declined, and many
nursing homes now have spare capacity. For the near term, the Commission will not
recommend efforts by the state to increase nursing home capacity, though this position
does not address the broader category of skilled nursing facility (SNF) beds, many of
which are located in facilities other than nursing homes.
Conclusion

Hawaii’s people will face some daunting challenges that will come with the aging of the baby boom generation. Families and state budgets will come under increasing pressure over the next two decades, as the proportion of the population needing expensive long-term care services grows quickly. The state has already begun the process of adapting to new realities, by successfully shifting to managed care for Medicaid and with recent successful efforts in the Quest Expanded Access (QExA) program, to shift the balance of care away from hospitals and nursing homes and towards the significantly less expensive and more popular home-based care services.

The goal of the Commission is to conduct a comprehensive assessment of the long-term care system in Hawaii and present the policy recommendations to the state most likely to improve the system, rooted in the most current and accurate information available about what works.

Without drawing from state budgets, the Commission has been engaged in a careful assessment of the Hawaii long-term care system, and has made preliminary selections of the policies that appear most promising to address Hawaii’s challenges. Over the remainder of the Commission’s charter, we will be implementing Phase 2 of our work plan by assessing the financial costs and viability, cost-effectiveness, and potential administration of the options prioritized in this report.
APPENDIX A:
Update on Commission Activities and Meetings

The Long Term Care Commission has met 18 times since fall 2008 to assess the state’s long-term care system and lay the groundwork for presenting policy recommendations to the state.

Fifteen voting Commissioners with expertise in Hawaii’s long-term care system were appointed by the Governor (five appointees), House Speaker (five appointees), and Senate President (five appointees). In addition, the Directors of five state agencies with significant responsibilities in the long-term care system serve as non-voting ex-officio Commissioners.

In addition to the instructions of Act 224, the Commission is governed by the state’s sunshine and ethics laws. All meetings meet quorum requirements, are publicized with advance notice on the state calendar and with the Lt. Governor’s office, are open to the public, and minutes are maintained and available to the public. Commissioners are not compensated, but instead serve as volunteers.

The Commission spent the early portion of its time conducting two tasks. First, it assembled a work plan to structure its work over two years (see Appendix D). Second, it raised private funds to pay for its work. All funds supporting the Commission are unrestricted donations to the state of Hawaii and are further governed by state and
University of Hawaii accounting, ethics, and conflict of interest rules.

With funding secured and a work plan established, the Commission solicited competitive bids from experts in long-term care policy, to aid the Commission in fulfilling its work plan. We published a Request for Proposals in July 2009, and received five excellent proposals. A subcommittee carefully scrutinized and rated the proposals on key criteria, and presented its recommendation to the Commission - a recommendation unanimously accepted by the full Commission. The Research Triangle Institute (RTI) team led by Dr. Joshua Wiener was selected through this process to aid the Commission. As one of the nation’s leading experts in long-term care policy with a lot of state policy experience, Dr. Wiener is ideally suited to help the Commission present well-informed policy recommendations for Hawaii.

During 2010 and early 2011, RTI conducted two studies of peoples’ attitudes and knowledge in Hawaii about long-term care, and authored a total of four reports about long-term care in Hawaii. RTI’s reports are available at the Commission’s website.  

**RTI Reports available at** [www.publicpolicycenter.hawaii.edu/LTCC.html](http://www.publicpolicycenter.hawaii.edu/LTCC.html)  
- “An Overview of Long-Term Care in Hawaii”  
- “Stakeholders’ Views on Hawaii’s Long-Term Care System: Problems, Solutions, and Barriers to Reform”  
- “Assessing Long-Term Care Policy Options in Hawaii: Results from the Hawaii Long-Term Care Survey”  
- “Long-Term Care Reform Options in Hawaii”
BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

PART I. FINDINGS AND PURPOSE

SECTION 1. The legislature finds that virtually all of Hawaii's elders want to age-in-place at home rather than in a care home or institution, and that many elders will require more intensive services and caregiving at the end of their lives. Over the years, a number of initiatives have been undertaken to begin the needed transformation of the services and programs that support seniors and persons with disabilities in Hawaii, such as Quest-Ex, the expansion of Kupuna Care, the Aging and Disability Resource Center, and the Going Home Program. However, the State of Hawaii has not taken a comprehensive look at needed systems reforms, nor developed a solid plan about how to prepare for the future service needs of these rapidly expanding, vulnerable populations.

The legislature further finds that the costs of institutional care have escalated beyond the financial means of most elders. The State's portion of medicaid expenditures has
increased steadily over the years and is projected to increase significantly as baby boomers begin to retire. As Hawaii's population ages, the number of frail and disabled individuals will also increase, placing a precipitous demand on the need for long term care services, as well as significant cost pressures on the state budget. The legislature therefore finds that there is a need to plan for the future to make quality long term care services as accessible, efficient, and effective as possible.

The legislature further finds that it is necessary to explore public and private sector approaches to support payment for long term care services, which can assist elders to age-in-place and prevent the State from becoming fiscally liable for unsustainable costs under medicaid.

The purpose of this Act is to establish long term care policy goals and guiding principles, and establish a long term care commission to identify needed reforms of the long term care system, research program changes and resources necessary to meet the State's long term care public policy goals, and explore an array of funding options that may help support the provision of long term care services in the future.

PART II. LONG TERM CARE POLICY GOALS AND GUIDING PRINCIPLES
SECTION 2. To make possible the array of services that are necessary to meet the long term care needs of Hawaii's elders and persons with disabilities, the following shall be the long term care policy goals of the State of Hawaii:

(1) Encourage the planning of and provision for a continuum of care, up to and including the end of life;

(2) Coordinating referral, case management, and service delivery through co-location and other means;

(3) Strengthening family caregiver support systems to encourage aging-in-place;

(4) Stimulating workforce development and training programs to expand the number and capabilities of long term care service providers;

(5) Developing financial mechanisms to help Hawaii's families meet the cost of long term care;

(6) Increasing public resources to expand home and community-based care options;

(7) Fostering public understanding of caregiving issues; and
(8) Encouraging research and education on aging, long term care, and related subjects through the University of Hawaii system.

SECTION 3. The development of a long term care system in Hawaii shall also be guided by the following principles:

(1) Consumers should have as much choice as possible in the selection and use of services;

(2) Services should be accessible and foster the level of self sufficiency desired by the consumer;

(3) Programs and services serving all seniors and disabled populations should be accountable, cost effective, and provide quality care;

(4) All services should be organized and administered in a way that fosters efficient use of limited state resources;

(5) Consumers should have access to information to help them make timely and appropriate decisions when needed;

(6) Health, long term care, and social services should be connected through the use of preadmission screening, standardized assessments, care planning, coordination, and case management; and
(7) Technology should be used to improve accountability, efficiency, quality of care, and to help keep people in their homes.

PART III. LONG TERM CARE COMMISSION

SECTION 4. (a) There is established a long term care commission within the University of Hawaii college of social sciences public policy center for administrative purposes. The commission shall:

(1) Identify problems with current long term care capacity, programs, and services;

(2) Develop a five-year comprehensive long term care plan to accomplish long term care policy goals that, when implemented, will ensure the availability of a full continuum of institutional and community-based services, including benchmarks to evaluate accomplishments for each year;

(3) Research public and private financing options and develop recommendations about financial resources, including a mix of public and private financing, necessary to achieve needed state long term care reforms and state public policy goals;
(4) Monitor federal legislation for changes that may impact the program and adjust the long term care plan accordingly; and

(5) Collaborate with interested stakeholders, including community coalitions or organizations concerned with educating the public regarding long term care.

(b) The long term care commission shall consist of:

(1) Five members appointed by the governor;

(2) Five members appointed by the president of the senate;

(3) Five members appointed by the speaker of the house of representatives; and

(4) Five non-voting, ex-officio members, who are the directors of the following departments, or their designees, and who shall collaborate with and support the work of the commission, as requested:

(A) Department of commerce and consumer affairs;

(B) Department of health;

(C) Department of human services;

(D) Department of labor and industrial relations; and

(E) Department of taxation.

(c) Members shall have a background in business, economics, finance, management, health care, long term care,
social services, or public policy development, or be an advocate
for or consumer of long term care services. Members of the
commission shall be appointed as soon as practicable, but by no
later than September 30, 2008. Any vacancies occurring in the
membership of the commission shall be filled for the remainder
of the unexpired term in the same manner as the original
appointments.

(d) A simple majority of voting members shall constitute a
quorum, whose affirmative vote shall be necessary for all
actions.

(e) The members shall serve without compensation, but
shall be allowed necessary expenses incurred in the performance
of commission duties.

(f) The University of Hawaii college of social sciences
public policy center shall convene the first commission meeting
as soon as practicable, but by no later than November 1, 2008.
At this first meeting, the commission shall elect from among its
members a chairperson, who shall convene commission meetings,
and a vice chairperson, and shall adopt rules for the conduct of
its work.

(g) The long term care commission shall:
(1) Submit an interim report to the legislature no later than February 28, 2010, describing the progress made in the development of the five-year plan and preliminary proposed system reforms; and

(2) Submit a final report to the legislature no later than September 30, 2010, which shall include the final five-year plan, how the reforms will be prioritized and phased in, and a description and final recommendations regarding the financing of long term care services, including support for caregivers.

(h) The long term care commission may:

(1) Conduct or initiate studies as it deems necessary; and

(2) Hire staff and contract with third parties to conduct studies, including an actuarial study, as it deems necessary for the purpose of evaluating various options about systems reforms and about how to help State residents pay for needed long term care and supportive services in the future. Any contract executed pursuant to this subsection shall be exempt from chapter 103D, Hawaii Revised Statutes; provided that any such contract is approved by the commission in an open meeting.
(i) The University of Hawaii college of social sciences public policy center shall provide administrative and policy support to facilitate the work of the long term care commission.

(j) The term of the long term care commission shall expire on November 30, 2010.

SECTION 5. There is appropriated out of the general revenues of the State of Hawaii the sum of $100,000 or so much thereof as may be necessary for fiscal year 2008-2009 for the long term care commission.

The sum appropriated shall be expended by the University of Hawaii for the purposes of this Act.

SECTION 6. This Act shall take effect on July 1, 2008.

APPROVED this day of , 2008

GOVERNOR OF THE STATE OF HAWAII
April 15, 2010

The Honorable Colleen Hanabusa, President
and Members of the Senate
Twenty-Fifth State Legislature
State Capitol, Room 409
Honolulu, Hawaii 96813

Dear Madam President and Members of the Senate:

This is to inform you that on April 15, 2010, the following bill was signed into law:

HB1902 HD1 A BILL FOR AN ACT
RELATING TO LONG TERM CARE.
ACT 024 (10)

Sincerely,

LINDA LINGLE
A BILL FOR AN ACT

RELATING TO LONG TERM CARE.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

SECTION 1. Act 224, Session Laws of Hawaii 2008, section 4, is amended as follows:

1. By amending subsection (g) to read:

"(g) The long term care commission shall:

(1) Submit an interim report to the legislature no later than [February 28, 2010] January 19, 2011, describing the progress made in the development of the five-year plan and preliminary proposed system reforms; and

(2) Submit a final report to the legislature no later than [September 30, 2010] January 18, 2012, which shall include the final five-year plan, how the reforms will be prioritized and phased in, and a description and final recommendations regarding the financing of long term care services, including support for caregivers."

2. By amending subsection (j) to read:

"(j) The term of the long term commission shall expire on [November 30, 2010] adjournment sine die of the regular session of the 2012 legislature."
SECTION 2. Statutory material to be repealed is bracketed and stricken. New statutory material is underscored.

SECTION 3. This Act shall take effect upon its approval.

APPROVED this 15 day of APR , 2010

GOVERNOR OF THE STATE OF HAWAII
The Hawaii Long Term Care Commission

Act 224 of the State of Hawaii established the Long Term Care Commission in 2008. The Commission is composed of 15 appointees with a broad range of experience and expertise in long-term care. The five directors of the departments of Health, Human Services, Taxation, Labor, and Commerce sit as non-voting ex-officio members. The Commission is charged with identifying needed reforms of the long-term care system, researching program changes and resources needed to meet the state’s long-term care goals, and exploring funding options that my help support the provision of long-term care services. The Public Policy Center at the University of Hawaii facilitates the work of the Commission by providing administrative and policy support.

Spring 2011 Calendar

Public Hearing Announcement

The Commission will hold a public hearing to present its draft interim report in the Auditorium of the State Capitol March 10 2011, from 3:00-5:00pm. Those wishing to testify should send written comments by March 9 to dnixon@hawaii.edu or address hard copies to: Long Term Care Commission, c/o Social Science Public
Reports to the Commission
The Commission will receive a number of reports from researchers, prior to assembly of its own final report. These documents will inform our deliberations and recommendations, but the reports from contractors do not stand as official positions of the Commission.

- Overview Report (RTI)
- Stakeholder Interviews (RTI)
- Public Opinion Survey (RTI)
- Policy Options Report (RTI)

Meeting Minutes
As a public agency, the Commission meets in accordance with Hawaii sunshine laws. Meetings (with a written agenda) are posted on the state calendar at least 6 days ahead of time, and minutes of meetings are publicly available.

- Powerpoint presentation from RTI at the March 12, 2010 meeting.
- Powerpoint presentation from RTI at the August 13, 2010 meeting.
- Powerpoint presentation from RTI at the October 6, 2010 meeting.
- Spring 2011 Calendar

Request For Proposals
The Public Policy Center issued a call for proposals to execute a two year research project supporting the Long Term Care Commission. After disseminating an open Request for Proposals, the Commission received five excellent proposals. Following a competitive selection process, the Research Triangle Institute (RTI) was awarded the contract. RTI's proposal is posted here.

Appointed Commissioners
- Dr. Patricia Blanchette
  Professor, Geriatric Medicine, John A. Burns School of Medicine, University of Hawaii
- Dr. Mary G. Boland Dr.PH, RN, FAAN
  Dean and Professor, School of Nursing and Dental Hygiene, UH Manoa
Waynette K.Y. Cabral, M.S.W.
Executive Administrator, Hawaii State Council on Developmental Disabilities

Robin Campaniano
President, AIG Hawaii

Sister Agnelle Ching
CEO, St. Francis Healthcare of Hawaii

Dr. John Henry Felix
Chairman and CEO, Hawaii Medical Assurance Association

Dr. Kenneth Fink
Administrator, State Med-Quest Division, Department of Human Services

Ron Gallegos
National Sales Director, Primerica Financial Services

Stuart Ho
President, AARP

Tony Krieg
Chief Executive Officer, Hale Makua

Russell Okata
formerly Director, Hawaii Government Employees Association

Linda J. Posto, LUTCF, LTCP
Financial Advisor

Gerard Russo (deceased, seat vacant)
Associate Professor, Department of Economics, UH Manoa

Chuck Sted
President and CEO, Hawaii Pacific Health

Eldon Wegner
Professor Emeritus, Department of Sociology, UH Manoa

Ex-Officio Commissioners

Director, Department of Commerce and Consumer Affairs
Department designee: Martha Im

Director, Department of Health
Department designee: Keith Ridley

Director, Department of Human Services
Department designee: Patty Johnson

Director, Department of Labor and Industrial Relations
Department designee: Audrey Hidano

Director, Department of Taxation
Department designee: Mark Yee
Appendix D

LONG-TERM CARE COMMISSION
TWO-PHASE WORK PLAN

EXECUTIVE SUMMARY

The work of the Long-Term Care Commission (LTCC) is described in Act 224, Session Laws of Hawai’i 2008. In a nutshell, the work of the Commission is to take stock and determine where Hawai’i stands with respect to our long-term care needs, near-term and future; to recommend long-term care objectives; and, finally, to recommend ways and means for policy-makers to attain those objectives. Importantly, the Commission shall also address the question of how to finance the attainment of those objectives.

The work will be divided into two phases, each phase taking approximately 12 months to complete, and each producing a full report of the work covered, as follows:

Phase 1. Twelve months

1. Policy Objective: The goal is to produce a report containing an assessment of the current state of long term care in Hawaii, with recommendations to improve the system of services.

2. Work Objective: (a) Ascertain what Hawai’i currently has in place in facilities, programs and predictable funding; (b) Assess the current system's strengths, weaknesses and limitations; (c) Assess Hawai’i's current ability to manage and meet current demand for long-term care services; (d) Project demand for long-term care services; (e) Learn from the experience and best practices of other states; (f) Report findings and make recommendations for meeting near-term and future demand for long-term care services; and (g) Solicit the opinion of the public on the Commission's recommendations.

Phase 2. Twelve months

1. Policy Objective: Produce a five-year action and financing plan.

2. Work Objective: (a) Study financing alternatives and recommend an equitable solution to financing the needs of the long-term care system; and (b) Integrate the financing recommendation and all Phase 1 recommendations into a five-year action plan to deal with Hawai’i's near-term and future long-term care needs.
I. INTRODUCTION: HAWAI‘I'S LONG-TERM CARE CRISIS

A. PRESENT: Unaffordable; few options available; Hawai‘i's people are worried.

A 2006 survey of Hawai‘i registered voters found that 75% of respondents were not confident (not at all confident: 49%; not very confident: 26%) they could afford the cost of a nursing home for even one year. Moreover, 47% of registered voters were not confident they could afford the cost of a home health aide for even one year.

So concerned are Hawai‘i residents that in a large 2008 survey, almost two-thirds (62%) of the registered voters surveyed favored a proposal to develop a public long-term care insurance program designed to defray the costs associated with disability and chronic conditions. (Only 9% strongly oppose such a proposal; another 11% somewhat oppose the proposal.)

Local nursing homes operate at full occupancy. Home and community-based services are under-funded, and only a few attempts have been made to vertically integrate services. The industry is fragmented among myriad service providers rather than coordinated and systemic, with caregivers left to sort out what services are available to meet their needs. Yet, two-thirds (69%) of registered voters surveyed responded that they would prefer to receive long-term care services at home. Hawai‘i spends fewer of its long-term care dollars on community-based care for the aged and disabled than the U.S. average (18% vs. 31%).

B. FUTURE: More people to care for; fewer people to care for them; a problem for employers and employees alike—and something has to give.

Hawai‘i's 65+ population is projected to grow by 78% over the next 20 years as the Boomers pass into retirement. Conversely, the 50-64 population—the age cohort of many volunteer caregivers—will shrink by 10% over the same period. Today the ranks of unpaid family caregivers in Hawai‘i are significant. They currently number, at any given time, approximately 169,000, and a conservative value of their unpaid service annually is nearly $1.5 billion. Clearly, this is a cost the state government would not like to see laid at its doorstep.

A demographic finger directly points towards a coming social and economic collision: People on the job with increased family responsibilities at home. The problem is identical to our Social Security challenge: a few people working for many. Something will need to give, and the risk of lost productivity in the work place will only be one problem that emerges.

II. WORK PLAN DETAILS – PHASE 1

A. Research, Assessment, Interim Report (nine months)

1. Collect and analyze information that describes the state of long-term care in Hawai‘i. Develop reports and recommendations based on input from the LTCC with these subjects in mind:
a. Program and service responsibilities of executive departments and agencies relating to long-term care.
b. Gateways into the LTC system.
c. Controls on the supply of institutional (e.g., nursing home) services, e.g., state certificate of need process.
d. Programs to provide public education addressing individual responsibility for long term care, associated costs and personal and insurance funding options.
e. Programs to assist individuals in transitioning from hospitals, nursing homes, and other institutions to community living.
f. Residential service choices available to consumers.
g. The array of home and community-based services available to consumers.
h. Use of information technology to support services administration and delivery.
i. Availability of consumer-directed (rather than agency-provided) services, where consumers hire and manage their own caregivers.
j. Quality controls and management of LTC programs and services.
k. Estimates of future need for services.
l. Programmatic support for caregivers.
m. Workforce adequacy.

2. Study reports, plans, budgets, and the official record, and develop information from:

   a. Interviews with stakeholders, including government leaders and administrators, LTC service providers, LTC advocates and, in some cases, LTCC commissioners
   b. Two surveys: one a survey of public perceptions, awareness and attitudes about LTC, the other a survey of LTC stakeholders.

3. Synthesize all facts and findings into an interim report to the LTCC.

   a. Identify problems, if any, with current capacity, programs, services, system access, and system integrating mechanisms and make recommendations for system improvements. (The report will use the federal template, Technical Assistance Guide for Assessing a Long Term Care System, and will disclose gaps in Hawai‘i’s LTC system and enable comparisons with other states.)
4. Distribute the interim report to stakeholders and the public, and convene a series of public hearings to receive comments.

5. Identify the need for additional research because of input obtained at the public hearings and/or topics identified in the Phase 1 assessment.

B. Public Hearings, Further Input, Development of Final Report (three months)

1. Compile all findings, reports and stakeholder comments into a final (Phase I) report

2. Upon LTCC acceptance of the report, the Commission submits the report to the Governor and the 2010 Legislature.

III. WORK PLAN DETAILS – PHASE 2

A. Develop Plan to Implement Reform Proposals (six months)

1. Develop cost estimates for proposed LTC system reforms.
2. Conduct additional research on projecting service needs and costs.
3. Develop and analyze options for public and private financing of LTC services.
4. Synthesize all facts and findings into an interim report by the LTCC

B. Develop Final Report – Five-Year Plan (four months)

1. Complete development of the Commission’s final report—Five-Year Plan
2. Assist in developing drafts of necessary legislation
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Long-Term Care Services and Funding in Hawaii

Introduction

This report provides a “primer” or overview of long-term care services in Hawaii and the public programs that pay for those services. It aims to provide a basic understanding the state of long-term care in Hawaii. It relies mostly on publicly available information, which is limited. Exhibit 1 defines long-term care. Long-term care services for persons with serious mental illness are discussed only in passing in this overview.

Like every other state, Hawaii has a range of long-term care services. Although these services could be considered to make up a state long-term care “system,” with few exceptions they are standalone services and are not integrated into a coherent whole.

Exhibit 1. What Is Long-Term Care?

Long-term care includes a wide range of services and supports:

- Assistance with activities of daily living (ADLs). ADLs include eating, bathing, dressing, transferring from bed to chair, controlling bowel and bladder function, and moving about the house safely.
- Assistance with instrumental activities of daily living (IADLs). IADLs include preparing meals, shopping for food and personal items, managing medications, managing money, using telephones, doing housework, and using public transportation.
- Assistance with other activities needed to maintain community living, such as heavy chores.
- Supervision to safeguard health and safety.
- Skilled and unskilled nursing services and rehabilitation services such as physical and occupational therapy to maintain or improve functioning.
- A range of other services and supports needed to function in community settings, such as habilitation and supported employment for persons with developmental disabilities or serious mental illness.

The first section of this report provides basic information on the size of the elderly population in Hawaii and how it is projected to increase in the future. It also includes an estimate of the number of people who need long-term care. The second section describes the types of long-term care services available in Hawaii. The third section describes the public programs that pay for these services for some individuals under certain circumstances, primarily those with low income and few assets. The fourth section of this report very briefly describes the developmental disabilities services system. Finally, the report concludes with a brief summary of the long-term care system in Hawaii.
Demographic Characteristics of Older People

The elderly population in Hawaii is projected to increase significantly over the next two decades (Exhibit 2). The increase in the population aged 65 and older—and particularly people aged 85 and older—will lead to an increase in the number of people needing long-term care because older people have a higher prevalence of disability than younger people.

Exhibit 2. Elderly Population in Hawaii, 2007 and 2030

<table>
<thead>
<tr>
<th>Population</th>
<th>2007</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population 65+</td>
<td>185,622</td>
<td>326,957</td>
</tr>
<tr>
<td>Percent of Overall Population</td>
<td>14.0</td>
<td>22.3</td>
</tr>
<tr>
<td>Total Population 85+</td>
<td>26,294</td>
<td>48,254</td>
</tr>
<tr>
<td>Percent of Overall Population</td>
<td>2.0</td>
<td>3.3</td>
</tr>
</tbody>
</table>


Adjusting earlier estimates of the number of people with disabilities in Hawaii, Nixon estimated that there were 21,789 people needing long-term care in Hawaii in 2007 (Exhibit 3). The criteria for needing long-term care were that individuals had (1) two or more ADL limitations lasting 90 days or more or (2) a cognitive impairment (including Alzheimer’s and senility).

Exhibit 3. Estimated Number of People Requiring Long-Term Care in Hawaii, 2007

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Total Population in Age Range</th>
<th>Total Persons Requiring Long-Term Care in Age Range</th>
<th>Percent of Population Requiring Long-Term Care in Age Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>25+</td>
<td>783,372</td>
<td>21,789</td>
<td>2.8</td>
</tr>
<tr>
<td>25–64</td>
<td>639,597</td>
<td>5,097</td>
<td>0.8</td>
</tr>
<tr>
<td>65+</td>
<td>143,775</td>
<td>16,692</td>
<td>11.6</td>
</tr>
</tbody>
</table>


---


Long-Term Care Services

Long-term care comprises a range of services—from licensed skilled nursing services to homemaker and chore services. The major service types discussed below are used primarily by older people and younger persons with physical disabilities. Long-term care services and supports for persons with developmental disabilities are discussed separately.

Nursing Homes

In 2010, Hawaii had 48 nursing homes with 4,191 beds certified to participate in Medicare or Medicaid. A total of 3,889 individuals resided in these nursing facilities. Nursing homes provide medical, nursing, and health-related care in a residential setting. Hawaii differentiates between skilled nursing facilities (SNFs) and intermediate care facilities (ICFs), indicating that the state operates two types of nursing facilities. However, federal law abolished the distinction between Medicaid SNFs and ICFs in the Omnibus Reconciliation Act of 1987, and requires states to provide both a skilled and an intermediate level of care in a single nursing facility.

Hawaii has a much lower supply of nursing home beds relative to its elderly population than other states. As shown in Exhibit 4, in 2009, Hawaii had 43.4 nursing home beds per 1,000 persons aged 75 and older, compared to the national average of 88.9 nursing home beds per 1,000 persons aged 75 and older. Between 1997 and 2009, the nursing bed/population ratio declined, both nationally and in Hawaii. It is not known why the nursing home bed ratio is so much lower in Hawaii than in the nation as a whole. One possible explanation is that the high level of three-generation households in the state combined with a strong tradition of informal caregiving has resulted in low demand for nursing home care. Another explanation is that the high cost of real estate and construction needed to expand existing facilities or build new ones constrains the number of nursing home beds.

The relatively low supply of nursing home beds in Hawaii has several consequences. First, the state’s nursing facility occupancy rate is very high—92.8 percent in 2010 compared to the national average of 83.6 percent. Second, because of high occupancy rates, some individuals with a high level of impairment and extensive nursing needs cannot be discharged from acute care hospitals because no nursing home will take them. Third, with so few beds, nursing homes tend to serve a more severely disabled population than the national average. The average nursing home ADL Index—a measure of the need for assistance with ADLs—is 4.52 for Hawaii compared to the national average of 4.02; Hawaii’s index is the highest of any state.


4 Ibid.

Reflecting the high cost of nursing homes in Hawaii, in 2010, 70.0 percent of Hawaii’s nursing home residents were eligible for Medicaid compared to the national average of 63.6 percent. Moreover, fewer Hawaii nursing home residents have their care covered by Medicare: 9.2 percent of residents in Hawaii compared to 14.2 percent for the nation as a whole. A total of 20.9 percent of residents in Hawaii paid out of pocket or through another payer compared to 22.2 percent of residents for the country as a whole. Exhibit 5 presents the distribution of payment sources by nursing home residents over time, demonstrating that the percentages have been quite stable, going back to at least 1997.

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6 Ibid.
Exhibit 5. Nursing Home Resident Payment Sources, 1997–2010


Residential Care Homes/Facilities

Hawaii has a very complex system of community-based residential care settings. These include Adult Residential Care Homes (ARCHs), Extended Care Adult Residential Care Homes (EC-ARCHs), Community Care Foster Family Homes (CCFFHs), and assisted living facilities. Unless specifically licensed or certified to provide a higher level of care, these homes provide room and board, supervision, and limited assistance with personal care and health-related needs.7 Prior to 2009, Medicaid paid for services in these residential care settings through two home and community-based services waiver programs. In February 2009, the Section 1115 Medicaid

7 The complexity of Hawaii’s system stems in part from the use of a single term to describe multiple residential care settings and the use of different terms to describe the same setting. For example, even though some ARCHs and EC-ARCHs are large facilities serving 20 or more residents, the Hawaii Department of Human Services’ website uses the program name “Adult Foster Care Program” to cover services provided in ARCHs and EC-ARCHs, as well as CCFFHs. The website also states that the Department of Human Services’ Adult and Community Care Services Branch licenses adult foster homes through its Residential Alternatives Community Care Program. Yet ARCHs—which are part of Department of Human Services’ Adult Foster Care Program—are licensed by the Department of Health.
The research and demonstration program QUEST Expanded Access (QExA) was implemented and Medicaid residential care services are now paid through the managed care programs established under the demonstration.

**Adult Residential Care Homes**

ARCHs are licensed by the Hawaii Department of Health. In addition to room and board, ARCHs provide limited assistance with ADLs, custodial care, and supervisory oversight. Type I ARCHs care for up to 5 residents in a private home; Type II ARCHs care for 6 or more residents in larger, more institutional settings that may care for as many as 50 to 60 residents. Medicaid does not pay for services provided in ARCHs. Residents either pay privately or turn over their Supplemental Security Income (SSI) federal benefit plus state supplement payment (minus a $50 personal needs allowance) to the provider. In 2011, the state had 248 Type I ARCHs with 1,135 beds and 4 Type II ARCHs with 92 beds.

**Extended Care Adult Residential Care Homes**

EC-ARCHs are licensed by the Department of Health but the Department of Human Services oversees placement and case management services to Medicaid-eligible clients in these settings. To receive these services, individuals must be eligible for SSI, Medicaid, or other financial assistance from the Department.

EC-ARCH operators must meet additional Department of Health staffing and other requirements to be allowed to offer expanded services and accept residents who need nursing home level care. EC-ARCHs serve both private pay residents and those who are Medicaid eligible. Type I EC-ARCHs may serve up to two residents (out of five) who need a nursing home level of care. In Type II EC-ARCHs, only 20 percent of the residents can need a nursing home level-of-care. In 2011, the state had 225 Type I EC-ARCHs with a capacity of 1,109 beds and 20 Type II EC-ARCHs with a capacity of 306 beds.

**Community Care Foster Family Homes**

CCFFHs are certified by the Department of Human Services to serve both private pay residents and Medicaid-eligible residents who meet the state’s nursing home level-of-care criteria as certified by a physician. Medicaid-eligible and private pay individuals entering a CCFFH must have a case manager from a Department of Human Services–licensed Case Management Agency.

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12 Hawaii Department of Health, Office of Health Care Assurance, op.cit.
coordinate their health and long-term care services and ensure that their health care needs are met.

CCFFHs are certified for one, two, or three individuals and are required to serve at least one Medicaid-eligible resident. If a CCFFH is certified for two or three persons, the home is allowed to have one private-pay, non–Medicaid-eligible individual in addition to the Medicaid-eligible resident. A CCFFH may accept a second private-pay individual if certain conditions are met.13

As of January 2011, there were 1,053 facilities with a capacity of 2,444 beds.14 Monthly Medicaid reimbursement rates differ by the level of care required: $724.48 for Level I clients and $1,222.92 for Level II clients. The monthly room and board payment for Medicaid-eligible residents was $1,278.90—the amount of the SSI federal benefit payment plus the state supplement. Residents turn over their SSI payment to the facility to pay for room and board, except for a small personal needs allowance. Thus, facilities serving Level I facilities received $724.48 plus $1,278.90 or $2,003.38 per month minus the personal needs allowance.

Assisted Living Facilities

Assisted living facilities are licensed and regulated by the Department of Health. As noted above, they are one of three types of residential care settings permitted to serve individuals who meet the state’s nursing facility level-of-care criteria. Assisted living facilities differ from other types of residential care facilities in that they are required to provide apartment units with cooking facilities (which may be removed if the resident cannot safely use them). These facilities provide room and board, health care services, and personalized supportive services to meet individual residents’ needs. In 2010, Hawaii had 11 assisted living facilities with 1,872 units.15 Some independent living retirement facilities are converting a section of their buildings to assisted living to accommodate individuals who need assistance.

According to a recent study, the state agency responsible for enforcing building codes is requiring assisted living facilities that meet the R-1 (residential apartment) code to serve only residents who are ambulatory and can evacuate in an emergency.16 Providers contend that enforcement of this requirement limits their ability to implement other aspects of the regulations that support aging in place.

Residents of assisted living facilities who are Medicaid eligible and meet the state’s nursing home level of care criteria can receive home and community-based services through the QExA program. Medicaid covers services in three of these settings for individuals who need a nursing

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13 Community Care Foster Care Family Homes, Act 13, Session Laws of Hawaii (SLH) 2009. For additional information, see http://hawaii.gov/dhs/protection/social_services/adult_services/CCFFH%20Factsheet%201.6.10.pdf.
home level of care: CCFFHs, EC-ARCHs, and assisted living facilities. In accordance with federal law that limits certain reimbursement to institutions, Medicaid does not cover room and board in these settings.

**State Supplemental Payments**

Residents of all domiciliary care homes in the state who are current SSI recipients; state-funded aid to the aged, blind, and disabled; or general assistance payments are eligible for “state supplemental payments.” These payments are provided through general fund appropriations to provide payments for special care needs individuals. **Exhibit 6** presents the combined monthly federal and state supplemental payment levels for various residential care facility settings.


<table>
<thead>
<tr>
<th>Category</th>
<th>2010 Total Monthly Payment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Independent living status</strong></td>
<td></td>
</tr>
<tr>
<td>Eligible person</td>
<td>$674.00</td>
</tr>
<tr>
<td>Eligible couple</td>
<td>$1,011.00</td>
</tr>
<tr>
<td><strong>Living in a foster care home</strong></td>
<td></td>
</tr>
<tr>
<td>Eligible person</td>
<td>$1,325.90</td>
</tr>
<tr>
<td>Eligible couple</td>
<td>$2,651.80</td>
</tr>
<tr>
<td><strong>Domiciliary care (five people or fewer)</strong></td>
<td></td>
</tr>
<tr>
<td>Eligible person</td>
<td>$1,325.90</td>
</tr>
<tr>
<td>Eligible couple</td>
<td>$2,557.80</td>
</tr>
<tr>
<td><strong>Domiciliary care (more than five people)</strong></td>
<td></td>
</tr>
<tr>
<td>Eligible person</td>
<td>$1,433.90</td>
</tr>
<tr>
<td>Eligible couple</td>
<td>$2,867.80</td>
</tr>
</tbody>
</table>

Note: The amounts include both federal and state supplemental payments combined. Not all SSI recipients receive the maximum amount. Individual payments may be lower if the beneficiary has other income.


**Adult Day Care and Adult Day Health Centers**

In addition to directly assisting participants, both adult day care and adult day health centers provide respite for caregivers. All-day programs can enable family caregivers to continue working at paid employment.

**Adult Day Care Centers**

The Department of Human Services licenses adult day care centers providing supportive services to four or more adults with physical or mental disabilities. These centers provide a sheltered setting and activities to promote functioning and the ability to remain safely in their homes or a relative’s home. If specifically licensed to do so, they provide meals and snacks.

“Adult day care services” are defined as services provided through an organized program of personal care, supervision, social services, therapy, and group and leisure activities. Centers also provide family consultation or referral services to appropriate community resources and assistance to clients to learn about, apply for, and receive income entitlements such as Social Security.
Security and SSI benefits, Medicaid, the Supplemental Nutrition Assistance Program (i.e., food stamps) and state supplemental payments. In 2010, the state had 35 adult day care centers with the capacity to serve 830 clients.\textsuperscript{17}

**Adult Day Health Centers**

Adult day health centers are licensed by the Department of Health; they provide a more medical service than adult day care centers. Adult day health centers provide medical services, nursing services, dietetic services and planned therapeutic and social activities, social services, speech therapy, physical therapy, occupational therapy, and psychiatric or psychological services in a group setting. In 2010, the state had 10 adult day health centers.\textsuperscript{18}

**Case Management Services**

Case managers assess individuals to identify unmet needs, explore service options, develop service plans, and coordinate services in home and community-based settings for both private pay and Medicaid clients. They assist in the placement of individuals who meet Medicaid nursing home level-of-care criteria to CCFFHs and EC-ARCHs and oversee their care to ensure that their medical and other needs are met. The Department of Human Services licenses Community Case Management Agencies.

**Licensed Nursing Services**

Registered nurses and Licensed Practical Nurses provide unskilled and skilled nursing services. Licensed nurses who provide services in private homes are generally the employees of home health agencies. However, they may also be hired as independent contractors. The state has 26 Medicare certified home health agencies, which are licensed by the Department of Health.\textsuperscript{19}

**Nurse Aides, Home Health Aides, Personal Assistants/Personal Care Aides**

Nurse aides, certified nurse assistants, home health aides, personal assistants, and personal care aides provide assistance with ADLs and IADLs. These individuals can be employees of an agency or may provide services as independent contractors. Home health agencies employ home health aides and nurse aides and nursing homes employ certified nurse assistants who provide health-related and unskilled nursing services in addition to assistance with the ADLs. All of these workers may be allowed to provide some nursing care tasks, functions, and activities if


they are specifically delegated—and their performance supervised, monitored, and evaluated—by a licensed nurse.\(^{20}\)

**Homemakers, Companions, and Attendants**

Some individuals may not need assistance with ADLs, but need assistance with IADLs such as meal preparation, shopping for grocery or personal items, housework, or laundering. (Hawaii state agencies consider some of these activities to be “chores.”) Some people—such as persons with Alzheimer’s disease—may need supervision to ensure personal safety, but not hands-on care. Although nurse aides, home health aides, personal care aides, and personal assistants are also capable of providing these services, it may be less expensive to hire homemakers, companions, or attendants to provide them—either through a home care agency or as independent contractors.

Home care agencies provide a variety of nonmedical personal, housekeeping, and other services. Until 2008, having a General Excise Tax I.D. number was the only requirement for operating a home care agency. In 2008, the Legislature passed a law requiring that such agencies be licensed by the Department of Health. As a result of budget shortfalls, however, the Department of Health has not implemented these requirements.

**Other Home and Community-Based Services**

Other services are available to help people with long-term care needs to remain in their homes, including assistance with heavy chores—such as washing windows and yard work—home-delivered meals, and transportation services.

**Public Funding for Long-Term Care Services**

Long-term care services can be very expensive—particularly when needed for more than a few months—and are unaffordable to many if not most individuals and families. Long-term care services in Hawaii are substantially more expensive than in the nation as a whole (*Exhibit 7*).

**Exhibit 7. Cost of Private-Pay Long-Term Care Services in Hawaii, 2010**

<table>
<thead>
<tr>
<th>Type of Care</th>
<th>Average Hawaii Cost</th>
<th>Average National Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year in nursing home care (private room)</td>
<td>$132,860</td>
<td>$83,585</td>
</tr>
<tr>
<td>Year in assisted living facility</td>
<td>$50,676</td>
<td>$39,512</td>
</tr>
<tr>
<td>Home health aide (per hour)</td>
<td>$22</td>
<td>$21</td>
</tr>
</tbody>
</table>


For individuals who need but cannot afford long-term care services, the state pays for these services through a variety of programs; the two most important are Medicaid (known as QUEST in Hawaii) and Kupuna Care. Additional public funding for long-term care services is available through other state-funded programs and the federal Older Americans Act (OAA), which supports programs administered by the U.S. Administration on Aging.

**Medicaid**

Medicaid is a federal- and state-funded program and the largest public funding source for long-term care. For example, as shown in Exhibit 5, approximately 70 percent of nursing home residents have their care paid by Medicaid. Hawai‘i’s Department of Human Services administers the Medicaid program through its Med-QUEST division. **Exhibit 8** presents Hawaii Medicaid expenditures for long-term care services for 2008.21

**Exhibit 8. Medicaid Long-Term Care Expenditures for Older People and Younger Persons With Physical Disabilities in Hawaii, by Service, 2008**

<table>
<thead>
<tr>
<th>Service</th>
<th>Expenditure ($)</th>
<th>Percentage of Total Long-Term Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing Homes</td>
<td>$221,667,411</td>
<td>80.9</td>
</tr>
<tr>
<td>Personal Care</td>
<td>$0</td>
<td>0.0</td>
</tr>
<tr>
<td>Home Health</td>
<td>$654,464</td>
<td>0.2</td>
</tr>
<tr>
<td>Home and Community-Based Services Waiver</td>
<td>$50,945,892</td>
<td>18.6</td>
</tr>
<tr>
<td>Targeted Case Management</td>
<td>$782,226</td>
<td>0.3</td>
</tr>
<tr>
<td>Total Long-Term Care</td>
<td>$274,049,993</td>
<td>100.0</td>
</tr>
</tbody>
</table>


Under federal law, nursing home and home health care are mandatory services that all states must cover. In addition, states may cover a number of optional services. The Hawaii Medicaid program does not cover the optional state plan personal care benefit, but it does operate several Medicaid home and community-based services that cover personal care. Under the QExA research and demonstration program (discussed below), chore services are covered up to a maximum of 1,600 persons. Hawaii recently reached the maximum allowed number of chore beneficiaries under the demonstration program and now maintains a waiting list for these services.

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21 Starting in 2009, detailed service-specific expenditure data are no long available because payment to managed care plans under QExA is made on an overall capitated basis and not on the basis of services actually provided.
Prior to the implementation of QExA, the proportion of Hawaii’s long-term care expenditures spent on home and community-based services for older people and younger persons with physical disabilities was about a third less than the national average—18.8 percent compared to 31.6 percent in 2008 (Exhibit 9). In addition, Hawaii spent much less per person on home and community-based services than the national average. The proportion of expenditures for home and community-based services was stable in Hawaii between 2004 and 2008, while it has increased nationally. In 2008, Hawaii spent about half the amount per person on Medicaid home and community-based services for older people and younger persons with physical disabilities as the national average—$526,206 per 1,000 older people aged 75 and older in Hawaii versus $1,213,298 per 1,000 older people aged 75 and older nationally (Exhibit 10). Similarly, expenditure levels per person in Hawaii were stable between 2004 and 2008, while they have increased nationally.

Exhibit 9. Percentage of Medicaid Long-Term Care Expenditures for Older People and Younger Persons With Physical Disabilities for Home and Community-Based Services, 1995 to 2008


Exhibit 10. Medicaid Home and Community-Based Services Expenditures for Older People and Younger Persons With Physical Disabilities per 1,000 People Aged 75 and Over, 1997 to 2008

Note: Expenditures adjusted for inflation by the national Consumer Price Index-All Urban Consumers to 2008 levels established by the U.S. Bureau of Labor Statistics.


QUEST Expanded Access

In 2007 Hawaii decided to shift the Medicaid aged, blind, and disabled population from fee-for-service Medicaid into managed care plans in an effort to achieve cost savings, improve quality of care, and increase coordination across acute and long-term care.23 In the Medicaid program, the “aged” population includes persons aged 65 and older and the “disabled” population includes

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persons under age 65 with severe disabilities. Hawaii received a federal Section 1115 research and demonstration waiver to operate the new program.

In February 2008, a competitive bidding process led to the awarding of a $1.5 billion contract to subsidiaries of two for-profit health plans: UnitedHealth Group’s Evercare subsidiary and WellCare Health Plans, Inc.’s Ohana Health Plan. The state has two QExA health plans: Evercare and Ohana. Both plans are available on five islands. Only Ohana is available on Molokai. Together the plans serve more than 41,000 aged, blind, and disabled Medicaid clients. Since February 2009, all Medicaid primary, acute, and long-term care services for aged, blind, and disabled Medicaid populations have been provided through the managed care QExA program. Medicare services are not included.

Enrollment is mandatory for aged, blind, and disabled beneficiaries and includes all Medicaid beneficiaries who are eligible at 100 percent of the federal poverty level, at the SSI and SSI plus State Supplement levels. Enrollment is also mandatory for all aged and disabled clients in nursing homes, including those eligible through spend down/medically needy rules.

QExA covers all Medicaid long-term care services, including nursing home care, home health services, and all home and community-based services that were formerly covered by Medicaid home and community-based services waiver programs, such as service coordination, adult day care, personal care, attendant care, and services in residential care settings. The managed care program replaced all Medicaid home and community-based services waivers, except for the home and community-based services waiver for people with intellectual disabilities/developmental disabilities. Self-direction is an option for personal care, respite, and attendant services.

The goals for QExA include the following:

- Improving the health status of seniors and people with disabilities
- Establishing a “provider home” through the use of primary care providers
- Empowering beneficiaries by promoting independence and choice
- Ensuring access to high-quality, cost-effective care that is provided, whenever possible, in beneficiaries’ homes and communities
- Coordinating care, including primary, acute, behavioral health, and long-term care supports and services
- Ensuring that beneficiaries are able to receive needed care in their choice of settings

Preliminary data from QExa suggest that the program has been very effective in increasing the number of people receiving home and community-based services. QUEST reports that the


number of Medicaid beneficiaries receiving home and community-based services increased from 2,110 in February 2009 to an average of 3,876 in the second quarter of 2010, an 84 percent increase. Moreover, almost all of the increase was a result of people receiving care in their own homes rather than in residential care facilities. During this same period, the number of nursing facility residents declined from 2,840 to 2,650, a 7 percent decline. As a result, home and community-based services beneficiaries increased from 43 percent of long-term care beneficiaries in February 2009 to 59 percent in the second quarter of 2010.

Programs of All-inclusive Care for the Elderly

Programs of All-inclusive Care for the Elderly (PACE) are managed care programs that include all Medicare and Medicaid services for older people who need nursing home-level care. QExA only includes Medicaid services; it does not include Medicare services. Hawaii implemented two PACE programs in the past 10 years. However, as a result of low enrollment, both closed.

Medicaid Home and Community-Based Services (HCBS) Waiver Programs

Under Section 1915(c) of the Social Security Act, states may apply to the U.S. Department of Health and Human Services for Medicaid HCBS waivers designed to give states greater flexibility to meet the needs of community-dwelling persons with disabilities. Unlike personal care offered through the regular Medicaid program, states must limit waiver programs to beneficiaries who need nursing homes, ICFs for people with intellectual disabilities, or hospital services. The federal government imposes this requirement because the waivers services are intended to substitute for institutional care. In addition, under the waivers, states must establish in advance how many people they will serve during the course of a year. In contrast to the regular Medicaid program, states may establish waiting lists for these waiver programs; thus, the waivers are not entitlements, although they operate within a program that is normally an entitlement. States may also provide Medicaid eligibility to persons in the community with incomes up to 300 percent of the federal SSI level, which far exceeds regular Medicaid income eligibility limits.

A major advantage of these waivers is that states may cover a very wide range of services, including case management, homemaker, home health aide services, personal care services, adult day health care, habilitation, respite care, nonmedical transportation, home modifications, adult day care, and other services approved by the Secretary of the Department of Health and Human Services. As noted above, although services in congregate residential facilities such as assisted living facilities may be covered, room and board may not be covered. Room and board may only be covered by Medicaid in nursing homes, ICFs for people with intellectual disabilities, and hospitals.

To ensure cost neutrality of providing these additional services, average Medicaid expenditures for waiver beneficiaries must be the same as or less than they would have been without the waiver. As a practical matter, for older people and younger adults with physical disabilities, this

means that average expenditures have to be equal to or less than the average cost of Medicaid nursing home care.

In addition to QExA, the state operates three Medicaid HCBS waiver programs—a program for people with HIV/AIDS, a program for people less than 21 years of age who are medically fragile, and a waiver program for individuals with developmental disabilities. The QExA managed care program folded in two HCBS waiver programs: Nursing Home without Walls and Residential Alternative Community Care.

**HIV/AIDS Community Care Waiver Program**

The HIV/AIDS Community Care Waiver Program provides services to persons who are eligible for Medicaid, HIV positive, and needing a nursing home level of care. The program offers an array of services, including case management, nonmedical transportation, personal assistance, home-delivered meals, adult day health care, counseling and training, private duty nursing, personal emergency response, respite care, home maintenance, environmental accessibility, adaptations, moving assistance, and specialized medical equipment and supplies. In 2006, Hawaii’s Medicaid HIV/AIDS Community Care program served 54 participants. The average per participant cost was $7,573 for a total of $408,917. FY 2009 spending for this waiver was $550,452.

**Medically Fragile Community Care Waiver Program**

The Medically Fragile Community Care Waiver program provides services to Medicaid eligibles under 21 years old who are determined to be medically fragile and in need of a hospital or nursing home level of care. The targeted medical condition must be expected to last longer than 12 months. The participant also must have at least two caregivers trained to provide needed care in a home that is able to accommodate the necessary equipment and personnel. The program offers an array of services, including habilitation, respite, home modifications, special equipment, day health services, nursing, transportation, medical day care, attendant care, family training, and case management. In 2006, Hawaii’s Medically Fragile Community Care waiver program served 48 participants. The average per participant cost was $37,394 for a total of $1,794,915.

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State Programs

Hawaii has several non-Medicaid programs that provide long-term care services, which are administered through the Department of Human Services and the Department of Health.

Department of Human Services

The Department of Human Services administers several long-term care programs.

Chore Services for Community Long-Term Care Program

The Chore Services program provides essential housekeeping services to enable eligible adults to remain in the community. Services may include housecleaning, laundering, shopping, and meal preparation. To receive services, an individual must be eligible for SSI, financial or Medicaid assistance from the Department, and must meet other program requirements. Individuals receiving services from Medicaid’s QExA are not eligible for this service. Services may be provided without regard to income in adult protective service situations. Most providers are family members.

Senior Companion Program

The Senior Companion Program is a part-time volunteer program that recruits low-income seniors to provide in-home companionship and limited personal care to frail elders and respite to caregivers in exchange for a small stipend. The program is funded by the federal Corporation for National and Community Service. To be a Senior Companion, individuals must be at least 55 years of age, physically able to volunteer 20 hours per week, and have relatively low incomes.

Department of Health, Executive Office on Aging

Chapter 349 of the Hawaii Revised Statutes establishes the Executive Office on Aging (EOA) 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 Hawaii. The EOA works with four Area Agencies on Aging (AAAs) to administer various programs for older people, including Kupuna Care and programs funded by the U.S. Administration on Aging.

Kupuna Care

Kupuna Care is an entirely state-funded program designed to meet the needs of frail older adults who cannot live at home without adequate help from family or formal services. The program was developed by the EOA in partnership with the AAAs to address the growing number of older persons with long-term care needs. The AAAs administer the program.

Kupuna Care services include the following:

- adult day care

- assisted transportation
- attendant care (volunteer companion)
- case management
- chore services
- home delivered meals
- homemaker-housekeeper
- personal care

The bulk of Kupuna Care spending is for personal care (28%), home-delivered meals (22%), case management (20%), and transportation (15%).

The program has no financial eligibility criteria and services are free, although priority is given to lower-income older people. Clients are asked to make voluntary donations to the service provider for any service provided. Donations are used to provide services to additional clients.

To be eligible for Kupuna Care, an individual must be

- 60 years or older;
- not eligible for services from another public program, such as Medicaid, or already receiving private pay services;
- living in an apartment or house (not an institution, residential care facility, or foster home); and
- impaired in two or more ADLs or IADLs or have significantly reduced mental capacity, and have one or more unmet ADL or IADL need.

Clients receiving a single service are assessed by the service provider. Clients receiving more than one service are assessed by case managers. In State Fiscal Year 2009, Kupuna Care expenditures were $4,708,816.

U.S. Administration on Aging-funded Programs

The federal OAA provides funding for elderly support services, nutrition services, preventive health services, elder rights protection, and family caregiver support services. The OAA created a network of federal, state, and local agencies to plan and provide services that enable older adults to live independently in their homes and communities, and also to provide family caregiver support services; this infrastructure is known as the “Aging Network.” The EOA is designated as the State Unit on Aging for Hawaii. The EOA is the designated lead agency for the

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33 Ibid.
coordination of a statewide system of aging and caregiver support services, as authorized by federal and state laws.

Each of the state’s four counties has an AAA, which is responsible for planning, developing, and administration of services to older adults and family caregivers residing in their distinct geographic planning and service area. Each AAA contracts with service providers in their geographic area. Services include chore services, adult day care respite, homemaker/housekeeping services, assisted transportation, legal assistance, attendant care, case management, congregate meals, personal care assistance, transportation, home-delivered meals, and family caregiver services.

The federal and state funding for services is available to assist older adults and family caregivers regardless of income. However, because of limited funding, special considerations are given to those older adults and family caregivers who have the greatest economic and social needs, focusing particularly on low-income minorities, limited English-speaking populations, and people with disabilities.34

The Family Caregiver Support Program, one of the programs funded by the OAA, provides caregiver support services to help people with disabilities to remain in their homes. Services are available to adult family members or other individuals who are informal, unpaid providers of in-home care to older adults aged 60 and older.35 Caregiver support services are also available to grandparents or relatives (not parents) aged 55 or older who are taking care of a child aged 18 and younger or a relative 18 and older with a disability.

Aging and Disability Resource Center

The Aging and Disability Resource Center (ADRC) program is a collaborative effort of the U.S. Administration on Aging and the Centers for Medicare & Medicaid Services (CMS). The purpose of ADRCs is to simplify and streamline access to long-term care services. ADRCs provide states with an opportunity to integrate the full range of long-term supports and services into a single, coordinated system.36 The target population for ADRCs includes individuals of all ages with all incomes and types of disabilities, including serious mental illness and developmental disabilities. Although Hawaii has been working to develop a fully functioning ADRC for several years, it currently provides only limited services and information, primarily through toll-free telephone numbers and a website.

ADRCs provide information and assistance to individuals in need of services, to professionals seeking assistance on behalf of their clients, and to individuals planning for their future long-term care needs. ADRCs also serve as the entry point to publicly administered long-term supports including those funded under Medicaid, the OAA, and state revenue-funded programs.

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34 Pendleton, op. cit.
In 2005, an ADRC development grant funded by the U.S. Administration on Aging and CMS was awarded to the Hawaii Executive Office on Aging in partnership with the Hawaii County Office of Aging and the City and County of Honolulu Elderly Affairs Division on Oahu. These two counties served as the original ADRC pilot sites. Hawaii’s ADRC is a collaborative project funded by the U.S. Administration on Aging; CMS; the State of Hawaii, the counties of Kauai, Maui, and Hawaii; and the City and County of Honolulu. All four counties have operational ADRCs.

Hawaii’s ADRC has a website—www.hawaiiadrc.org—which is a one-stop source for long-term care information and services for older adults, people with disabilities, and caregivers who need assistance.37 The website was developed by the City and County of Honolulu Elderly Affairs Division in conjunction with Kaua’i County Agency of Elderly Affairs. Additional state funding expanded the website to include all four counties. The website’s main page directs users to information for four counties: Hawaii, Honolulu, Kauai, and Maui. In addition to this website, individuals can contact any local ADRC site operated by the county AAAs by phone or in person for further assistance. Although the website provides limited information to individuals who are computer literate and have access to a computer, it cannot address the needs of people with limited English language skills and those who cannot use computers.

The Hawaii County ADRC is a physical location where people can go to receive help in person. With additional funding support from Hawaii County, a physical site in Hilo was renovated to co-locate the Hawaii County Office of Aging and other aging and disability agencies onsite. The ADRC brings together several county and private programs serving seniors and individuals with disabilities, including the Adult Community Care Services Section of the State Department of Human Services, the ARC of Hilo, Services for Seniors, Hawaii County Nutrition Program, Coordinated Services for the Elderly Program, the Senior Employment and Training Program, the Legal Aid Society of Hawaii, the State Department of Health’s Adult Case Management Program, the Alzheimer’s Association, and the University of Hawaii at Hilo School of Pharmacy.

The Hilo site is open to the public to obtain information about and assistance to obtain a wide range of services such as adult day care, transportation, Medicaid services, legal aid, respite care, and other community programs for elders and people with disabilities. Additional ADRC sites are planned for the Hamakua district of the Big Island, and the rural communities of Waianae, Hauula, and North Shore on Oahu.

Adult Mental Health Division, Department of Health

The Adult Mental Health Division promotes, provides, coordinates, and administers the mental health system for individuals aged 18 and older who have serious and persistent mental illness and who do not have access to services or the resources to purchase supports. Although the mental health system provides primarily treatment services, it also provides some community supports for persons who would otherwise be institutionalized.

Developmental Disabilities System

The Department of Health administers services for persons with developmental disabilities. The Department ensures the provision of an array of individually appropriate services and care to persons with developmental disabilities through the utilization of existing resources within the community; coordination with supports and services provided under other federal, state, or county acts; and through specific funding when no other resources are available within the limits of state and federal resources allocated for the purpose. These services include but are not restricted to case management; residential, developmental, and vocational support, including supported employment; training; habilitation; residential habilitation; active treatment; day treatment; day activity; respite care; domestic assistance; attendant care/personal assistance; skilled nursing; speech, physical, occupational, and recreational therapy; recreational opportunities; counseling, including counseling to the person’s family, guardian, or other appropriate representative; development of language and communications skills; interpretation; transportation; and equipment.

The Department funds services through state matching funds for Medicaid programs, other governmental programs, and private programs. For example, through its Partnership in Community Living program, the Department’s Developmental Disabilities Division provides up to $2,000 per year to fund services or learning materials to increase independence and functional living for persons with intellectual disabilities and other developmental disabilities.

Only individuals eligible for community services, but not eligible for Medicaid waiver services or other federally reimbursed programs, or for whom such services are not appropriate or not available based on their individual service plan, receive services and supports with solely state funds.

The Department of Health’s Office of Health Care Assurance licenses developmental disabilities domiciliary homes (DDDHs) and ICFs for people with developmental disabilities.

Intermediate Care Facilities for Persons With Intellectual Disabilities

Intermediate Care Facilities for People with Intellectual Disabilities (ICF/IDs) are an optional Medicaid benefit created to fund institutions (four or more beds) for people with developmental disabilities. These facilities provide room and board and “active treatment” for individuals with developmental disabilities.

Hawaii has 18 ICF/IDs. All but one facility, which serves nine residents, are “Community ICF/IDs” serving four or five residents. Four facilities are on Maui and 14 are on Oahu. In 2009, the state Medicaid program spent $9.9 million for ICF/IDs.38

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Residential Care Settings for Persons With Developmental Disabilities

DDDHS provide services to adults with intellectual disabilities and other developmental disabilities.

These settings provide services and supports to promote normalization, community and social integration, and personal development to the fullest potential. These facilities must also protect the health and ensure the safety of their residents. Only 79 individuals out of 2,600+ served in the development disabilities waiver program live in a licensed home such as Development Disabilities Domiciliary homes. The Department of Health’s Developmental Disabilities Division Certification Section recruits, orients, and certifies foster homes and foster caregivers for the community placement of adults with developmental disabilities.

Developmentally Disabled Medicaid Home and Community-Based Services Waiver Program

Although the Department of Human Services is the designated Medicaid State Agency, the Department of Health’s Developmental Disabilities Division is mandated by state law to lead initiatives to develop a comprehensive system of supports and services for persons with developmental disabilities. This responsibility includes administration of the Medicaid home and community-based services waiver for people with developmental disabilities and for the provision of case management services for this population.

Persons who are Medicaid eligible and certified as requiring an ICF/ID level of care are eligible for the intellectual disabilities/developmental disabilities HCBS waiver. In 2006, this waiver had 2,242 participants. Total Medicaid spending for the waiver was $83 million with an average of $37,202 per participant. In 2009, total Medicaid spending for the waiver was $113 million.

The mental retardation/development disabilities waiver program provides supports and services to enable participants to live as independently as possible in the least restrictive environment. More than 600 individuals use a consumer direction option. This option is very important—particularly in places where there are labor shortages, such as rural areas—because it allows Medicaid waiver participants to hire relatives, friends, and neighbors to provide direct care.

Waiver services include the following:

39 The term “residential” in the developmental disabilities service system encompasses all types of living arrangements, from family homes to institutions. In this report, the terms “residential care setting” or “residential care facility” refers only to settings/facilities that are provider-operated.
41 In 2006, the most recent year for which data are readily available, the developmental disability waiver served 2,242 people, the HIV waiver served 54 people, and the Medically Fragile waiver served 48 people. Ng and Harrington, op. cit.
42 Eiken et al., op. cit.
Summary

This paper provides a basic summary of the long-term care system in Hawaii. Long-term care includes helping people with daily activities, such as getting dressed, bathing, preparing meals or eating, or taking medications, over an extended period of time. Providers of long-term care include nursing homes, residential care facilities, adult day care centers, and home care agencies. The report’s primary focus is on services and financing for older people and younger people with physical disabilities, but it also briefly addresses the system for people with intellectual disabilities/developmental disabilities.

Demographic Characteristics of Older People
- Like the rest of the country (indeed, the world), the population of Hawaii is getting older. Between 2007 and 2030, the population aged 85 and older, which has the greatest need for long-term care, will increase by almost two-thirds.
- There are approximately 22,000 adults aged 25 and older in Hawaii with significant disabilities.

Long-Term Care Services
- Compared to the rest of the country, Hawaii has many fewer nursing home beds per older population. The ratio of nursing home beds per 1,000 people aged 75 and older in Hawaii is about half the national average. Possible reasons for this lower bed supply include the high cost of land and the tradition of three-generation households. As a result of the relatively low bed supply, occupancy rates are high, some high-need patients in hospitals have difficulty
obtaining placements, and Hawaii nursing home residents are more disabled than in other states.

- A possible consequence of the limited nursing home supply has been the growth of a complicated and confusing system of residential care facilities, including Adult Residential Care Homes, Extended Care Adult Residential Care Homes, Community Care Foster Homes, and assisted living facilities. Some of these facilities serve people who need a nursing home level of care and receive Medicaid reimbursement for services but not room and board. These facilities are regulated by the Department of Human Services and the Department of Health; some facilities are regulated by both agencies.

- Home and community-based services in Hawaii include a wide range of services including case management, licensed nursing services, licensed nursing services, nurse aides, adult day care and adult day health centers, home health aides, personal attendants/personal care aides, homemakers, and other community services. The Department of Health is authorized to license home care agencies, but lacks the funds to implement these requirements.

Public Funding for Long-Term Care Services

General Cost

- Long-term care services are expensive everywhere, but are particularly costly in Hawaii. For example, the private-pay price for the average private room in a nursing home is almost 50 percent higher in Hawaii than in the country as a whole.

Medicaid

- Medicaid is the primary payer for long-term care services. In FY 2008, the state spent approximately $274 million on long-term care for older people and younger persons with physical disabilities.

- Compared to other states, Hawaii’s Medicaid long-term care spending has historically been much more oriented toward institutional services. In 2008, the most current year for which data are available, only 19 percent of Medicaid long-term care services spending in Hawaii for older people and younger persons with physical disabilities, compared to 32 percent nationally. Not surprisingly, then, Medicaid spending for home and community-based services per capita aged 75 and older in Hawaii was half of what it was nationally.

- Medicaid long-term care services in Hawaii underwent a radical change in 2009 with the introduction of QUEST Expanded Access, which combined Medicaid primary, acute, and long-term care services for aged, blind, and disabled beneficiaries into a managed care program. Enrollment is mandatory, with beneficiaries able to choose between two managed care plans. By combining medical and long-term care, policymakers hope to create a more efficient and seamless integrated care system, which will have much greater flexibility in meeting the needs of older and younger people with disabilities. Very little public information is available about how the program is performing. However, preliminary data suggests that the demonstration has substantially increased the number of people receiving home and community-based services and modestly reduced the number of people receiving nursing home care.

- In addition to the Medicaid HCBS waivers absorbed into QExA, Hawaii Medicaid operates HCBS waivers: the HIV/AIDS Community Care Waiver program, the Medically Fragile
Community Care Waiver program, and the Developmentally Disabled Medicaid Home and Community-Based Services Waiver program.

State Programs

- Similar to other states, Hawaii also operates several other long-term care programs focusing on home and community-based services, which are much smaller than Medicaid home and community-based services. These programs are managed by the Department of Human Services and Department of Health.

- The largest of these non-Medicaid programs, including the entirely state-funded Kupuna Care and those programs funded by the U.S. Administration on Aging, are run by the Executive Office on Aging of the Department of Health.

- The Aging and Disability Resource Center Program is a collaborative effort of the U.S. Administration on Aging and CMS. The purpose of ADRCs is to simplify and streamline access to long-term care services. ADRCs provide states with an opportunity to effectively integrate the full range of long-term supports and services into a single, coordinated system. Although the state has been working to develop a fully functioning ADRC for several years, it currently provides only limited services and information, primarily through toll-free telephone numbers and a website. The state currently has a contract with a consultant to upgrade these services.

Intellectual Disabilities/Developmental Disabilities System

- The Hawaii Department of Health administers programs for people with intellectual disabilities/developmental disabilities.

- Like other states regarding services for people with intellectual disabilities/developmental disabilities and unlike services for older people and younger persons with physical disabilities, Hawaii has radically shifted services for people with intellectual disabilities/developmental disabilities from institutions to home and community-based services. For example in 2009, Medicaid’s expenditures for the Developmentally Disabled Home and Community-Based Services Waiver were more than 11 times the expenditures for ICFs for people with intellectual disabilities.
Stakeholders’ Views on Hawaii’s Long-Term Care System: Problems, Solutions, and Barriers to Reform

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Acknowledgements

We would like to thank the many individuals who took time to speak with us about their views of the problems with Hawaii’s long-term care system, needed reforms, and barriers to reform. This report would not have been possible without their insights and knowledge.
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Executive Summary

Act 224, Session Laws of Hawaii 2008, established the Hawaii Long-Term Care Commission in 2008. The Commission is charged with identifying needed reforms of the long-term care system, researching program changes and resources needed to meet the State’s long-term care goals, and exploring funding options that may help support the provision of long-term care services. Long-term care includes helping people with daily activities, such as getting dressed, bathing, preparing meals or eating, or taking medications, over a long period of time. Providers of long-term care include nursing homes, home health agencies, home care agencies, adult day care programs, meals-on-wheels programs, and community-care homes.

Every state’s long-term care system has groups that are affected by and can influence the way in which services are organized and financed and quality assured. As part of the Long-Term Care Commission’s analysis of Hawaii’s long-term care system, RTI International conducted interviews with stakeholders—including providers, consumer advocates, government officials, and researchers—to obtain their views about the problems of the State’s long-term care system, what changes they believe are needed to reform the system, and what they believe are the major obstacles to reform and how to overcome them. In summarizing their opinions, we sought to capture the range of views, identifying areas of consensus and areas where there was diversity of opinion.

This report summarizes the views of the individuals interviewed for the report. Although they were selected for participation based on their knowledge and expertise, the contents of this report should not be viewed as findings of fact. In addition, they do not necessarily represent the views of the report’s authors, RTI International, or the Hawaii Long-Term Care Commission. Nonetheless, given the importance of stakeholders in any reform effort, their views provide important perspectives that should be considered in designing initiatives to reform the State’s long-term care system.

Problems With the Current Long-Term Care System

All stakeholders thought that the aging of the population would place great additional strain on the current long-term care system. Most respondents identified the main problems of the current long-term care system as the following:

- **Insufficient third-party financing.** Most stakeholders believed that not enough Medicaid and long-term care insurance financing is available to pay for long-term care services. For most people, services are too expensive to be paid out of pocket. Although a longstanding issue, the strong downturn in the economy has severely exacerbated this problem.

- **Inability of informal caregiving to meet need.** Historically, unpaid care by informal caregivers has been a particularly important component of care of people with disabilities of all ages. But informal care cannot be counted on to meet the growing need for care because of geographic mobility, people living longer, the high cost of living in Hawaii, and the lack of interest among some of the younger generation. The strain on informal caregivers of helping disabled relatives and the lack of support for caregivers may result in an increased demand for paid services.
• **Lack of long-term care service capacity.** Going hand in hand with inadequate financing and strained informal caregivers, stakeholders said that there is an across-the-board shortage of nursing home, community care home, and home care service capacity, especially for people with complex medical needs. The new Medicaid QUEST Expanded Access program has substantially changed service arrangements, but few stakeholders knew much about the impact of the program.

• **Fragmentation of the long-term care and health systems.** Many older people and persons with disabilities have both long-term care and medical needs and must navigate complex and fragmented service delivery and financing systems. Respondents emphasized that there are issues both within long-term care and health care systems and between the two systems. Some stakeholders questioned whether one could even refer to a long-term care “system” because the service and financing components were so “siloed” and disconnected.

• **Poor quality/insufficient monitoring of home and community-based services.** Unlike other states, stakeholders did not identify the quality of nursing home care as a major problem. Rather, respondents focused on the regulation of community care homes and, to a lesser degree, home care. Given severe levels of disability and complex medical/nursing needs among many community care home residents, stakeholders expressed concerns about the lack of staff training, case management, and fragmented oversight of these facilities.

**Reforms Needed to Address the Problems**

Although considerable consensus exists among stakeholders about the problems of the long-term care system, there is much less agreement about the solutions to the problems. Proposed solutions include the following:

• **Solve the financing problem.** Stakeholders were strongly divided about whether the public or the private sector needed to expand to solve the financing problem. Some respondents believed that long-term care is fundamentally a social responsibility of government and that either taxes will need to be increased to pay for Medicaid or a new public long-term care insurance program will need to be established, financed by premiums and general revenues. Other respondents believed that long-term care is ultimately an individual responsibility and that the goal should be to reduce the role of government programs in financing long-term care. Advocates of this view tended to support education on the financial risks of long-term care and tax incentives for purchase of private long-term care insurance policies.

• **Increase service capacity.** Several respondents stressed the need to increase the availability of all types of long-term care services (nursing homes, community care homes, and home care), particularly for people who are not eligible for Medicaid and to provide respite for informal caregivers. While recognizing the need for institutional care, they stressed that the State should not rely only on nursing homes to address long-term care needs. Other stakeholders, however, cautioned that home care does not necessarily lead to cost savings, particularly when individuals need extensive care and supervision.

• **Reform components of the service delivery system.** Stakeholders had a variety of highly specific recommendations, including revising the eligibility determination and service allocation approach for Kupuna Care and increasing the use of consumer-directed services. Some observers stressed the importance of understanding the
current system and designing solutions to its problems before adding new funding, which would just expand the current inadequate system.

- **Reduce system fragmentation and improve service coordination.** At the policy level, some stakeholders advocated consolidating long-term care policy and regulation into one agency, as is done in Oregon and in Washington. Many stakeholders believed that strengthening the Aging and Disability Resource Center could help consumers receive the services they need.

- **Address quality problems with community care homes.** Stakeholders proposed a number of initiatives to improve the quality of care in community care homes, including increasing training and case management, implementing uniform and systematic screening of community care home applicants to ensure appropriate placement, and developing specialized licensing for facilities that serve residents with severe disabilities and complex medical/nursing needs. Some observers thought that regulatory consolidation was particularly needed for oversight of community care homes, which is currently split between the Department of Health and Department of Human Services.

- **Develop adequate reimbursement rates.** Some stakeholders proposed better linking reimbursement for nursing homes and care homes to residents’ needs, a major goal of which would be to pay more for severely disabled and medically complex residents. In their view, the current rates are inadequate and have a negative impact on the quality of care provided to residents. One stakeholder dismissed providers’ concerns about reimbursement, noting that they manage to stay in business with the current rates.

- **Change the State’s decision-making process.** In addition to possibly reorganizing state government to consolidate decision-making on long-term care in a single organization, several stakeholders recommended making decision-making more inclusive and transparent. In particular, respondents said that long-term care stakeholders should be more involved in the decision-making process.

### Obstacles to Reforming the Long-Term Care System

Stakeholders identified several barriers to reforming Hawaii’s long-term care system:

- **Opposition to new or higher taxes.** Both advocates for and opponents of increased government spending identified opposition to additional taxes as a major barrier to increasing government revenues for long-term care. Some stakeholders believed that the public would view a social insurance premium differently than a tax, but not all respondents held this view. Most stakeholders did not think it was politically realistic to propose any tax increase until the economy improves.

- **Opposition to expansion of the public sector.** The appropriate role of government was an area of disagreement among stakeholders, with some wanting a larger role and others wanting a smaller role. This is a philosophical difference that is very difficult to bridge.

- **Lack of knowledge about long-term care issues.** Most stakeholders expressed frustration concerning the lack of knowledge by government officials, the legislature, and the general public about long-term care issues. Bold initiatives are not possible if policymakers are unaware of the issues and the problems underlying them.

- **Leadership lacks the will.** Most stakeholders did not believe that top government policymakers are committed to addressing long-term care issues. The strong division
between the underlying philosophies of the current governor and the current legislature make it hard to argue for investment of time and energy in long-term care reform at this time. Some observers saw the election in November as an opportunity to bring the governor and the legislature into closer ideological alignment.

- **Lack of effective advocacy.** Although stakeholders faulted government policymakers, they also faulted long-term care providers and consumer advocates for being largely ineffective in advancing the cause of long-term care reform. According to observers, this lack of effectiveness breeds indifference because advocates do not see successes on which to build.
Introduction

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This report summarizes the views of the individuals interviewed for the report. Although they were selected for participation based on their knowledge and expertise, the contents of this report should not be viewed as findings of fact. In addition, they do not necessarily represent the views of the report’s authors, RTI, or the Hawaii Long-Term Care Commission. Nonetheless, given the importance of stakeholders in any reform effort, their views provide important perspectives that should be considered in designing initiatives to reform the State’s long-term care system.

This report begins with a description of the study’s methodology, including selection of stakeholders and the discussion guide. The following sections discuss the views of the stakeholders regarding the problems of the long-term care system in Hawaii, their recommendations for reform, and the barriers to implementing reforms. The report concludes with a summary of the findings.

Stakeholder Selection

To ensure that we would obtain a wide range of perspectives, with input from staff and commissioners of the Hawaii Long-Term Care Commission, we compiled a list of key stakeholders: aging and long-term care advocacy groups; state provider associations; state legislative and executive branch policymakers; public and nonprofit program administrators; and individual long-term care providers, researchers, and other expert and knowledgeable individuals. In the course of our interviews, some respondents suggested that we speak with certain individuals and we asked the Healthcare Association of Hawaii to recommend knowledgeable service providers to include in our interviews. In all, we interviewed a total of 47 individuals (Exhibit 1).
### Exhibit 1. Individuals Interviewed

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<td></td>
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<tr>
<td>Rosalyn H. Baker</td>
<td>Senator</td>
<td>Senate</td>
</tr>
<tr>
<td>Les Ihara</td>
<td>Senator</td>
<td>Senate</td>
</tr>
<tr>
<td>Marilyn Lee</td>
<td>Representative</td>
<td>House</td>
</tr>
<tr>
<td>John M. Mizuno</td>
<td>Representative</td>
<td>House</td>
</tr>
<tr>
<td>Suzanne Chun Oakland</td>
<td>Senator</td>
<td>Senate</td>
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<tr>
<td><strong>Government–Governor’s Office (1)</strong></td>
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<tr>
<td>Linda Smith</td>
<td>Senior Policy Advisor</td>
<td>Governor’s Office</td>
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<tr>
<td><strong>Government–Executive Administration (9)</strong></td>
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<tr>
<td>Patricia Bazin</td>
<td>Administrator for the Health Care Services Branch</td>
<td>Med-Quest Division, Hawaii Department of Human Services</td>
</tr>
<tr>
<td>Dr. Kenneth S. Fink</td>
<td>Division Administrator</td>
<td>Med-Quest Division, Hawaii Department of Human Services</td>
</tr>
<tr>
<td>John Grant</td>
<td>Community Assistance and Grants Management</td>
<td>Hawaii Executive Office on Aging</td>
</tr>
<tr>
<td>Susan Jackson</td>
<td>First Deputy to the Director</td>
<td>Hawaii Department of Health</td>
</tr>
<tr>
<td>Noreen Moon-Ng</td>
<td>Program Officer of the Policy &amp; Program Development Office</td>
<td>Med-Quest Division, Hawaii Department of Human Services</td>
</tr>
<tr>
<td>Noemi Pendleton</td>
<td>Director</td>
<td>Hawaii Executive Office on Aging</td>
</tr>
<tr>
<td>Keith Ridley</td>
<td>Chief</td>
<td>Office of Health Care Assurance</td>
</tr>
<tr>
<td>Marilyn Seely</td>
<td>Former Director</td>
<td>Hawaii Executive Office on Aging</td>
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<tr>
<td>Audrey Suga-Nakagawa</td>
<td>Former Project Director</td>
<td>Hawaii Aging and Disability Resource Center</td>
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<td><strong>Government–County (4)</strong></td>
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<tr>
<td>Elizabeth Bethea</td>
<td>County Executive on Aging</td>
<td>Elderly Affairs Division, Honolulu County Department of Community Services</td>
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<tr>
<td>Deborah Morikawa</td>
<td>Director</td>
<td>Honolulu County Department of Community Services</td>
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<tr>
<td>Alan Parker</td>
<td>Executive</td>
<td>Hawaii County Office of Aging</td>
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<tr>
<td>Lei Shimizu</td>
<td>Coordinator of Information and Assistance</td>
<td>Elderly Affairs Division, Honolulu County Department of Community Services</td>
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<td><strong>Providers and Provider Associations (16)</strong></td>
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<tr>
<td>Lani Akee</td>
<td>President</td>
<td>Adult Foster Homecare Association of Hawaii</td>
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<tr>
<td>Coral Andrews</td>
<td>Vice President</td>
<td>American Health Care Association of Hawaii</td>
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<tr>
<td>Norm Baker</td>
<td>Vice President, Community Building</td>
<td>Aloha United Way</td>
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<tr>
<td>Sananda &quot;Sandy&quot; Baz</td>
<td>Executive Director</td>
<td>Maui Economic Opportunity</td>
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<tr>
<td>Dr. Patricia Blanchette</td>
<td>Professor, Geriatric Medicine</td>
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Interview Process

To focus the discussion with stakeholders, we developed an open-ended discussion guide to elicit their views on four major topics (Exhibit 2):

- Does the State’s long-term care system have any problems that need fixing? What components of the State’s long-term care system most need reform?
- What is needed to reform/fix the problems of the long-term care system to meet current and future service needs?
- What obstacles have prevented past reform efforts from succeeding?
- What are the obstacles to the reforms that are needed?

To encourage respondents to be candid in expressing their views, we assured them that nothing they said would be attributed to them individually in this report. To ensure this confidentiality, we are reporting responses in the aggregate—rather than by type of stakeholder. Additionally, because providers are key stakeholders, and to ensure the confidentiality of their responses, we have combined responses from the stakeholder interviews and the provider survey. When synthesizing stakeholders’ responses and selecting specific responses to illustrate key points and perspectives, we paraphrased them for brevity and to ensure confidentiality. In a few cases, the results of more informal conversations are also included. Most interviews were conducted by telephone in February and March 2010.
Good afternoon. Thank you for taking the time to speak with us today. As described in the e-mail we sent you, RTI International has a contract with the State of Hawaii to conduct an assessment of the state’s long-term care system and policy options for addressing identified problems.

We are interviewing key stakeholders, including providers (and their trade associations) to obtain their input on a range of long-term care issues in the state and their views on how to address them.

**Consent**

Because we are obligated to provide the list of persons being interviewed to the state, you cannot participate in this interview anonymously.

However, we will not attribute any information obtained in this interview to you directly, unless you want to be "on the record." All information obtained through the interviews will be reported in the aggregate; any examples of statements made will be paraphrased and presented without attribution.

Any information that you want to provide "off the record" will be treated confidentially—that is, we will not report it or if we believe it is important, we will write it in a way that it cannot be traced back to you. In this case, we will send what we have written for your review and approval.

If there is any question that you do not wish to answer or that you are not comfortable answering, please let me know and I will move on to the next question.

If you agree with these conditions of participation, we can start our discussion.

**Do you agree?**

**Questions**

1. Does the state’s long-term care system have any problems that need fixing? What components of the state’s long-term care system most need reform?
2. What is needed to reform the system/fix the problems to meet current and future service needs?
3. What obstacles have prevented past reform efforts from succeeding?
4. What are the current obstacles to the reforms you believe are needed?
Interview Findings

We have organized stakeholders’ responses into three major categories:

- Problems with the State’s long-term care system
- Reforms needed to address the problems
- Obstacles—past and current—to solving the problems

I. Problems With the State’s Long-Term Care System

The longevity of Hawaii’s population and its rapidly growing elderly population were noted by several respondents as setting the context for the problems of Hawaii’s long-term care system. With few exceptions, stakeholders said that the long-term care infrastructure is inadequate to accommodate this growing population, with many observers noting the failure of both the public and private sector to keep pace with the increased demand for services. Stressing that in 10 years, 25 percent of Hawaii’s population will be age 60 and older, many observers argued that the State needs to develop a plan to meet the needs of the aging population and noted the centrality of solving the problem of insufficient public and private financing. The large amount of unmet need among people who are not eligible for Medicaid and cannot afford to pay for services is a particular problem and some observers reported that persons with severe disabilities who are eligible for Medicaid are not getting enough assistance.

Stakeholders also noted that because of the lack of nursing home beds, care for many individuals who need a nursing home level of care is being provided by family foster care homes and adult residential care homes. While recognizing that many people prefer to be served in these community care homes rather than in a nursing home, several observers expressed concerns about the ability of these homes to provide the intensive level of care needed and about the quality of care provided in those facilities.

A few respondents said that everything about the long-term care system needs fixing, but most mentioned three or four major issues. With a few exceptions, there was a remarkable consensus among respondents regarding the problems that needed to be addressed:

- Insufficient third-party financing
- Inability of informal caregivers to meet need
- Lack of long-term care service capacity, both for nursing homes and home and community-based services
- Fragmentation of the long-term care system
- Poor quality/insufficient monitoring of community care homes

Stakeholder views of the problems of the long-term care system in Hawaii are summarized in Exhibit 3.
Exhibit 3. Problems of the Current Long-Term Care System

All stakeholders thought that the aging of the population would place great additional strain on the current long-term care system. Most respondents identified the main problems of the current long-term care system as the following:

- **Insufficient third-party financing.** Most stakeholders believed that not enough Medicaid and long-term care insurance financing is available to pay for long-term care services. For most people, services are too expensive to be paid out of pocket. Although a longstanding issue, the strong downturn in the economy has severely exacerbated this problem.

- **Inability of informal caregiving to meet need.** Historically, unpaid care by informal caregivers has been a particularly important component of care of people with disabilities of all ages. But informal care cannot be counted on to meet the growing need for care because of geographic mobility, people living longer, the high cost of living in Hawaii, and the lack of interest among some of the younger generation. The strain on informal caregivers of helping disabled relatives and the lack of support for caregivers may result in an increased demand for paid services.

- **Lack of long-term care service capacity.** Going hand in hand with inadequate financing and strained informal caregivers, stakeholders said that there is an across-the-board shortage of nursing home, community care home, and home care service capacity, especially for people with complex medical needs. The new Medicaid QUEST Expanded Access program has substantially changed service arrangements, but few stakeholders knew much about the impact of the program.

- **Fragmentation of the long-term care and health systems.** Many older people and persons with disabilities have both long-term care and medical needs and must navigate complex and fragmented service delivery and financing systems. Respondents emphasized that there are issues both within long-term care and health care systems and between the two systems. Some stakeholders questioned whether one could even refer to a long-term care “system” because the service and financing components were so “silenced” and disconnected.

- **Poor-quality/insufficient monitoring of home and community-based services.** Unlike other states, stakeholders did not identify the quality of nursing home care as a major problem. Rather, respondents focused on the regulation of community care homes and, to a lesser degree, home care. Given severe levels of disability and complex medical/nursing needs among many community care home residents, stakeholders expressed concerns about the lack of staff training, case management, and fragmented oversight of these facilities.

**Insufficient Third-Party Financing**

With very few exceptions, respondents said that insufficient financing to meet long-term care needs is a major problem and for many, it is the principal problem that the State needs to address, particularly funding for Medicaid and for home and community-based services. As one respondent put it:

> The cost of long-term care is high for individuals and for the State. For most individuals, a need for long-term care means impoverishment. For the State’s long-term care system, the costs will rise dramatically as the population ages.
The key question is: How should these high costs be shared? The current funding sources—including out-of-pocket spending and Medicaid—are inadequate. We have to find a new financing mechanism that will bring in additional funds, one which people will be willing to support.

One respondent observed that although state Medicaid funds are matched by federal dollars, the governor has not budgeted enough Medicaid funds to meet service needs, noting that even the intake and assessment system to determine eligibility for services has a waiting list. Moreover, the State Unit on Aging has been level funded for many years.

There was agreement among a broad range of stakeholders that the demand for services has been increasing over the past years and that state government and the private sector have failed to keep pace with the growth in the elderly population. In particular, many stakeholders said that there is a growing number of people who are not financially eligible for Medicaid but cannot afford to pay for long-term care—even costs incidental to the provision of informal care, such as incontinence supplies. Although this population is eligible for Kupuna Care, the program has a long waiting list (currently 500 individuals) and spends an average of only $800 per year per client. Moreover, few people have private long-term care insurance, which one observer attributed to people waiting to buy it until they are older when policies are more expensive—and thus unaffordable—or the presence of health problems which make them uninsurable.

Effect of the Current Economic Crisis

Most stakeholders noted that the long-term care financing problem has been exacerbated by the current economic downturn and the governor’s policy of cutting spending to balance the budget rather than raising taxes. Supporters of the governor’s policy argued that there is no political support to raising taxes and that there is no alternative. Many observers expressed major concerns about the impact of budget cuts on those in need of assistance and noted that because the governor is refusing to spend all of the funds appropriated for Kupuna Care, the program is serving fewer people.

The governor has announced major delays in paying Medicaid providers in FY2010 and some respondents said that similar delays occurred in FY2009 and that the State has not yet completely paid what is owed. Some stakeholders reported that providers have to wait 9 months or more to be paid and some have accounts receivable going back to February 2009. A few providers noted that if lack of payment continues, some adult residential care homes will go out of business because they will not be able to make their mortgage payments.

One stakeholder reported that long-term care providers contacted the Centers for Medicare & Medicaid Services (CMS) regional office to protest the delays in payment. They were told

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1 Kupuna Care is a small state-funded home and community-based services program for people age 60 and older administered by the Hawaii Executive Office of Aging. Services include case management, transportation, attendant care, personal care, homemaker, chore, home delivered meals, and adult day care. Unlike Medicaid, eligibility for Kupuna Care is not limited solely to low-income people with very limited assets.
that Hawaii’s Medicaid Director had informed CMS of the plan to delay provider payments and had assured CMS that no harm would come to any Medicaid recipients as a result of the delay. When the provider coalition went to the legislature to seek a solution to the payment problem, they were told that the executive branch was responsible for the administration, regulation, and monitoring of the Medicaid program.

Many respondents believed that the long-term care system is under siege by the governor, with one stakeholder expressing concerns that the budget cuts were “shredding the safety net.” But one respondent noted that the State’s inability to pay Medicaid providers was affecting not only long-term care providers but also health care providers and was, in part, a consequence of a substantial increase in the number of people eligible for Medicaid during the current economic downturn. Because the State accepted federal stimulus funds to get a higher Medicaid match (now 67 percent), it cannot tighten eligibility criteria.

An unanticipated consequence of the economic downturn is that the nursing home utilization rate has decreased somewhat. Stakeholders were not able to definitely attribute the decrease to particular factors, but some said they believed that the managed care companies are making greater use of home and community-based services to avoid the high cost of institutionalization. One person theorized that because people who are unemployed can stay home and take care of their family members, there is less pressure to place older people into nursing homes.

**Strain on the State’s Finances From the “Compact of Free Association”**

Two respondents mentioned that under the Compact of Free Association, people from the Marshalls and other islands can move freely between their island and the United States to obtain education and health care. Most are enrolled in the Hawaii Medicaid program and many need dialysis. One noted that although the federal government pays states for their care, the payments do not come close to covering Hawaii’s costs and that funding for this group was one of the first items the governor reduced.

**Inability of Informal Caregiving to Meet Need**

Many respondents stressed the cultural traditions in Hawaii of taking care of one’s elders and living in multigenerational households, which facilitates the provision of informal care for aging relatives. Some respondents attributed the State’s low use of nursing homes—compared to the national average—to these traditions. A few observers noted that high housing costs also contribute to multigenerational households. Several respondents contended that these cultural traditions are weakening and that it is now more acceptable to place family members in nursing homes and other residential settings. As one stakeholder put it:

> Asian populations have a long tradition of caring for their elders. We have the highest rate of multigenerational families living in one home in the country. Because we make the assumption that they will continue to do so, this tradition prevents people from thinking about public solutions to the long-term care problem. But the mindset is changing—in part because of high female labor force participation. We’re seeing caregiver burnout. The cultural tradition is starting to break down.
Other reasons offered for the change in these cultural traditions include the following:

- **Geographic mobility.** Adult children move out of state for various reasons, including education and jobs. As a result, many families now have members who live on the mainland. Some providers reported that they increasingly get calls from adult children on the mainland who are worried about their aging parents.

- **Because people are living longer, more people have extensive long-term care needs which place strains on caregivers.** People with disabilities may have special needs that require expensive supplies, such as incontinence pads, and dietary problems that require nutritional supplements. Additionally, the State has high levels of obesity, which greatly increases the physical demands on caregivers. Families may provide care for years, but then face a crisis when care needs increase and they are unable to meet them or to pay for services.

- **The high cost of living in Hawaii, particularly of housing, means that many households need two or more wage earners, reducing the number of potential caregivers.** A few respondents noted that people in their 60s are working and are not able to take care of aging parents. The high cost of housing means that many living units are small and cannot accommodate multigenerational families.

- **Lack of interest among some of the younger generation, who no longer want to provide care or feel they cannot because of other priorities.** One respondent said that the children of residential care home operators—generally a family business—are not interested in this work.

Several stakeholders noted that many caregivers are burning out as their family members’ needs become more complex and that the nonprofit organizations that provide evening, overnight, and weekend respite are cutting back on services because of lack of funding. They particularly noted the pressing need for services to help informal caregivers who are not eligible for Medicaid.

Some respondents expressed major concerns that a weakening of the informal care system will increase the number of people who will need paid services, including those who rely on Medicaid. One respondent noted that a substantial portion of Medicaid home and community-based services funding is spent on residents of adult foster care and expanded adult residential care homes rather than on individuals receiving care in their own homes. Although community care homes are an important part of the long-term care system, this respondent said that assisting informal caregivers is essential to delay or prevent entrance to community care homes and nursing homes.

Other stakeholders said that informal caregivers needed more support from employers in both the private and public sectors, noting that even in state government, although an individual supervisor may have some authority to provide some flexibility in work hours, no formal provisions allow government workers to adjust their schedules to accommodate caregiving responsibilities.

Several service providers felt that weakening of the informal care system has already occurred—evidenced by the extent of unmet needs they encounter in their work. Given this, they noted that the State cannot rely on informal caregivers to address current and especially future needs.
Lack of Long-Term Care Service Capacity

The overwhelming majority of respondents said that lack of service capacity is a major issue, noting shortages for nursing homes, home care, community-based services, and adult residential care homes. The lack of capacity is most acute for nursing home and adult residential care home residents with high needs (e.g., obesity, mental illness, complex medical needs, severe dementia, and combinations of these conditions). Because of excess demand, providers can be selective about who they admit without worrying about vacancies.

Some respondents said that because the State is made up of islands, some of which do not have sufficient services, geographic access barriers present challenges to meeting people’s needs. Some people have to travel to different islands for health and long-term care and some get “stuck” in a particular facility because they need services that cannot be provided where they live. Not surprisingly, one stakeholder noted that islands with larger populations have many service providers compared with others. Contradicting these views, one stakeholder said that there are no major geographic differences in access to Medicaid home and community-based services (possibly with the exception of meals-on-wheels and transportation services) and that each island has “enough” community care homes.

Insufficient Nursing Home Beds

Most stakeholders said that the State lacks sufficient nursing home beds to meet current demand and that the nursing home bed shortage would become even more of a problem as the elderly population increases. A few said that although additional nursing home beds were needed, nursing homes were just too expensive to be viewed as a primary or major solution to the State’s lack of service capacity in the long-term care system. Although some respondents cited the chronic nursing home waiting list as evidence of the nursing home bed shortage, only a few thought the waiting list itself was a major problem for the long-term care system. Some observers saw the waiting list primarily as a problem for hospitals that are not receiving payments for patients on the waiting list who are uninsured or not eligible for Medicare or Medicaid.

One respondent attributed the lack of nursing facility beds to Medicaid reimbursement that is lower than cost, noting that this is particularly a problem for subacute care patients. Moreover, because nursing homes historically have not provided care to these patients with such extensive needs, data are lacking which could be used to calculate more appropriate rates. According to this observer, the Level D Medicaid subacute payment is only for patients who have tracheotomies or who are on ventilators, but it needs to be expanded to include other complex conditions (e.g., a need for skilled services, complex wound care, comorbidity with behavioral issues, or patients who are morbidly obese).

Given the increased demand for services by the subacute/medically complex patient population, this stakeholder argued that the State needs to develop tailored “niche” services (e.g., an eight-bed facility for morbidly obese patients), but providers cannot obtain Medicaid reimbursements to cover such services. Two respondents noted that to care for many of the medically complex and high-need patients on the waiting list, nursing homes have to provide their staff with additional training, which is costly.
When asked why nursing homes would not admit the postacute patients on the waiting list who would be eligible for Medicare reimbursement, one stakeholder replied that these residents would stay in the nursing home after their Medicare coverage ended. If nursing homes admit these individuals, they will have to continue caring for them with much lower Medicaid reimbursement. Thus, it is not in the interest of nursing homes to admit these heavy care patients until Medicaid long-term care reimbursement rates are higher. Until then, hospitals will remain the default care setting for this patient population.

One stakeholder argued that if the State and providers wanted to solve the waiting list problem, they would. Another stakeholder agreed, noting that the State’s Medicaid program has no financial incentive to move waitlisted Medicaid beneficiaries from the hospital to nursing homes. One respondent asserted that the waiting list for nursing homes beds is the result of a deliberate state policy not to certify for Medicaid participation all of the nursing home beds available because the State does not have the money to fund more Medicaid nursing home beds.

**Insufficient Adult Residential Care Homes in Certain Geographical Areas**

Several stakeholders mentioned a shortage of adult residential care home beds, which is particularly acute in certain communities. Many of these homes were geographically “segregated”—located primarily in fairly small ethnic communities on Oahu and Hawaii. Some respondents said that this pattern of service location creates problems for people who want to receive care in these homes but do not want to leave their own communities. Their location also reduces opportunities for community integration. As one respondent put it:

*Family foster care and adult residential care homes are predominantly run by people from the Philippines. This is a good thing when they are located in communities where many people from the Philippines live. It ensures that this population has providers from the same culture with the same language. It is not always a good match when people from other ethnic groups need care in these homes.*

The location of community care homes in limited geographic areas is a longstanding problem, observers noted, partly because of the residential location of people who want to provide this care. However, resistance from local communities who do not want these homes in their neighborhoods is also a factor. A family’s proposal to convert its home to a residential care home can generate considerable opposition from neighbors because of concerns about inadequate parking, wandering by residents, and noise caused by ambulances.

Another factor limiting the growth of adult residential care homes is that real estate is expensive and these homes are costly to outfit to meet state requirements. One stakeholder estimated that it usually costs between $100,000 and $150,000 in renovations to meet Department of Health certification requirements. A few respondents noted the difficulty of operating financially sustainable community care homes, noting that because housing is expensive, people with large homes are often better off financially renting out rooms than operating as a foster care or adult residential care home.
Insufficient Home and Community-based Services Infrastructure and Financing

Home and community-based services are also in short supply, according to many observers, which contributes to a strong institutional bias. Several stakeholders said that most people cannot afford to pay the $25 per hour it costs to purchase services from home care agencies. Many stakeholders said that it was essential for the State to provide additional funding for home and community-based services, in part because failing to do so would increase the need for more expensive health care and increase the demand for nursing home care.

One respondent contended that the State and others support home and community-based services because they are believed to be less expensive than nursing homes, but there are economies of scale in nursing homes. According to one stakeholder:

*The cost of home care can be very high for people who need supervision or the availability of assistance 24 hours a day. In fact, depending on the amount of services required, home care can cost as much as or more than nursing home care. It is important not to take a simplistic view regarding the relative costs of institutional care and home care.*

In particular, Medicaid pays an all-inclusive rate for nursing home care. In the community, however, each discrete service (e.g., transportation costs, case management, Registered Nurse, home health aide) is unbundled and billed separately, so costs can be high. One stakeholder contended that some providers own businesses in each of the discrete service lines and “self-refer” from one of their service lines to another.

With the implementation of the Medicaid QUEST Expanded Access (QExA) program for older people and persons with disabilities, use of home and community-based services has reportedly increased by 20 percent and waiting lists for home and community-based services waiver services have ended. Some stakeholders also noted that the program has a consumer-direction option that allows individuals who need personal assistance to hire friends and family members. One respondent expressed concern that the higher capitation rate in QExA for enrollees who need home and community-based services will lead to unnecessary use because of the financial incentives for the health plans to increase the number of people in that payment category. On the other hand, two stakeholders contended that chore services have been cut back drastically since the implementation of QExA, although one person said the change was appropriate because some people receiving services did not need them.

Several stakeholders noted that the state-funded Kupuna Care program has about 500 people on a waiting list and federal Older Americans Act-funded programs also have waiting lists. Specific home and community-based services shortages were noted for respite and adult day health services. Several respondents said that the need for weekend respite care

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2 Medicaid QExA is a Medicaid managed care program for older persons and younger persons with disabilities. It covers both health and long-term care services. Currently, two plans are available—Evercare and the Ohana Health Plan.
for family caregivers is especially great. Maui reportedly has a good adult day care program, but the number of people it can serve is limited and it cannot address the needs of people with complex medical needs.

**Fragmentation of the Long-Term Care and Health Systems**

Many respondents identified fragmentation of the long-term care system as a major problem, noting that there is no real long-term care “system”; every component was designed for a different purpose and they do not work together. Consequently, the system is so confusing that people do not know what resources are available and cannot figure out how to get services. Particularly when caregivers are feeling overwhelmed or are dealing with a crisis, they do not have the time or the knowledge to find and arrange the services that family members need in the most appropriate setting. As one stakeholder put it, “It’s a maze that even professionals acknowledge is convoluted and difficult to sort through.”

In addition to confusion among the general public, some health and long-term care providers also do not understand the system and its various options. When the need for long-term care arises, understanding the eligibility rules for various services and differences among services can be daunting. In particular, according to several observers, Hawaii’s system of foster family care, adult residential care homes, and expanded adult residential care homes, with the different levels of care that they provide, is very difficult for consumers to understand. In a summary judgment by one stakeholder, “The ‘system’ is just a lot of disjointed programs with different eligibility criteria.”

The fragmentation of the delivery and financing system is not limited to long-term care. One stakeholder argued that people served in the long-term care system also need and receive services across the entire health and long-term care continuum and that both systems are fragmented. As one stakeholder summarized it for Medicaid:

*The Medicaid system is not designed to provide cost-effective and high-quality care. There is a lack of coordination and communication among health care providers (mainly due to lack of reimbursement for coordination and communication services), which limits the system’s ability to support individuals in the community and to prevent health and functional decline. More efforts should be focused on how proper coordination and case management of individuals entering the acute care system can be used to promote better outcomes and reduce costs, which would contribute to a decrease in aggregate Medicaid long-term care costs.*

Some respondents asserted that transitions between health and long-term care settings could be much better managed. They said that because people are not getting adequate services in the community, they develop health problems and are hospitalized or admitted to a nursing home. This is particularly a problem among lower income older persons and those without informal support networks. Service coordination and follow-up postdischarge

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3 Foster family care homes and expanded adult residential care homes are allowed to serve a limited number of individuals who need a nursing home level of care, but adult residential care homes are not allowed to serve this population.
to prevent rehospitalizations and nursing home admissions is lacking. One respondent stated that the State’s managed care plans are attempting to address this problem.

In addition, one commenter observed that the system does not deal well with certain subpopulations who are aging—for example, people with developmental disabilities, serious mental illness, and HIV/AIDS. Often the agencies that serve older persons and those that serve discrete populations, such as persons with developmental disabilities or serious mental illness, believe that the “other” agency is responsible for serving older people with these conditions. Reportedly, some providers serving older people are attempting to work with agencies that serve other populations but doing so is difficult because public funding is siloed and services have been cut.

Some stakeholders noted the lack of coordination among the many entities that provide services to older people and their families. Difficulty navigating the system was the reason that the State developed an Aging and Disability Resource Center (ADRC). Although the State received a federal Systems Change grant from CMS in 2001 to begin development of an ADRC and an Administration on Aging/CMS ADRC grant in 2005, the ADRC was described by one stakeholder as having “just been launched” and by another as being “in its infancy.” Additionally, with the exception of one physical office in Hilo, it remains largely a series of Web sites rather than an organization that interacts with consumers on an ongoing basis to provide help navigating the long-term care system. One respondent expressed concern that people using the ADRC are discouraged to learn that there is a waiting list for many publicly funded services. According to several stakeholders, older adults of many different ethnic backgrounds have neither computers nor the language skills to use the ADRC Web site.

Moreover, some long-term care stakeholders had never heard of the ADRC. One provider said she had heard about it but did not know how to contact it, noting:

*If I don’t know about it, how is the general public supposed to know? All they know is that the hospital said to call a particular case manager or case management agency. It’s easier for discharge planners to call a case manager than to call 50 different foster care or adult care providers to find an appropriate placement.*

Compounding the problems of the limitations of the ADRC, several stakeholders noted that the State laid off hundreds of workers in the Department of Health and the Department of Human Services and closed several Medicaid eligibility application centers to address the budget crisis. Currently, there are only two physical offices in the State—one in Honolulu and one in Hilo—where people can apply for Medicaid in person. One respondent said:

*People seeking services now either use the telephone or the Internet to get information but many people need face-to-face contact because they do not have computers, or do not understand English or the bureaucratic process. It is impossible for them to navigate the system by phone, computer, or written communication.*
Lack of an Effective Referral System Between Hospitals and Long-Term Care Settings

Several stakeholders said that hospital discharge planning was inadequate, especially in terms of its relationship to community care homes. As one stakeholder put it:

We can improve the long-term care system by ensuring appropriate placement post-hospital discharge. Not everyone needs to go to a nursing home, or if they do, they may only need postacute care for a short period of time. Some people may be able to be cared for at home or in an adult care home. Individuals should be discharged to the least intensive level of care that meets the individual’s needs. Anything more would be considered waste. However, discharging an individual to a lower intensity of services when more care is required potentially jeopardizes patient health and safety, and can increase the risk of rehospitalization.

Respondents noted that because discharge happens so quickly and nursing home beds are lacking, many people are discharged home too soon without necessary services in place. As a result, they are not able to care for themselves nor are their families adequately prepared to care for them. In addition, some people are discharged too soon to family foster care providers, which is particularly a problem for elderly persons who may not have the cognitive capacity to engage in discussions about their needs postdischarge and thus are at risk for rehospitalization.

Several respondents emphasized the importance of matching individuals who have long-term care needs with the right setting and caregiver, noting that placements are often not based on residents’ desires. One stakeholder contended that discharge planners sometimes collude with the proprietors of particular homes to ensure that their beds are filled, regardless of the client’s needs or preferences. One respondent alleged that hospital employees who are relatives of facility operators steer patients being discharged to their relatives’ facilities.

Poor Quality/Insufficient Monitoring of Home and Community-Based Services

Somewhat surprisingly, because it is usually a matter of great concern in other states, none of the stakeholders interviewed raised concerns about nursing home quality. Concerns about the quality of home and community-based services were raised in four areas:

- Competency of long-term care workers generally; language barriers; and cultural differences.
- Low levels of training and the potential for fraud when people hire workers privately rather than through agencies. Some observers stated that many home care workers are paid “under the table,” contributing to the State’s grey economy and decreasing tax revenues.
- Lack of monitoring of some home and community-based services providers. Although a 2009 law requires licensure of home care agencies that primarily serve the private pay market, it has not been implemented because of lack of funding. Home health agencies are licensed.
- Insufficient oversight and monitoring of community care homes.

The overwhelming majority of quality concerns voiced by stakeholders related to community care homes. Respondents stressed the importance of ensuring that family foster care and adult residential care home providers are able to provide adequate care because when they cannot address their clients’ complex health issues, they bring them to hospital emergency rooms, which is very expensive and sometimes unnecessary. Some stakeholders said that poor staffing was an issue and others said that low reimbursement made it difficult to provide good quality care.

One respondent contended that monitoring and oversight were generally weak, but that quality monitoring varies across the counties. A few noted some egregious lapses, such as when an operator convicted of criminal activity was allowed to open up a new home. (This incident was also reported in the Honolulu Advertiser in a series of articles running on March 28, 29, and 30, 2010.)

Several stakeholders said that adult residential care homes have successfully opposed additional quality regulations, including rating systems, criminal background checks for workers, and a Web site for complaints. One respondent claimed that in many adult residential care homes, only one person has received training and is qualified to care for residents; the other staff are family or friends of the owner with no training. This lack of training can lead to abuse (e.g., overmedication to solve behavior problems) and a failure to meet residents’ needs. In defense of the industry, one respondent contended that there were only a few instances of poor quality care in adult residential care homes and that similar rare instances occurred in other long-term care settings, but are not reported in the media.

Other quality-related issues respondents raised regarding community care homes include the following:

- **Inability to age in place.** The inability to age in place is an issue when adult residential care homes cannot continue serving residents who need more services as they become more disabled. Although some adult residential care homes are licensed to provide a higher level of care—expanded adult residential care homes—not all adult residential care homes are so licensed.

- **Regulatory inconsistencies.** The Department of Health regulates adult residential care homes using a medical model while the Department of Human Services regulates foster homes using a social model even though foster homes are required to serve at least one individual who needs a nursing home level of care and adult residential care homes are not permitted to serve individuals who need this high level of care. Both the Department of Health and the Department of Human Services oversee individuals in expanded adult residential care homes who need a nursing home level of care. One respondent contended that the overlapping responsibilities meant that neither agency was truly accountable for the quality of care in community care homes and each agency tended to fault the other for problems.

Expanded adult residential care homes have proposed that they be allowed to serve more than two nursing facility level-of-care residents (out of five maximum residents). Although a third resident at this level would help facilities financially because of the higher
reimbursement, some stakeholders questioned whether these homes could provide the level of care needed.

II. Reforms Needed to Address the Problems

Although there was considerable consensus among respondents about the long-term care system’s problems, there was less agreement about what should be done to solve them, primarily as a result of conflicting views regarding financing mechanisms. Respondents generally believed that many, if not most, of the needed reforms could not be accomplished without first addressing the financing issue—the “elephant in the room” as one person called it. Several stakeholders cited the urgency of doing so given the expected increase in the older population. As one person put it:

> With an aging population, the biggest concern is that we need to prepare for future long-term care needs. We need to determine what those needs will be and how to meet them; how we will provide services and most importantly who will pay for them—how the services will be financed.

Several stakeholders stressed that solutions needed to come from both the private and the public sector and one felt strongly that the State needed to make a major shift in thinking about aging and what it means to be old, noting that many older people are active into their 70s and that no one wants to be called elderly when they are 60 years old. Given the longevity of the population in Hawaii, some observers urged the State to take steps to help people adopt healthy lifestyles to prevent chronic illnesses, frailty, and other conditions that can lead to a need for long-term care.

Exhibit 4 summarizes stakeholders’ views on needed reforms in the long-term care system.

Solve the Financing Problem

Virtually all respondents mentioned financing and many focused on it as the key reform needed to address current and future long-term care needs. Several persons interviewed noted that it would not be possible to address financing issues until the recession ended and the legislature and the governor were in more philosophical agreement. One stakeholder felt that fixing the long-term care financing system was part of the government’s overall responsibility to aid the poor, aged, and disabled. This person stated, “The State is going to have to find the funds. Although people don’t want taxes raised, they will have to pay the cost somehow.”

Because Medicaid services are partly financed at the state level with general revenues and must compete with funding for other state services, some respondents argued that the State needed to develop a new source of dedicated funding for long-term care—one that would rise with inflation and with need. Some stakeholders related that consumer advocates are proposing an increase in the sales tax to fund services for seniors and long-term care. Advocates of higher taxes cautioned that the State needs to find ways to raise revenue that do not have a negative economic impact or adversely affect lower-income people.

The first step, some said, in tackling the financing issue would be to compile a comprehensive long-term care budget for the State; currently, funding for programs for
Exhibit 4. Reforms Needed to Address the Problems

- **Solve the financing problem.** Stakeholders were strongly divided about whether the public or the private sector needed to expand to solve the financing problem. Some respondents believed that long-term care is fundamentally a social responsibility of government and that either taxes will need to be increased to pay for Medicaid or a new public long-term care insurance program will need to be established, financed by premiums and general revenues. Other respondents believed that long-term care is ultimately an individual responsibility and that the goal should be to reduce the role of government programs in financing long-term care. Advocates of this view tended to support education on the financial risks of long-term care and tax incentives for purchase of private long-term care insurance policies.

- **Increase service capacity.** Several respondents stressed the need to increase the availability of all types of long-term care services (nursing homes, community care homes, and home care), particularly for people who are not eligible for Medicaid and to provide respite for informal caregivers. While recognizing the need for institutional care, they stressed that the state should not rely only on nursing homes to address long-term care needs. Other stakeholders, however, cautioned that home care does not necessarily lead to cost savings, particularly when individuals need extensive care and supervision.

- **Reform components of the service delivery system.** Stakeholders had a variety of highly specific recommendations, including revising the eligibility determination and service allocation approach for Kupuna Care and increasing the use of consumer-directed services. Some observers stressed the importance of understanding the current system and designing solutions to its problems before adding new funding, which would just expand the current inadequate system.

- **Reduce system fragmentation and improve service coordination.** On the policy level, some stakeholders advocated consolidating long-term care policy and regulation into one agency, as is done in Oregon and in Washington. Many stakeholders believed that strengthening the Aging and Disability Resource Center could help consumers receive the services they need.

- **Address quality problems with community care homes.** Stakeholders proposed a number of initiatives to improve the quality of care in community care homes, including increasing training and case management, implementing uniform and systematic screening of community care home applicants to ensure appropriate placement, and developing specialized licensing for facilities that serve residents with severe disabilities and complex medical/nursing needs. Some observers thought that regulatory consolidation was particularly needed for oversight of community care homes, which is currently split between the Department of Health and Department of Human Services.

- **Develop adequate reimbursement rates.** Some stakeholders proposed better linking reimbursement for nursing homes and care homes to residents’ needs, a major goal of which would be to pay more for severely disabled and medically complex residents. In their view, the current rates are inadequate and have a negative impact on the quality of care provided to residents. One stakeholder dismissed providers’ concerns about reimbursement, noting that they manage to stay in business with the current rates.

- **Change the state’s decision-making process.** In addition to possibly reorganizing state government to consolidate decision-making on long-term care in a single organization, several stakeholders recommended making decision-making more inclusive and transparent. In particular, respondents said that long-term care stakeholders should be more involved in the decision-making process.
older people and persons with disabilities are not examined together. Additionally, although Medicaid is the dominant public funding source for long-term care, it is important to understand how much money is being spent on other programs for younger people with physical and mental disabilities and for Older Americans Act programs. According to this view, the State needs a better sense of the total spending on long-term care and current funding allocations to identify areas that need more funding and to discuss alternatives for financing services. As one person stated, "We need to know how much we're spending and come up with alternatives for financing it differently. The State must determine what resources are available and what its priorities are for spending them."

When asked if the State should develop a global long-term care budget that combined all state long-term care funding as is done in Oregon and Washington, one respondent said that the State was not yet ready for this approach because much more needs to be known about current funding. He noted that legislators and even people knowledgeable about long-term care know something about different programs, but not how they are funded. (This view was borne out in the interviews; people who were very knowledgeable about certain aspects of the long-term care system did not always know how specific services were funded.) Some stakeholders stated that to meet the projected increase in long-term care needs, the State needs to stop looking at the old mechanisms for financing and to start thinking about new approaches. One stakeholder insisted:

If the State is not able to provide the necessary funding, we have to look at other ways to address long-term care needs instead of sitting around and complaining or pointing fingers. If the State has not responded to calls for more money for aging services for the past 20 years, then we need to propose new solutions that might get state support.

Finally, one respondent said that the current system provides a very poor foundation for expansion and simply adding money to it is not the solution. Rather, the State needs to decide on the specific service delivery model it wants before adding additional funds. It needs a better understanding of the current system of service delivery, its gaps, and its shortcomings to design a model to ensure quality, choice, and cost efficiency. In his view, a good starting point would be to combine the regulatory and administrative infrastructure from multiple organizations into one agency.

Respondents were divided on whether the State should promote “personal responsibility” and encourage individuals to voluntarily purchase private long-term care insurance or implement a mandatory public long-term care insurance program. One respondent noted that fixing the financing problem will be much more difficult than fixing problems with the service delivery systems because what is needed is what is hardest to get: thoughtful conversation about long-term care issues—devoid of partisan politics—and the crafting and enactment of solutions.
Enact a Public Social Insurance Program

Several stakeholders said that a mandatory social insurance model that spreads risk across the entire population would be the best solution by providing universal coverage for a basic long-term care benefit. Another respondent thought that a major goal of reform should be to prevent people who have been financially independent all of their lives from becoming impoverished and ending up on welfare in the form of Medicaid.

Those people who supported requiring everyone to participate in a public insurance program believed that spreading the risk across the entire population is the only realistic solution to raise the funds necessary to pay for the growing number of people with disabilities. One stakeholder argued:

*People are more likely to pay premiums that provide benefits to the people enrolled in the insurance program rather than to pay taxes that subsidize “other” people, such as Medicaid beneficiaries. People will be more willing to pay for their own long-term care than for others. Cross-subsidies are hard to sell politically.*

This basic program could be supplemented by private long-term care insurance with Medicaid as the safety net. One respondent noted that had the 2002 proposal for a state public long-term care insurance program, Care-Plus, been enacted, the State would currently be reaping its benefits during the current economic crisis because a dedicated funding stream would be available to finance long-term care. Another person said that unless the State mandates insurance coverage, it is unlikely that people will purchase it, and noted that Hawaii has had mandatory health insurance for many years and most people now take it for granted.

Additionally, several observers did not believe that sufficient numbers of people would enroll in a voluntary public insurance program to make it actuarially sound, so enrollment should be mandatory. One stakeholder predicted that enrollment in the CLASS Act would be low because it is voluntary.

When asked about the likelihood of a Hawaii-specific social insurance program being enacted in the coming years, those who thought it would be possible agreed that it would have to wait until the current economic recession was over because mandating payment of premiums would be a “nonstarter.” However, once the recession ends, they believed that the legislature could consider such a program if the new governor supported it. They noted that the State came quite close to enacting this type of program in the early 2000s.

Stakeholders who support a public social insurance program acknowledged that it will be difficult to convince the public of its need because people know little about long-term care. Additionally, some stakeholders seemed unfamiliar with the basic financial underpinnings of

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4 Most of the interviews took place before the enactment of the Community Living Assistance Services and Supports (CLASS) Act as part of the Patient Protection and Accountable Care Act of 2010. These new provisions establish a voluntary, public insurance program for long-term care. Thus, for the most part, the conversation focused on Hawaii-specific rather than national options.
insurance programs—that they must pool the relatively small number of people with high risk of needing services and the large number of people with a low risk of needing services to create an affordable premium. For example, one respondent said that Care-Plus was poorly conceived because everyone would pay into it but not everyone would receive long-term care benefits.

Because most of the public does not know there is a long-term care problem, many people—especially young people—will resist paying even a fairly nominal premium/tax. To gain the public’s support, supporters of a public insurance approach argued that the State and long-term care advocates will have to explain the long-term care financing problem to the public to convince people that the private sector is not an adequate solution.

One respondent noted that a social insurance approach might be needed but that the federal government rather than the State should be responsible for this initiative. One stakeholder noted the importance of the State understanding how the long-term care provisions of the new legislation—particularly the new CLASS program—will affect the State.

Several respondents were opposed to a mandatory public social insurance program, some strongly so. One stated that the government should help those in need, but that a government insurance plan is not the solution. One observer observed that Republicans resist public social insurance because they believe that financing for long-term care is the responsibility of individuals and their families. One stakeholder summarized the opposition by saying, “If the government provides the care, then it reduces personal responsibility. It’s socialism.” Others noted that the insurance industry and the Chamber of Commerce also oppose social insurance programs for long-term care.

**Encourage the Purchase of Private Long-Term Care Insurance**

Several respondents believed that private long-term care insurance is the solution to the financing problem. Just as people understand the need for homeowner’s insurance, they need to understand the need for long-term care insurance. One stakeholder said, “The best way to deal with the long-term care issue is for individuals to plan in advance and use the expert capabilities of the long-term care insurance industry.” One person related that people must learn that if they buy long-term care insurance when they are young, then it will be relatively inexpensive; if they wait until they are older, then it will be much more costly.

Supporters of private long-term care insurance did not believe that the government could mandate its purchase; instead they said that the State had to work to change people’s attitudes so that more people would buy it. Advocates of private long-term care insurance said that people need to be educated to prepare financially for possible long-term care needs, not just for aging parents but for themselves. Others noted that educational campaigns about the risk of needing long-term care have been conducted for years (e.g., by AARP) but have not been effective. In addition, in the current economic climate, it is particularly difficult to convince people to buy a relatively expensive product such as private long-term care insurance.

One respondent said that a major obstacle to getting the public to take responsibility for providing for themselves was that our society expects that the government will take care of them. This person said that this attitude is a particular problem in Hawaii because the State
has many immigrants from other countries, who are used to having government programs support them. One respondent noted: “This is part of their experience and they see little need to do things on their own; they are shocked that we do not provide all the things they are used to.”

Several stakeholders said that long-term care insurance can make a difference for the middle class and that the State should educate the public about the need to plan for their retirement years, including a possible substantial period of needing long-term care. They said that a cultural change is needed so that this middle class recognizes that they have to be responsible for their own long-term care needs. Unless they do, the pressure will be on the Medicaid program. As one respondent argued:

People need to understand that the State does not have the money to provide long-term care for everyone who is going to need it. Medicaid is not an unlimited source of funds. People need to be able to take care of themselves. States do not have and will never have enough money to care for everyone who needs care.

One respondent who opposed the Care-Plus legislation said that the tax/premium of $10 a month was “a lot of money for many people.” When it was pointed out that private long-term care insurance policies can cost over $100 a month, this person replied that the cost of private long-term care insurance could be reduced by fostering competition in the insurance industry, getting rid of regulatory barriers, and lowering taxes. In addition, this stakeholder said:

More competition is needed to drive down costs. In addition, a bigger pool of people buying policies will reduce premiums. One option that could decrease prices would be for insurers to lower premiums for individuals with advance directives stating that they do not want heroic measures at the end of life.

Several respondents thought that the State needed to provide financial incentives for the purchase of private long-term care insurance. Some advocates suggested that the State should make premiums for long-term care insurance tax deductible and that tax incentives should be aimed at 30- to 40-year-olds—when long-term care insurance will cost less—to further encourage its purchase. Others noted that such tax incentives primarily help those with relatively high incomes, and that even with the incentives, many people would still not be able to afford insurance. Another said that tax incentives primarily would help those who would have purchased insurance without the tax benefit. In the view of one stakeholder, even if actuarially sound products are available for most people, it does not make sense to purchase policies unless they have sufficient assets to protect—at least $100,000.

**Increase Service Capacity**

Several respondents stressed the need to increase the availability of all types of long-term care services, particularly for people who are not eligible for Medicaid and to provide respite for informal caregivers. While recognizing the need for institutional care, however, they stressed that the State could not rely only on nursing homes to address long-term care needs. As one stakeholder put it:
Past studies have shown that we need more acute, subacute, and long-term care beds—we know that. But for the long term, we need more home and community-based services to better balance expenditures between the two settings. We need to strengthen the infrastructure for home and community-based services and deemphasize institutional care.

One respondent recommended that the Hawaii Long-Term Care Commission focus on increasing the proportion of Medicaid long-term care expenditures spent on home and community-based services. Other stakeholders, however, cautioned against expecting cost savings by shifting funding from institutions to home and community-based services. Another stakeholder argued that the goal should be to “level the playing field” between institutional and home and community-based services and then let consumers decide what services they want.

One person stressed the importance of developing the home and community-based services infrastructure on all of the islands so that people are not forced to leave their homes or the State to get services. Another suggested providing incentives to home and community-based services providers to expand services on islands with shortages.

Given the high cost of institutional services and the desire by most people to stay at home, one stakeholder suggested that the State provide more services that help informal caregivers to keep their relatives at home, such as adult day care. One respondent noted that the overwhelming majority of Medicaid home and community-based services funding is spent on residents of family foster care and expanded adult residential care homes rather than on individuals receiving care in their own homes. Although residential care homes are an important part of the long-term care system, this respondent argued for assisting informal caregivers to delay entrance to community care homes and nursing homes.

Other stakeholders said that informal caregivers need more support from employers in both the private and public sectors, noting that even in state government there are no formal provisions allowing government workers to adjust their schedules to accommodate caregiving responsibilities. They proposed that the State work with employers to encourage them to offer benefits to support caregivers, such as flex time, working from home, job sharing, and paid family leave. However, they also noted that the business community has opposed such proposals in the past.

**Reform Components of the Service Delivery System**

Although some stakeholders felt that it was pointless to discuss reform of the service delivery system in the absence of sufficient funding, many respondents proposed needed improvements, acknowledging that most would require additional financing. Moreover, these observers thought that obtaining additional funding would be easier if there was a clearer vision of what the money would be used for. Some observers believed that the long-term care system could work more effectively and efficiently by addressing service delivery reform, even without additional funding.

Some of the suggested reforms suggested addressed specific problems that stakeholders had raised as problems, such as the waiting list for Kupuna Care services. One stakeholder suggested that Kupuna Care’s current policy of providing services on a first-come first-
served basis, regardless of income, should be changed. Instead, public funds should be used to provide services to those at greatest risk for nursing home placement who do not have the personal resources to pay for them. To implement this approach, the State would need a common eligibility, intake, and assessment process across all points where people enter the Kupuna Care system. However, another stakeholder felt that this approach would divert too much funding from services to an eligibility determination process.

Another stakeholder said that consumer-directed service options should be expanded, not just in Medicaid but in Kupuna Care, because such options offer greater flexibility than agency-delivered service models. They also permit payment of family members—particularly important if relatives quit their jobs to provide care. Paying informal caregivers ensures that they continue to build Social Security retirement credits and continue to pay taxes.

Respondents noted that any solutions to current service delivery problems need to be sensitive to the varied service models currently operating in the islands and to rural/urban differences. One observer said that before undertaking reforms, it is very important to have an overarching policy with respect to the service delivery models that will be promoted. The service options should allow for a balance of choice and the efficient use of Medicaid resources. The State also needs to develop a delivery system that is not based solely on either a social or medical model—but instead on a blended model that addresses both social and medical needs.

Reduce System Fragmentation and Improve Service Coordination

Several respondents commented on the need for better coordination within the long-term care system and between the health and long-term care systems. As a strategy to improve coordination and facilitate service implementation, some stakeholders believed that a new department should be created to bring together all state long-term care financing and policy into a single agency, as Oregon and Washington have done.

Some advocates said that the State’s ADRC should be strengthened to bring together all of the different components of the private and public long-term care system, including state agencies, county offices on aging, the state office on aging, service providers, elderly advocacy groups, and the disability community. Stakeholders agreed that there is a need for a “one-stop shop” where social workers and nurses conduct timely assessments to determine what services people need, determine eligibility for different programs, and help them get the support they need.

Several stakeholders proposed that each of the islands have a physical ADRC facility in addition to the Web site. They also said that Area Agencies on Aging are at different stages of development with regard to regard to intake, eligibility determinations, and referral procedures and more uniformity in these procedures is needed. As one observer noted:

It would be helpful to have a physical site for ADRCs, which is necessary for the population it is supposed to serve. A large island like Oahu needs more than one site. People need to know the sites are available. It is also important to have access to interpretive services. We need to determine if telephonic interpretive services would work because there are so many languages, it would be difficult to ensure that all of them would be spoken at each site. We
know that for some language groups, telephonic interpretive services will not work because it is not culturally appropriate.

One observer noted that the State does not have money to fund case managers for the ADRC. Making the case for these case managers would be especially difficult because the Department of Human Services laid off many Medicaid and other program eligibility workers and has changed to a computer-based, online application system.

To resolve the problem of people waiting in hospitals for nursing home placement, observers said that actions are needed by the Department of Health, the Department of Human Services, hospital CEOs, and the representatives of the community care home industry. As part of this process, the hospitals and community care homes should develop better working relationships and referral systems. Other stakeholders said that certifying all available nursing home beds for Medicaid participation would increase the effective bed supply and ease placement backlogs.

**Address Quality Problems With Community Care Homes**

Several stakeholders proposed strategies for improving the quality of care that they provide, including the following:

- Provide more training for adult residential care homes’ staff and more oversight of the services they provide.
- Improve case management for residents of expanded adult residential care homes and foster care homes who meet nursing facility level-of-care criteria to help ensure that their needs are being met.
- Develop a systematic mechanism to screen adult residential care home and foster care home provider applicants for licensure.
- Consider specialized licensing to address the needs of particular populations and residents with higher acuity.

To address the overlapping oversight of community care homes, some stakeholders recommended revamping the current regulatory system. First, to ensure coordination across levels of care, they recommended that regulation of foster care homes, adult residential care homes, and expanded adult residential care homes be consolidated into a single agency. Second, to end what they saw as artificial distinctions across facilities, they proposed substituting the three current types of residential care with a single model of residential care with multiple tiers to serve residents with low to high levels of need, and reimbursement rates tied to these tiers, allowing for a better match of reimbursement and need.

**Develop Adequate Reimbursement Rates**

A few respondents emphasized the need for Medicaid payment rates to reflect the costs of providing care to residents with different acuity levels. One commenter noted that a reimbursement system based on resident disability and medical needs would make the residential care industry more attractive to potential providers. Another said that such rates should provide an incentive for nursing homes to admit high-need residents. In particular,
they argued that higher Medicaid rates are needed for medically complex medical patients—especially for those in hospitals waiting for discharge to nursing homes.

Currently, the level of care tool (DHS Form 1147) does not acknowledge additional labor requirements that nursing facilities and home and community-based services providers need to care for some residents. As a result, community care home providers find that their residents need many more services than they were assessed for. In their view, the current rates are inadequate and have a negative impact on the quality of care provided to residents. One respondent, however, dismissed concerns about reimbursement, saying that “providers manage to stay in business despite them, so they must be adequate.”

One respondent proposed allowing foster care homes and expanded adult residential care homes to serve a higher number of residents per facility. Specifically, this stakeholder argued that foster homes with sufficient rooms should be allowed to take three to four residents (with up to two private pay residents), and expanded adult residential care homes should be allowed to serve three residents who need a nursing facility level of care rather than just two. This stakeholder argued that these changes are needed to make care homes more financially viable. However, several respondents had reservations about expanding the use of community care homes to care for individuals who need a nursing home level of care because they felt that the homes are not adequately monitored and that quality of care problems are frequent.

**Change the State’s Decision-Making Process**

Several stakeholders made recommendations for changes in the State’s overall decision-making process for long-term care. One respondent said that the State should more systematically include stakeholders in discussions about potential changes, noting that:

> State agencies need to involve those who will be affected by the changes, but they currently do not and this is a problem. Involving stakeholders may require a longer process but the product at the end will be better and it will increase cooperation when it is time for implementation. Much more consumer involvement is needed.

A few respondents said that more effective advocacy is needed to advance long-term care policy and that older people need to be more assertive in their demands. Several observers said that the general public and many policymakers are not well informed about long-term care and need to be educated about issues and options before reforms will be possible.

Several observers felt that that nothing will be done for the aging population without support at the highest policy levels, including the governor, and stressed the need for the new gubernatorial administration to make long-term care a high priority. One participant said that proposals for addressing Hawaii’s long-term care issues over the past 20 years have not been successful because policymakers have not made it a priority. Thus, it is essential to look at other mechanisms, including those that do not necessarily require more state funding, to address long-term care issues (e.g., changing how the culture and state policy views aging and retirement). For example, the Older Americans Act qualifies people for services at 60 years of age, implying that they are old. The State needs to reconsider the age at which people are considered “old.”
According to one respondent, Hawaii is a highly unionized state where many workers can retire at relatively young ages, but many individuals do not need or really want to retire. Retirement benefits planning should include not just financial planning but activity planning as well to keep older people socially connected and engaged, which are factors associated with successful aging and good health. Doing so may help to prevent the physical and mental decline that can lead to a need for long-term care. This observer also felt that the State needs to increase funding for health education, health maintenance, and health promotion programs that are of proven benefit in improving health during later periods in life. Although doing so in tough economic times may seem wishful thinking, this participant thought that possible savings in overall medical care may offset the cost of these services.

III. Obstacles to Reforming the Long-Term Care System

Stakeholders provided many lessons learned on why past reform efforts failed—particularly the effort to enact the Care-Plus program. Respondents said that all of the obstacles that prevented past reform efforts from succeeding still needed to be overcome for future efforts to succeed. In addition, a new obstacle—the current economic recession—had to end before any major financing reforms could occur. Stakeholders specifically mentioned five major obstacles: opposition to taxes, opposition to expansion of the public sector, lack of political will among government policymakers, lack of knowledge and understanding of long-term care issues, and lack of effective advocacy. Stakeholder views of obstacles to reforming the long-term care system are summarized in Exhibit 5.

Opposition to Taxes

Many options for reforming the long-term care system depend on increased tax revenues but the current governor, the business community, the insurance industry, and many legislators oppose tax increases. Some stakeholders highlighted the strong lobbying by the Chamber of Commerce and the insurance industry against past long-term care financing reforms and pointed to their opposition as a major obstacle.

Some respondents thought that cigarette and soda taxes may be raised in the near term, although not to pay for long-term care services. Rather, several stakeholders noted that the State's priorities are education, rail transportation, and green energy jobs. Another said that the governor's priorities are energy, business development, and children, noting that the governor had publicly stated that there is not much she can do for seniors and that it is more cost-effective to provide services to children. Another said that because the economic crisis had led to cutbacks for many services, the first priority when the recession ends will be to restore cuts for children and education and that senior services will be a much lower priority.

Most stakeholders thought that until the State is out of the recession, it is unrealistic to think that any new tax revenue will be possible. Several observers said that the State has to figure out how to pay current long-term care costs and does not anticipate a return to its prerecession budget until 2012. Some observers argued that a public insurance premium that provides benefits to the insured would be viewed differently than a tax and could have more support but others did not agree with this view.
Exhibit 5. Obstacles to Reforming the Long-Term Care System

Stakeholders identified several barriers to reforming Hawaii’s long-term care system:

- **Opposition to new or higher taxes.** Both advocates for and opponents of increased government spending identified opposition to additional taxes as a major barrier to increasing government revenues for long-term care. Some stakeholders believed that the public would view a social insurance premium differently than a tax, but not all respondents held this view. Most stakeholders did not think it was politically realistic to propose any tax increase until the economy improves.

- **Opposition to expansion of the public sector.** The appropriate role of government was an area of disagreement among stakeholders, with some wanting a larger role and others wanting a smaller role. This is a philosophical difference that is very difficult to bridge.

- **Lack of knowledge about long-term care issues.** Most stakeholders expressed frustration concerning the lack of knowledge by government officials, the legislature, and the general public about long-term care issues. Bold initiatives are not possible if policymakers are unaware of the issues and the problems underlying them.

- **Leadership lacks the will.** Most stakeholders did not believe that top government policymakers are committed to addressing long-term care issues. The strong division between the underlying philosophies of the current governor and the current legislature make it hard to argue for investment of time and energy in long-term care reform at this time. Some observers saw the election in November as an opportunity to bring the governor and the legislature into closer ideological alignment.

- **Lack of effective advocacy.** Although stakeholders faulted government policymakers, they also faulted long-term care providers and consumer advocates for being largely ineffective in advancing the cause of long-term care reform. According to observers, this lack of effectiveness breeds indifference because advocates do not see successes on which to build.

**Opposition to Expansion of the Public Sector**

Some approaches to reform—such as a social insurance program—include a larger role for the public sector, which many oppose as a matter of principle. Another respondent said there is no clear cut agreement about the appropriate role of government in long-term care. Conservatives, it was noted, lack trust in the government and assert that because there is so much waste in government, the public has lost faith that their money will be used appropriately. One stakeholder characterized the Republican view of social responsibility as encouraging volunteerism and having the community fix its own problems.

A few respondents said that the problem is political (i.e., that legislators are focused on getting reelected so they do not want to take strong stands that will offend some constituents). Moreover, one observer noted that although Republicans are ideologically united, Democrats include legislators with a wide range of political views, some of which are quite conservative.
Lack of Knowledge About Long-Term Care Issues

The majority of respondents felt that lack of knowledge and understanding about long-term care issues is a major obstacle to reform efforts. One respondent said that some members of the legislature do not know the difference between Medicare—the federal health insurance program for older people and some persons with disabilities, and Medicaid—the federal/state health care program for the low-income population with very few assets and people who are “medically needy” (i.e., they become poor because of the high cost of medical care). As one stakeholder put it, “People are always in denial about long-term care—until they or a family member needs it.”

The lack of understanding underlies the difficulty in gaining public support for major long-term care initiatives. According to stakeholders:

- Many people deny the seriousness of the problem and its implications for the future and do not understand their risk for needing long-term care and the need to plan for it. Others do not want to think about long-term care because it is unpleasant and distasteful to think about being dependent on others.
- Those who work in long-term care know there is a crisis because they see people falling through the cracks and not getting quality care, but neither the general public nor legislators know this.
- Influential people often have the financial resources to provide for their elderly relatives. As a result, they think that every family should and can do the same. They do not understand that not everyone can afford to provide or pay for this care.
- The public may think they can care for relatives at home, but do not understand how expensive paid home care is. They also do not know how expensive community care homes and nursing homes are. Some people rely on “solutions” that are unrealistic (e.g., divesting assets to become eligible for Medicaid without knowing that there is a 5-year look-back period).
- The belief that long-term care is a family responsibility is widespread. Although families certainly have an important role to play, few can handle it alone. When they do not receive support, caregivers burn out and the elder is institutionalized.
- The public does not understand the principle of risk-pooling that is central to insurance. This principle requires everyone to pay a modest amount to cover the high costs of a few, while providing financial protection for all at an affordable cost.
- The public wants services but does not want to pay for them—certainly not through taxes.
- People do not want to go to a nursing home when they are older so they do not want to pay taxes or a premium for insurance that pays for nursing home care.
- Private sector options for financing long-term care, such as reverse mortgages, have lessened perceptions about the urgency of financing reform because it enables some people to pay for services.

Many stakeholders noted that until people have personal experience with long-term care, they do not comprehend the issues. One said that the adult population is getting more concerned as they begin to deal with the long-term care needs of their aging parents and
that this direct experience should make them more supportive of long-term care reform efforts.

A few observers noted that for the past several years, the State has seen a very coordinated effort among advocates for the elderly and people with disabilities to reform the system—but nothing has resulted because the legislature needs to hear from the general public as well. But the general public does not understand that the system is broken. According to one stakeholder: “The public needs to demand changes, but they don’t and won’t until they are personally affected by the burden of long-term care—its costs or as a caregiver.”

A few respondents said the State needs to undertake a major education campaign so the public will demand long-term care financing reform but when asked what type of educational efforts would be effective, they had no concrete proposals, noting that past efforts have not been successful.

**Leadership Lacks the Will**

A majority of stakeholders felt that an obstacle to reform is the lack of top-level government leadership on long-term care issues. As one stakeholder put it:

> We have been talking about a range of issues—problems with the long-term care system, the need for more home and community-based services, inadequate Medicaid reimbursements, and workforce development, etc.—for a very long time. The issues have been talked to death but no one is willing to make a move. No one wants to give up the known for the unknown.

Several observers noted that most legislators lack personal experience with long-term care, do not understand how expensive it is, and do not understand the relationship between long-term care and the Medicaid budget. Another commenter said that because legislators need to be educated, long-term care reform will require incremental steps. On the other hand, one stakeholder said that incremental reforms could forestall the crises that may be needed to push the State to make the broad changes that are needed.

Because Hawaii has strong gubernatorial powers and a weak legislature, several respondents noted that it is hard to pass a bill if the governor opposes it. Even if the legislature overrides a veto and appropriates funds, the governor can refuse to spend the funds. The legislature can only force the release of funds if two thirds of both houses agree.

**Lack of Effective Advocacy**

A few stakeholders said that advocates for older people are not politically strong or well coordinated, noting that compared with legislative caucuses for children, Native Hawaiians, or Filipinos, those for elderly persons and persons with disabilities do not have the same clout. As one person noted:

> The population in need of long-term care is not a strong advocacy group. They need help to just live. So providers need to advocate, but we’re seen as self-serving even though many of us are nonprofits and care about the people we serve.
One respondent said that long-term care workers cannot participate in rallies because if they do not work they will not get paid. Also, many feel that rallies, letter writing, and other lobbying efforts will not make any difference. Another stated that the islands go to the legislature separately with their requests but what is needed is unified advocacy for a system that will work for the entire state. Similarly, different sectors of the long-term care system do the same (e.g., adult residential care homes have their own lobbying group as do foster care homes).

Summary

The purpose of this report is to provide information about the views of long-term care stakeholders in Hawaii on the problems of the State’s long-term care system, proposed reforms, and barriers to implementing the reforms. To that end, this report summarizes interviews that RTI International conducted with 47 long-term care stakeholders in Hawaii, including aging and long-term care advocacy groups; state provider associations; state legislative and executive branch policymakers; public and nonprofit program administrators; and individual long-term care providers, researchers, and other expert and knowledgeable individuals. To encourage candor, stakeholders were promised anonymity and were not quoted by name. Most interviews were conducted in February and March 2010.

Although there is broad agreement among stakeholders on the problems of the long-term care system and on the barriers to adoption of various reforms, there are sharp disagreements on which reforms are desirable. In general, stakeholders were highly critical of the current long-term care system. Of concern to almost all stakeholders is that the population of Hawaii is aging and the State lacks a plan to cope with the expected large increase in need for long-term care services. Most respondents said that the current financing system is inadequate and that the increase in the number requiring long-term care would further highlight its inadequacies. Many stakeholders did not think that Medicaid should be the main source of financing and that other approaches needed to be developed.

At the same time that demands on the financing system are increasing, informal care is also under strain. Moreover, the long-term care system lacks service capacity in all areas—nursing homes, community care homes, and home care—and will be unable to address future needs. Adding to the complexity, stakeholders thought that the long-term care and health care financing and delivery systems are fragmented and consumers are bewildered by their complexity. Finally, as in other states, there are significant concerns about quality of care, but they are primarily about care in community care homes rather than nursing homes.

Stakeholders disagreed about what should be done to solve the identified problems. The greatest divide is on financing, which splits along ideological/political lines. In the short term, because of the economic downturn, most respondents did not think that asking people in Hawaii to pay higher taxes or insurance premiums is politically feasible. In the longer term, after the economy recovers, some stakeholders believed that the government should establish a mandatory social insurance program for long-term care. In contrast, other respondents believed that the government should promote private rather than public long-
term care insurance through education and tax incentives. Underlying this division are major philosophical differences about who is responsible for long-term care.

Other recommendations by stakeholders would increase the availability of all types of long-term care services. For example, some respondents proposed increasing funding for Kupuna Care and approving more nursing home beds and certifying them for participation in Medicaid. Several stakeholders recommended upgrading the Aging and Disability Resource Center so that it could be a true “one stop shop” for consumers looking for access to the system. Some observers suggested consolidating various state agencies responsible for long-term care to make them more accountable and to improve policy and budgeting coordination.

Finally, most stakeholders expressed a high level of frustration about how hard it is to implement long-term care reforms in Hawaii. In the view of many, stakeholders have been talking about the issues for a long time, but little has happened. Fundamentally, opposition to higher taxes and to expansion of the role of the public sector is identified as the main reason that the social insurance approach, exemplified by Care First, has not been enacted. Although some stakeholders thought that an insurance premium would be perceived differently than a tax to support Medicaid, others did not agree. Beyond differences in what reforms should be implemented, stakeholders identified a lack of knowledge about long-term care issues, the fact that long-term care is not a priority issue, and the lack of effective advocacy as reasons for the lack of progress.
Assessing Long-Term Care Policy Options in Hawaii

Results from the Hawaii Long-Term Care Survey

Prepared for
Hawaii Long-Term Care Commission
2424 Maile Way
Saunders 723
Honolulu, HI 96822

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RTI Project Number 0212474.000.002
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1. Introduction

Act 224, Session Laws of Hawaii 2008, established the Hawaii Long-Term Care Commission. The Commission is charged with identifying needed reforms of the long-term care (LTC) system, researching program changes and resources needed to meet the state’s long-term care goals, and exploring funding options that may help support the provision of long-term care services. Long-term care includes helping people with daily activities, such as getting dressed, bathing, preparing meals or eating, or taking medications, over a long period of time. Providers of long-term care include nursing homes, home health agencies, home care agencies, adult day care programs, meals-on-wheels programs, and community-care homes.

As part of the Long-Term Care Commission’s analysis of Hawaii’s long-term care system, RTI International conducted a mail survey, the Hawaii Long-Term Care Survey, of state residents aged 18 and over to understand public perceptions, awareness, and attitudes about LTC and to elicit the general public’s views of various options for LTC reform. This report summarizes the results of the Hawaii Long-Term Care Survey.

2. Survey Methodology

This section describes the methodology used for the Hawaii Long-Term Care Survey. In particular, it outlines the following:

- Sample selection procedures
- Participant recruitment procedures
- Survey instrument design
- Data collection procedures
- Control system
- Participant compensation
- Sample weighting

Sample Selection Procedures

The Hawaii Long-Term Care Survey collected data through a mail survey. A random probability sample of 3,002 Hawaii addresses was obtained and matched, where possible, to names via batch tracing. To ensure representation of residents from each county in the state, a predetermined percentage of addresses was selected from each county.

Appendix A is a sampling table documenting the distribution of the address sample and respondents across counties in Hawaii.
The first question on the mail survey screened for eligibility based on age and residency status. Persons eligible for participation were 18 years of age or older and had lived at the Hawaii address to which the questionnaire was addressed for 60 days or longer. If no one in the household was eligible, the recipient was asked to indicate that by checking a box and returning the survey to RTI. If at least one household member was eligible, the recipient was instructed that the survey should be completed by the eligible adult in the household who had the most recent birthday.

**Participant Recruitment Procedures**

To increase the response rate, prospective participants were sent a signed cover letter from the Hawaii Long-Term Care Commission along with the questionnaire. The cover letter (Appendix B) described the purpose of the study, and advised them that their participation was voluntary and that their privacy and data would be protected. The cover letter offered a toll-free number for recipients to call if they had questions about the study and also explained that RTI would provide a financial incentive for questionnaire completion. Different cover letters were sent with each wave of the survey.

**Survey Instrument Design**

This survey, which contained 31 items, concentrated on the support of adult Hawaii state residents for different approaches to financing LTC, and included the following domains:

- Understanding the costs of LTC
- Preferences for LTC setting
- Opinions about different payment options for LTC
- Knowledge of Insurance program principles, familiarity with and opinions about the Community Living Assistance Services and Supports (CLASS) Act, which was enacted as part of the health reform law

The survey also asked information about respondent demographics, health status, health insurance coverage, and personal exposure to caregiving. The full survey instrument is included as Appendix C. The six-page mail survey took about 15 minutes to complete.

**Data Collection Procedures**

A total of three waves of questionnaire mailings were sent to the sample. Included with the questionnaire in each of these mailings was (1) a signed cover letter from the Long-Term Care Commission, (2) a business reply envelope with prepaid postage, and (3) an incentive postcard. Participants were instructed to provide their name and mailing address on the incentive postcard and mail it back separately from their questionnaire to protect their privacy. As with the questionnaire envelope, the postcard was preaddressed and postage was prepaid.
A reminder postcard (Appendix E) was mailed to the entire sample about a week after the first questionnaire mailing, thanking those who returned a completed survey and prompting those who had not yet done so to complete the survey.

Prior to the second wave questionnaire mailing, the mailing list was updated by removing addresses associated with completed surveys, ineligible households, and vacant or unreachable addresses. The address list was updated again prior to the third wave questionnaire mailing. See Table 1.

Table 1. Mailings of the Hawaii Long-Term Care Survey

<table>
<thead>
<tr>
<th>Wave</th>
<th>Date</th>
<th>Quantity</th>
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</thead>
<tbody>
<tr>
<td>Initial questionnaire mailing</td>
<td>6/30/10 &amp; 7/1/10</td>
<td>3,002</td>
</tr>
<tr>
<td>Postcard reminder</td>
<td>7/9/10</td>
<td>3,002</td>
</tr>
<tr>
<td>Second questionnaire mailing</td>
<td>7/26/10 &amp; 7/27/10</td>
<td>1,935</td>
</tr>
<tr>
<td>Third questionnaire mailing</td>
<td>8/19/10</td>
<td>1,557</td>
</tr>
</tbody>
</table>

**Control System**

An efficient and flexible control system was designed to track the status of each case throughout the data collection process. The control system also generated reports providing updates on data collection progress. Among the case statuses documented and tracked were those indicating that all persons at the sample address were ineligible, the address was vacant, and a completed interview had already been received in association with this address. The control system reduced the likelihood of operational error by automating certain tasks, including those associated with confirming eligibility for incentives and those required to remove addresses from the mailing list for future waves of mailings when warranted.

**Participant Compensation**

A $1 cash incentive was included in the questionnaire mailing in wave 1. The first two waves of the questionnaire mailing offered a $10 incentive for returning a completed survey. The third and final questionnaire mailing offered an incentive of $15 for survey completion to further encourage participation from those who had not responded to previous mailings.

Each incentive postcard and corresponding questionnaire was linked for verification of questionnaire completion via the project’s control system using their unique case number. The use of the control system to record and track unique case numbers enabled project staff to process and track one and only one incentive check for each sample address associated with a participant who both returned a completed survey and requested an
incentive. Incentives for completed surveys were sent in the form of a check and were accompanied by a “thank you” letter (Appendix F).

**Weighting**

Survey respondent data need to be weighted before they can be used to produce reliable estimates of the target population responses. Weighting of responses also attempts to compensate for practical limitations of surveys, such as differential nonresponse and undercoverage. Moreover, by taking advantage of auxiliary information about the target population, weighting can reduce the variability of estimates.

The weighting for this study was a two-step process. First, we assigned initial address weights (or design weight) to the 3,002 sampled addresses. This initial address weight is the inverse probability of selection of the address. It accounts for differing selection probabilities across counties.

The second weighting step required the logical imputation of gender for 24 cases and the use of weighted sequential hotdecking to impute a remaining 8 missing records for gender and 26 for age. Finally, we used PROC WTADJUST in the statistical program SUDAAN to apply poststratification adjustment factors to the initial address weight to force them to sum to the 2006–2008 U.S. Bureau of the Census’ American Community Survey 3-year estimates for age, county, and gender. The control totals for this adjustment are in Table 2.

**Table 2. Control Totals for Poststratified Weights by Age, Gender and County**

<table>
<thead>
<tr>
<th>Gender</th>
<th>County</th>
<th>Age</th>
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<td></td>
<td></td>
<td>18–24</td>
<td>25–34</td>
</tr>
<tr>
<td>Male</td>
<td>Hawaii</td>
<td>8,456</td>
<td>13,500</td>
</tr>
<tr>
<td></td>
<td>Honolulu</td>
<td>51,865</td>
<td>65,938</td>
</tr>
<tr>
<td></td>
<td>Kauai</td>
<td>2,849</td>
<td>4,529</td>
</tr>
<tr>
<td></td>
<td>Maui</td>
<td>5,710</td>
<td>11,688</td>
</tr>
<tr>
<td>Female</td>
<td>Hawaii</td>
<td>7,919</td>
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<tr>
<td></td>
<td>Honolulu</td>
<td>40,976</td>
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<tr>
<td></td>
<td>Kauai</td>
<td>2,437</td>
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<td>Maui</td>
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<td>Total</td>
<td></td>
<td>125,340</td>
<td>178,689</td>
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</tbody>
</table>


**Response Rate**

Response rates were calculated using standard American Association of Public Opinion Research (AAPOR) definitions, specifically RR2, which counts partial interviews as
respondents. A total of 1,244 completed questionnaires were returned, yielding an overall RR2 weighted and unweighted response rate of 46.9%. Table 3 presents counts of cases for each data collection status at the end of the data collection.

Table 3. Hawaii Long-Term Care Survey Response Rate, Using AAPOR Disposition Codes

<table>
<thead>
<tr>
<th>AAPOR Disposition Code</th>
<th># of Addresses</th>
<th># of Addresses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unweighted</td>
<td>Weighted</td>
</tr>
<tr>
<td>1.0 Interview (I+P)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.1 Complete interview</td>
<td>1,244</td>
<td>208,070</td>
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<tr>
<td>1.2 Partial interview</td>
<td>1</td>
<td>258</td>
</tr>
<tr>
<td></td>
<td>1,245</td>
<td>208,328</td>
</tr>
<tr>
<td>2.0 Eligible, Non-Interview (R+NC+O)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.112 Known respondent refusal</td>
<td>62</td>
<td>10,586</td>
</tr>
<tr>
<td>2.333 No interviewer available for language</td>
<td>1</td>
<td>258</td>
</tr>
<tr>
<td></td>
<td>63</td>
<td>10,844</td>
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<tr>
<td>3.0 Unknown Eligibility, Non-Interview (UH+UO)</td>
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<td></td>
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<tr>
<td>3.21 No screener completed</td>
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<td>220,507</td>
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<tr>
<td>3.18 Unable to locate address</td>
<td>33</td>
<td>3,793</td>
</tr>
<tr>
<td>3.20 Housing unit/Unknown if eligible respondent</td>
<td>7</td>
<td>997</td>
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<td></td>
<td>1,347</td>
<td>225,296</td>
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<tr>
<td>4.0 Not Eligible (NE)</td>
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<td></td>
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<tr>
<td>4.60 Vacant housing unit</td>
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<td>48</td>
<td>8,126</td>
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<td>4.50 Not a housing unit</td>
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<td>4.70 No eligible respondent</td>
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<td>5,286</td>
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<td></td>
<td>347</td>
<td>53,790</td>
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<td>498,259</td>
</tr>
</tbody>
</table>

RR2: (I+P) / (I+P+R+NC+O+UH+UO) = 46.9%.

3. Survey Results

This part of the report presents survey findings. All results are presented weighted and adjusted for survey nonresponse.

Demographics, Health Status, and Caregiving Experience

This section describes demographic characteristics of the survey respondents. In the survey, respondents were asked about their age, gender, race/ethnicity, total household income, education, employment status, and what type of primary health care coverage they have for their acute medical care. Respondents were also asked about their caregiving experience.

Demographics

Overall, Figure 1 shows that about 45% of respondents were 25 to 44 years of age, about 30% of respondents were 45 to 64 years of age, and almost 17% of respondents were 65 years old and older. Eight percent of all survey respondents were 18 to 24 years of age. Figure 2 shows the respondent age distribution by county.

Figure 1. Respondent Age
Figure 2. Respondent Age, by County

HAWAII
- 18-24: 7.7%
- 25-44: 16.9%
- 45-64: 35.6%
- 65 or older: 39.8%

HONOLULU
- 18-24: 8.9%
- 25-44: 16.9%
- 45-64: 28.2%
- 65 or older: 46.0%

KAUAI
- 18-24: 6.0%
- 25-44: 19.8%
- 45-64: 34.4%
- 65 or older: 40.0%

MAUI
- 18-24: 6.1%
- 25-44: 15.4%
- 45-64: 34.3%
- 65 or older: 44.2%
Figure 3 shows that slightly over 47% of all respondents were female and over 52% were male.

Figure 3. Respondent Gender
Figure 4 shows the race/ethnicity distribution of the survey respondents was as follows: slightly over 42% were Asian, 31% were white, over 17% were native Hawaiian, and 4.5% were other Pacific Islanders. African Americans and American Indians represented less than 3% and 2%, respectively.

**Figure 4. Race/Ethnicity**
Figure 5 shows that nearly three fifths of respondent families have income below $60,000 a year, 24% have incomes between $60,000 and $99,999, and almost 17% have incomes above $100,000.

Figure 5. Income Distribution
**Functional Status**

The survey elicited information on respondents’ functional status (ability to perform activities of daily living and instrumental activities of daily living) by asking the following question: “Does a physical or mental health problem currently limit your ability to do one or more of the following activities: bathing, dressing, getting around in the house, using the telephone, paying bills, taking medications, or doing laundry?” **Figure 6** shows that about 6% of all survey respondents reported physical or mental health problems that interfered with their daily activities. This proportion varied slightly by county from about 5% in Honolulu to about 7% in Maui.

![Figure 6. Respondent Functional Status, by County](image)

**Caregiving Experience**

Because prior studies show that personal caregiving experience affects how much people know and plan for LTC, the survey also asked respondents whether they provide personal care assistance to disabled family members, both young and aged. Overall, about 5% of all respondents reported taking care of a family member between the ages of 18 and 64 who is disabled. Providing such care included help with regular daily activities, such as eating,
bathing, dressing, going to the toilet; using the telephone; or taking medications. **Figure 7** shows that this proportion varied slightly from about 4% in Kauai to about 6% in Honolulu.

**Figure 7. Respondents Providing Care for Younger Disabled Family Members, by County**
A similar question was asked about providing care to disabled family members aged 65 and older. Overall, about 8% of all respondents reported taking care of a family member aged 65 and over who is disabled. Providing such care included help with regular daily activities, such as eating, bathing, dressing, going to the toilet; using the telephone; or taking medications. Figure 8 shows that this proportion varied slightly from about 5% in Maui to about 9% in Honolulu.

**Figure 8. Respondents Providing Care for Aged Family Members, by County**

![Bar chart showing the percentage of respondents providing care in different counties.]

**Cost of Care**

This survey domain examined respondents’ perception of how much nursing home and in-home care they can afford, given the cost of care in the state of Hawaii and what sources they are planning to use for payment.

To answer this survey question about the affordability of long-term care services, respondents were provided with the average cost of care in the state of Hawaii: A year in a nursing home or a year of 24-hour home care costs between $128,000 and $158,000. Given these costs, Figure 9 shows that 62% of all surveyed respondents reported that they could not afford to pay any of the costs of care. About a third of all respondents suggested that they could afford to pay less than half of the costs, and 3% of all respondents reported that
they could pay more than half but not all of the costs of care. Three percent of respondents also reported that they could afford to pay all the costs of needed care.

**Figure 9.** If You or Anyone in Your Family Needed Nursing Home Care or Round-the-Clock Home Care for a Year, How Much of the Cost Could You Afford to Pay?
In addition to affordability, respondents were asked what sources they are planning to use to pay for round-the-clock care. Figure 10 shows that nearly half of respondents (49%) do not know the answer to this question, suggesting that they have done little planning to cover this possible expense. About one third of Hawaii state residents will use their income and savings and about one third are counting on Medicaid to pay for their extensive care. Almost 19% reported that they plan to use private long-term care insurance, a number far higher than the actual number of policies in the state. This suggests that many people mistakenly think that they have long-term care coverage when they do not. Finally, about 13% of Hawaii state residents report that they will depend on their family to pay for the expense.

Figure 10. If You Needed Nursing Home or 24-Hour Home Care Over a Long Period of Time, How Would You Pay for It?

Most people receiving long-term care do not need as much care as is provided in a nursing home. Most of those people live at home. Two hours of daily home care costs about $18,200 a year in Hawaii. Figure 11 shows that, given these costs, 35% of all survey respondents reported that they could afford to pay less than half of the costs. Thirty-four percent reported not being able to afford any of the costs and 13% reported that they could afford to pay more than half, but not all of the costs. Only about 12% of respondents
reported that they are able to afford all of the costs associated with receiving 2 hours of home care daily for a year.

**Figure 11.** If You or Anyone in Your Family Needed 2 Hours of Home Care for a Year, How Much of the Cost Could You Afford to Pay?
In addition to affordability of 2 hours of daily care, respondents were asked what sources they are planning to use to pay for care of this amount. Figure 12 shows that this amount of care is perceived as more affordable, so the great majority of respondents (47%) are planning to use their income and savings. About a third of respondents do not know the answer to this question, suggesting that they have not planned for this possible expense. Twenty-eight percent of Hawaii state residents are counting on Medicaid to pay for the 2 hours of daily care. Almost 17% reported that they plan to use private long-term care insurance, again far more than the number of in-force policies in the state. Finally, about 16% of Hawaii state residents report that they will depend on their family to pay for the expense.

Figure 12. If You Needed 2 Hours of Home Care Over a Long Period of Time, How Would You Pay for It?

Preferences for Care Setting

Respondents were asked for their preference for LTC setting if they were disabled and needed substantial amounts of long-term care services over a long period of time and about whether the percentage of Medicaid long-term care expenditures that are for nursing home care are appropriate. They were also asked about their support for consumer-directed home care.
care, where consumers rather than agencies hire, supervise, schedule, and fire their direct care workers.

Similar to people in other states, Hawaii residents prefer to receive their long-term care in the community rather than in the institutional setting. **Figure 13** shows that about 41% prefer to receive such care from family and friends and almost 29% prefer to pay a nurse or a personal care assistant to provide such care at home. About 12% expressed a preference for an assisted living facility or a small group home. Nursing home is the setting of last resort: only 4% of Hawaii state residents prefer to be in a nursing home if they require long-term care. Almost 15% of respondents could not choose a setting and responded “Don’t Know.”

**Figure 13. Preference for Type of Long-Term Care Provider**

Hawaii has one of the highest percentages of Medicaid long-term care expenditures going for nursing home care; compared to other states, the proportion of Medicaid expenditures for home and community-based services is very low. To answer the question about whether respondents thought that the distribution of Medicaid expenditures across service types is appropriate, the survey informed respondents that, "Currently, 81% of Hawaii’s Medicaid spending for long-term care is for nursing home care and 19% is for home and community-
based services, such as personal care (help with eating, bathing, and dressing) and adult day care.” As shown in **Figure 14**, about a third of all Hawaii state residents do not have an opinion on the service distribution of Medicaid spending in their state. Only 27% think that the proportion of Medicaid spending on nursing homes is too high and about 30% think it is appropriate. Ten percent of all respondents reported that they think that the percentage of Medicaid LTC spending on nursing home care is too low. Given the relatively low levels of LTC service provision in the state compared to other states, respondents may be answering regarding the absolute level of spending instead of the distribution between institutional and noninstitutional services.

**Figure 14.** Do You Think That the Percentage of Medicaid Long-Term Care Spending for Nursing Home Care is?
Consumer direction is a relatively new model of home and community services where people are allowed to hire and pay their family and friends for providing personal care services. Figure 15 shows that this option is very attractive to Hawaii residents: almost three quarters of all respondents favor this option. About 13% are against consumer direction and 14% have no opinion about it.

Figure 15. Do You Favor or Oppose Allowing Government-Funded Home Care Programs to Pay Family Members and Friends Rather Than Private Agencies to Provide Home Care?

Opinion About Financing Options

Respondents were asked about their opinion of several LTC financing options where their support or opposition were measured. These options were the following:

1. Changing Medicaid so that more middle class people would qualify for help in paying for long-term care services
2. Having the government help pay for long-term care for all persons who need services regardless of how much money they have
3. Reducing state income taxes for people who provide a lot of care to their disabled relatives
4. Tax incentives to help people purchase private long-term care insurance
5. Increasing funding for small home care programs such as Kupuna Care
Medicaid is a joint federal and state program that helps pay for acute and long-term care for people who are poor or become poor because of the high cost of long-term care. Expanding Medicaid eligibility to middle-class individuals is one way to broaden public long-term care programs. As shown in Figure 16, this idea has wide support among Hawaii residents. Over 71% of respondents favor changing Medicaid eligibility to include more middle-class people. Fifteen percent oppose such an expansion and about 14% have no opinion in this matter.

**Figure 16.** Do You Favor or Oppose Changing Medicaid so That More Middle-Class People Would be Eligible for Government Help in Paying for Long-Term Care Services?
Although Hawaii residents favor Medicaid expansion to the middle class, they are more ambivalent about having the government pay for all persons in need of long-term care regardless of their income. As shown in Figure 17, Hawaii residents are almost evenly split between supporting and opposing this option (42% and 47%, respectively). Slightly over 11% expressed no opinion on this subject.

**Figure 17.** Do You Favor or Oppose Having the Government Help Pay for Long-Term Care for All Persons Who Need Services Regardless of How Much Money They Have?

![Pie chart showing the distribution of opinions on government funding for long-term care](chart.png)
One way to lighten the burden for caregivers is to reduce their state income taxes. As shown in Figure 18, this idea finds a lot of support among Hawaii residents: almost three quarters of all respondents favor such state income tax reductions. About 12% of respondents oppose it and almost 15% have no opinion.

Figure 18. Do You Favor or Oppose Reducing State Income Taxes for People Who Provide a Lot of Care to Their Disabled Relatives?
Purchasing private long-term care insurance is one viable option that people can choose to cover their long-term care expenses. However, few people can afford long-term care insurance because premiums are expensive. Tax incentives to help people defray the costs of premiums is one strategy to promote private long-term care insurance. This approach is quite popular among Hawaii residents. According to Figure 19, over 80% of respondents favor this idea and only 5% oppose it. About 14% have no opinion.

**Figure 19. Do You Favor or Oppose Tax Incentives to Help People Purchase Private Long-Term Care Insurance?**
Many states fund their own home and community-based programs. Kupuna Care is a home care program for older people funded by the state of Hawaii. Figure 20 shows that a great majority of Hawaii residents (over 61%) support Kupuna Care and favor increased funding for the program. About 13% oppose additional funding for the program. About a quarter of all respondents have no opinion about the program.

Figure 20. Do You Favor or Oppose Increasing Funding for Hawaii Programs Such as Kupuna Care?

Insurance Options: CLASS Act

The survey solicited opinions from respondents on the newly enacted CLASS Act: whether they favor or oppose it, whether they plan to enroll, and how much they are willing to pay for it. Additional questions were asked about whether respondents think enrollment should be voluntary or mandatory and whether Hawaii should implement a wraparound public program for LTC benefits in addition to CLASS. Because only a few people are aware of the legislation establishing the CLASS option, the following introduction was given to survey respondents to educate them about the CLASS option:

The health reform law includes the Community Living Assistance Services and Supports (CLASS) Act, a national public long-term care insurance program. Working people who want to participate in the program will pay monthly premiums which will cover the cost of the program. People who do not work are not eligible for the program. Enrollment in the program is voluntary.
To qualify for benefits, individuals must be 18 years old, have paid premiums for at least 5 years, and have a fairly severe disability. Disabled people who qualify for benefits will receive a daily cash payment based on their level of disability. The average payment will be $50 per day. The program will provide benefits for as long as the individual qualifies.

A solid majority of Hawaii state residents support the CLASS Act. As shown in Figure 21, more than half of all survey respondents favor the CLASS Act and slightly over 14% oppose it. About 30% of respondents have no opinion of the CLASS Act, probably because they are not familiar with it.

Figure 21. Do you Favor or Oppose the Newly Enacted CLASS Act?
Support for and opposition to the CLASS Act varies only slightly across Hawaii’s counties. As shown in Figure 22, more than half of all respondents in each county favor the CLASS act; its support is highest in Maui (58%), followed by Honolulu (55%) and Kauai (54%). Among all counties, the residents in Hawaii expressed the lowest support (51%), although still a majority.

**Figure 22. Do You Favor or Oppose the Newly Enacted CLASS Act? Data by County**
Support for and opposition to the newly enacted CLASS Act varies by respondent income category. Figure 23 shows that survey respondents with household income under $19,999 expressed the least support for the CLASS Act (41%), perhaps because they are least able to afford the premiums. The proportion of CLASS supporters was greatest among survey respondents with family income between $20,000 and $59,999 (slightly over 61%) and among those with family income higher than $100,000 (slightly less than 60%).

**Figure 23. Do You Favor or Oppose the Newly Enacted CLASS Act? Data by Income**
To examine the planned CLASS enrollment, we restricted the sample to include only respondents who reported that they are currently employed, because those who are not employed are not be eligible to enroll in the CLASS program. It appears that support for CLASS does not necessarily translate into plans for enrollment. **Figure 24** shows that only 20% of respondents reported that they are planning to enroll in CLASS and more than a quarter reported that they are not planning to enroll. More than half of all respondents have not made this decision yet.

**Figure 24.** Do You Think You Will Enroll in the CLASS Act Public Long-Term Care Insurance Program When it is Available in 2011? Data for Employed Respondents
Again, limiting the data to the working population, there are some differences on planned enrollment in CLASS by age. As shown in Figure 25, most people do not know if they will enroll in CLASS. Employed people aged 45–64 are the most likely to report that they are planning to enroll in CLASS—about 30% reported that they plan to enroll in the program. Not surprisingly, the proportion of those planning to enroll is the lowest in the 18–24 age group (10%), followed by 13% among those aged 25–44.

Figure 25. Do You Think You will Enroll in the CLASS Act Public Long-Term Care Insurance Program When it is Available in 2011? Data by Age
To examine the planned CLASS enrollment by income, we restricted the sample to include only respondents who reported that they are currently employed, because those who are not employed are not eligible to enroll in the CLASS program. As shown in Figure 26, planned enrollment in CLASS is lowest among working Hawaii state residents with total household income under $20,000, with only about 11% reporting that they plan to enroll in the program. Other income categories are almost twice as likely to enroll without much variation across categories. More than half of all employed survey respondents in each income category did not know whether they would enroll in the program.

Figure 26. Do You Think You will Enroll in the CLASS Act Public Long-Term Care Insurance Program When it is Available in 2011? Data by Income Among Employed Respondents

Decisions about program insurance enrollment are tied to the amount of money people are willing to pay to participate. During the debate on health reform, different organizations estimated the premiums for CLASS to be between $123 and $240 per month. The U.S. Department of Health and Human Services has not yet established the premiums. The Hawaii survey respondents were asked how much in monthly premiums they would be willing to pay to enroll in CLASS. Limiting the analysis to people who are currently employed and would be eligible to participate in CLASS, Figure 27 shows that, overall, only about 2%
of all survey respondents are willing to pay a premium above $120 per month. About the same proportion of respondents are willing to pay between $80 and $120 a month, and 17% are willing to pay between $40 and $80 a month. The large majority of respondents (57%) are willing to pay under $40 monthly and 23% of respondents are unwilling to pay anything to enroll in CLASS.

**Figure 27. How Much Would You be Willing to Pay to Enroll in the CLASS Act?**

*Data for Employed Respondents*

![Pie chart showing willingness to pay categories](chart.png)

The CLASS insurance program is voluntary; people do not have to participate. This is a departure from public social insurance programs like Social Security and Medicare Part A, but it has precedents in Medicare Parts B and D, which are voluntary. Because the insurance is voluntary, there is a risk of adverse selection that could drive up the cost of premiums and possibly create an insurance death spiral. Without medical underwriting to exclude them, people with disabilities who need long-term care—and those at high risk of needing long-term care—may disproportionately enroll in the program. If few people without disabilities enroll, the program’s ability to spread the costs of people using benefits across a broad population will be limited and premiums will be high, potentially causing nondisabled people to not enroll or to disenroll. Survey respondents were asked about whether they think the enrollment in CLASS should be mandatory for all people; that is, people should be
required to enroll as they will be required to enroll in health insurance or pay a penalty. As shown in Figure 28, which includes all respondents regardless of age or employment status, mandatory enrollment in CLASS did not find much support among Hawaii residents: only one fifth of all survey respondents thought that everyone should be required to enroll in CLASS; 59% did not think people should be required to enroll. About 21% of all respondents did not know how to answer the question on mandatory enrollment.

**Figure 28.** Do You Think Everyone Should be Required to Enroll in the CLASS Act Public Long-Term Care Program?
Disaggregating the data by income, Figure 29 shows that the idea of mandatory enrollment in the CLASS program finds the least support among lower income Hawaii residents; only 10% of those with household income of under $20,000 support the mandatory enrollment of all in the CLASS program. More support for mandatory enrollment exists among Hawaii residents of middle and higher income, but the level of support is still low. For example, 26% of those with total household income between $20,000 and $59,999 and 20% among those total household income between $60,000 and $99,999 with are in support of mandatory enrollment. Eighteen percent of people with family income over $100,000 support making the CLASS program mandatory.

Figure 29. Do You Think Everyone Should be Required to Enroll in the CLASS Act Public Long-Term Care Program? Data by Income
Sponsoring a supplemental State of Hawaii long-term care insurance program around the federal CLASS insurance program is one way to enhance the modest long-term care benefits planned for the CLASS insurance program. As shown in Figure 30, survey respondents expressed support for such a program: almost 57% of Hawaii residents favor an additional public long-term care insurance program sponsored by the state of Hawaii to supplement the CLASS program. Only about 13% of respondents oppose such a program, while about 31% have no opinion on the issue.

**Figure 30. Do You Favor or Oppose a Public Long-Term Care Insurance Program Sponsored by the State of Hawaii That Would Offer Benefits Additional to the CLASS Act Federal Insurance Program?**
As shown in Figure 31, support for an additional public long-term care insurance program sponsored by the state of Hawaii is similar across counties and ranges from 56% in Hawaii to 52% in Maui.

**Figure 31.** Do You Favor or Oppose a Public Long-Term Care Insurance Program Sponsored by the State of Hawaii That Would Offer Benefits Additional to the CLASS Act Federal Insurance Program? Data by County
Preferred Choice for Long-Term Care Reform

Finally, survey respondents were asked to identify the long-term care reform option that had their greatest support. As shown in Figure 32, providing tax incentives to encourage the purchase of private long-term care insurance was the most popular choice, supported by 33% of Hawaii state residents, followed by allowing middle-class Hawaii residents to qualify for Medicaid services, supported by 31% of respondents. Twelve and a half percent of respondents favored establishing the state wraparound insurance program to supplement the federal CLASS program and about 12% would like to see the state home care program, Kupuna Care, expanded. Eleven percent of respondents did not choose any options to support.

Figure 32. Among the Following Reform Options, Which One has Your Greatest Support?

<table>
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<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>33.2%</td>
<td>Provide tax incentives for private LTC insurance</td>
</tr>
<tr>
<td>31.4%</td>
<td>Expand Kupuna Care</td>
</tr>
<tr>
<td>12.5%</td>
<td>Establish HI LTC insurance to supplement CLASS</td>
</tr>
<tr>
<td>11.7%</td>
<td>Allow middle class to qualify for Medicaid</td>
</tr>
<tr>
<td>11.3%</td>
<td>Do not favor any of these options</td>
</tr>
</tbody>
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Options to Increase State Revenues to Finance Expansions of Long-Term Care

Aside from insurance premiums, expansions of long-term care must be financed either by increased tax revenues or by reducing spending on other state services, such as education
and transportation. This section explores the willingness of Hawaii residents to pay increased taxes to improve the long-term care system.

Increasing state taxes is one way to pay for additional long-term care services for state residents. As shown in **Figure 33**, only about one quarter of all respondents support tax increase to fund improvements in long-term care services; almost 58% oppose tax increase to pay for better long-term care services. About 16% of all respondents do not have an opinion.

**Figure 33. Do You Favor or Oppose Higher Taxes to Pay for Improved Long-Term Care Services?**

![Pie chart showing the distribution of responses to the question of whether to favor or oppose higher taxes to pay for improved long-term care services.](Image)

Despite the overall opposition to open-ended tax increases, when specific levels of tax increases were offered, a much higher percentage of respondents were willing to pay something to improve long-term care services. As shown in **Figure 34**, only 37% of all respondents reported that they are willing to pay nothing, compared to 58% who earlier reported opposing tax increase. About 35% of respondents are willing to pay under $40 a month to improve long-term care services in the state and 7% are willing to pay between $40 and $80 a month. About 1% of all respondents are willing to pay over $80. About one
fifth of all respondents did not know how much they would be willing to pay for improvement in long-term care services.

**Figure 34. How Much More per Month Would You be Willing to Pay in Taxes to Improve Long-Term Care?**

![Pie chart showing responses to the willingness to pay for improved long-term care.]

- **37.2%**: Between $80 and $120 per month
- **34.8%**: Between $40 and $80 per month
- **19.9%**: Less than $40 per month
- **7.0%**: $120 per month or more
- **0.9%**: Between $40 and $60 per month
- **0.3%**: Don't know
- **19.9%**: Nothing
Survey respondents were also asked which tax should be increased if the state made the decision to increase taxes to pay for improved long-term care services. As shown in Figure 35, increasing the state sales tax was the most popular option, chosen by 26% of Hawaii residents, followed by estate tax (17%). Increasing the state income tax was the least popular source for additional funds, favored by 12% of survey respondents. About 35% of survey respondents did not have an opinion on which tax should be increased.

**Figure 35. If You Were Required to Pay Higher Taxes to Improve Long-Term Care in Hawaii, Which Tax Should be Increased?**

4. Conclusions

In summer 2010, RTI International conducted the Hawaii Long-Term Care Survey on behalf of the Hawaii Long-Term Care Commission. State residents aged 18 and over were surveyed to understand public perceptions, awareness, and attitudes about LTC and to elicit the general public’s views of various options for LTC reform. Several important points may be inferred from the results:

- Overall, many people had “no opinion” on many questions, indicating that knowledge about long-term care services is low and that the costs associated with long-term care are not widely understood by the general public. Moreover, many people have no opinion about how these long-term care services should be
improved or what sources of revenue should be used to pay for the improvements. Similarly, about one third of all Hawaii residents do not have any opinion about the newly enacted CLASS program and more than half do not know whether they plan to enroll in it. Such lack of opinion may indicate a substantial need to educate the public about the options and costs of long-term care. In particular, as with the rest of the nation, residents of Hawaii need education about the CLASS program.

- Long-term care is not affordable for the large majority of Hawaii residents, with many people not knowing how they would pay for it. Affordability is perceived as a major problem: more than 60% of survey respondents reported that they could not afford any of the costs for round-the-clock care either at home or in a nursing home and about one third could not afford any costs for 2 hours’ worth of care a day.

- In terms of changing the balance of Medicaid spending between institutional and home and community-based services, which has been the focus of long-term care reform in most states, only about a quarter of respondents thought that the proportion of Medicaid long-term care spending for nursing home spending was too high; about 30% thought it was about right. These results were somewhat surprising because Hawaii has among the lowest percentage of Medicaid long-term care spending for home and community-based services in the country. Moreover, large majorities of Hawaii residents wanted to be cared for at home, either by relatives or paid caregivers; relatively few people wanted to receive care in residential care facilities and almost no one wanted to be cared for in a nursing home. Large majorities of Hawaii residents favored consumer-directed home care by which consumers could hire and fire their own workers.

- Large majorities of respondents favored expanding Medicaid eligibility to the middle class, reducing taxes to informal caregivers, tax incentives for purchase of private long-term care insurance, and increasing funding for Kupuna Care.

- Among those with an opinion, a solid majority of survey respondents favored the CLASS Act. However, most people did not know if they would enroll in CLASS and about one third of all respondents reported that they would not enroll. Additionally, what people are willing to pay for CLASS in premiums if they enroll is significantly less than what was estimated to be an average monthly CLASS premium. About half of all survey respondents said that they would pay less than $40 per month to enroll in CLASS; only a tiny proportion said that they would enroll if premiums were as high as estimated during the health reform debate. A substantial majority of Hawaii residents opposed requiring people to enroll in CLASS, which would dramatically reduce premiums and would protect the program against adverse selection. Instead, respondents preferred to keep enrollment voluntary. A substantial majority of respondents also favored a state-sponsored Hawaii wraparound program to supplement the long-term care services provided by the CLASS program.

- When forced to choose one option for reform to improve long-term care services as having their strongest support, about a third of survey respondents chose allowing the middle class to qualify for Medicaid, about a third of respondents chose tax incentives for private long-term care insurance, about an eighth each chose establishing a Hawaii LTC insurance plan to supplement CLASS and expanding Kupuna Care.
With the exception of the CLASS program, which is self-financed, Hawaii residents generally supported long-term care financing initiatives that either increased government spending or reduced government revenues. However, a substantial majority of Hawaii residents opposed higher taxes to pay for improved long-term care services, but when pressed, two thirds of respondents reported that they would be willing to pay something, but not too much, for improvements to the long-term care system. If taxes had to be increased, the sales tax was the most popular option, followed by estate tax.
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Long-Term Care Reform Options in Hawaii

Final Report

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Introduction

This report analyzes a range of long-term care reform options for Hawaii, providing background and advantages and disadvantages for each option. It is meant to be reference document for the discussion of reform strategies by the Hawaii Long-Term Care Commission. It is not meant to be a definitive listing of options and their pros and cons. The Commission may have other options that it wishes to consider or it may not wish to consider all of the options presented here.

The paper has four sections. The first is a brief discussion of some of the problems of the existing long-term care system and the goals of reform. The goals are meant to help frame some criteria for the evaluation of various options. The second section examines reform options that depend on promoting and strengthening private long-term care insurance. The third section examines a range of options to expand and strengthen public sector financing, including Kupuna Care, Medicaid, and the Community Living Assistance and Supports (CLASS) Act insurance product. The fourth section examines options to reform the long-term care delivery system.
Problems of the Current Long-Term Care System and the Goals of Reform

The current system of financing, organizing and delivering long-term care satisfies almost no one. Many analyses identify at least five goals that should be addressed by long-term care reform (Exhibit 1). Agreement on the goals of reform should help the Hawaii Long-Term Care Commission to evaluate various options. The Commission should decide whether the goals listed below are the ones it wishes to adopt or whether it wishes to delete, modify, or add goals.

Exhibit 1. Goals of Reform

- Treat the risk of needing long-term care as a normal life risk.
- Protect against catastrophic out-of-pocket costs.
- Prevent dependence on welfare in the form of Medicaid.
- Improve access to long-term care services.
- Make the long-term care system more responsive to consumers.
- Change the balance of institutional and home and community-based services.
- Design an affordable system, both for individuals and the government.

Treat the Risk of Needing Long-Term Care as a Normal Life Risk

Although not often explicitly discussed, perhaps the most important goal of reform is for society to treat long-term care as a normal risk of living and growing old. Fully 69 percent of people who turned age 65 in 2005 will have some long-term care needs before they die; among the 35 percent of older people who will spend some time in a nursing home before they die, about half will reside there for a year or longer (Kemper, Komisar, and Alecxih, 2005/2006). The large expenses of long-term care should not come as an unpleasant surprise that causes severe financial distress to individuals and their families. Currently, the problem of coping with chronic illness and disability is compounded by worries about paying for care. Older people and others fear that if they need long-term care, they will become a burden on their family. People should know how their long-term care expenses will be paid. Mechanisms need to be established so that people will know how to pay for services should they need them.

Protect Against Catastrophic Out-of-Pocket Costs

With very little public or private insurance coverage against the high costs of long-term care, it is not surprising that users of long-term care services often incur very high out-of-pocket costs. The average private pay cost for a year in a nursing home in Hawaii was $132,860 in 2010 (MetLife Mature Market Institute, 2010). In the Hawaii Long-Term Care Survey conducted for the Commission, about three-fifths of respondents said that they could not afford to pay any of the cost of a year in a nursing home or 24-hour home care (Khatutsky et al., 2010). The costs of long-term care can easily impoverish people with long-term care needs.
Prevent Dependence on Welfare in the Form of Medicaid

A separate but related goal is to prevent people who have been financially independent all their lives from depending on welfare—Medicaid—at the end of their lives. Most people believe that only a small proportion of the population should receive welfare. Yet, in 2010, 70 percent of nursing home residents in Hawaii had their care paid by Medicaid (American Health Care Association, 2010). A substantial portion of Medicaid nursing home residents were not eligible for the program when they were living in the community and turned to Medicaid because they had impoverished themselves paying for long-term care. Medicaid financial eligibility rules are very strict. For example, individuals in Hawaii with more than $2,000 in financial assets are ineligible for Medicaid (Walker and Accius, 2010).

Improve Access to Long-Term Care Services

Access to long-term care services in Hawaii is to be limited. On a population basis, the supply of nursing home care is half the supply in the country as a whole (O’Keefe and Wiener, 2010). Partly as a consequence, according to some observers, some people needing high levels of care have difficulty gaining access to services, forcing them to remain in acute care hospitals. Similarly, although the Medicaid QUEST Expanded Access demonstration appears to be expanding access to home and community-based services, Hawaii’s Medicaid spending on home and community-based services per 1,000 people aged 75 and older has historically been much less than the national average (O’Keefe and Wiener, 2010). Hawaii’s many islands impede access to long-term care services; people are not able to travel from island to island to receive long-term care. To the extent that they must do so, then they are separated from their family and friends.

Make the Long-Term Care System More Responsive to Consumers

The financing and delivery of long-term care services in Hawaii and most other places in the United States are fragmented, with a confusing array of programs, funders, eligibility rules, and provider types. For example, Medicaid is the dominant funder, but a very limited amount of long-term care is also funded by Medicare, Kupuna Care, the Department of Veterans Affairs, the U.S. Office on Aging, and other state programs. One of the goals of Medicaid’s QUEST Expanded Access is to create a more seamless system by making one organization responsible for all Medicaid medical and long-term care services for an individual. Similarly, Hawaii’s Aging and Disability Resource Center seeks to provide consumers with a “one-stop shop” for information about long-term care resources, but its services are still fairly underdeveloped, although initiatives are underway to improve them. Closely related to these activities is the movement to consumer-directed home care, which gives consumers rather than agencies the right to hire, train, schedule, supervise, and fire their workers (Foster et al., 2003; Schore, Foster, and Phillips, 2007; Wiener, Anderson, and Khatutsky, 2007).

Change the Balance of Institutional and Home and Community-Based Services

The overwhelming majority of people who need long-term care live in their homes and want to stay there. In the Hawaii Long-Term Care Survey, only 4 percent of respondents said that they want to be cared for in a nursing home and only 12 percent want to live in assisted
living or small group homes (Khatutsky et al., 2010). The overwhelming majority of people want to be cared for at home, either by friends and relatives or home care providers. Despite these preferences, public expenditures for long-term care for older people are overwhelmingly for nursing home rather than home care. Few data are available to evaluate how the demonstration program is performing, but nursing home use appears to have dropped somewhat and home and community-based services use has increased significantly.

**Design an Affordable System, Both to the Individual and Government**

Political reality dictates that any reforms be “affordable” to both users and tax payers. Although there is little consensus about how much society is willing to pay for long-term care services, there is little doubt that raising taxes to pay for a public program is always difficult, even for popular programs like Social Security and Medicare.

With the aging of the population in Hawaii and nationally, demand for long-term care will increase, as will public and private expenditures. Reforming the system will require additional resources and a key issue is how to obtain them. Additional funding for long-term care can be obtained through general revenue taxes, private insurance, or public insurance. Another key issue is how to convince people to either prepare financially so they can afford to pay privately to meet long-term care needs or to be willing to pay more taxes to support public programs that provide long-term care services.
Options for Long-Term Care Financing Reform

The debate over long-term care financing is primarily an argument over the relative merits of private versus public sector approaches. Some people believe that the primary responsibility for care of older people and younger persons with disabilities belongs with individuals and families and that government should act only as a payer of last resort for those unable to provide for themselves. Policymakers who hold this view generally advocate private sector initiatives, such as private long-term care insurance, and may advocate tightening eligibility for public programs to prod people to plan for their own long-term care needs. The long-term care financing systems of the United Kingdom, New Zealand, and the United States largely reflect this view (Organization for Economic Co-operation and Development, 2006).

The opposite view is that the government should take the lead to ensure that all people who need long-term care, regardless of ability to pay, receive the services they need. In this view, long-term care for older people should be treated more like health care for older people and should not require people to be poor or become poor to receive government aid. The long-term care financing systems of Germany, Japan, the Netherlands, and Sweden reflect this view. U.S. policymakers who hold this view generally favor expansions of Medicaid, Medicare, the Older Americans Act, and other public programs and advocate a social insurance program for long-term care. Between these polar positions, many variations are possible.

Countries such as Germany, the Netherlands, and the United Kingdom that have populations older than the United States spent between 1.35 and 1.44 percent of GDP for total (public and private) long-term care for older people in 2000; Sweden, where 17 percent of the population was elderly in 2000, was the outlier, spending a little under 3.0 percent of GDP for long-term care for older people (Organization for Economic Co-operation and Development, 2006).

Public long-term care expenditures are a small proportion of the national economy, accounting for about 0.9 percent of the U.S. gross domestic product in 2005 (Organization for Economic Co-operation and Development, 2006). Long-term care is also a small proportion of total health care expenditures. In 2005, health care was 16.0 percent of the overall U.S. economy and long-term care was approximately 5.6 percent of total health expenditures (author’s calculations using data from the Organization for Economic Co-operation and Development, 2006 and the Centers for Medicare & Medicaid Services, 2011).

With the aging of the population, the percentage of GDP for public long-term care expenditures is projected to double or triple by 2050 (Organization for Economic Co-operation and Development, 2006). Although this change is a big increase in percentage terms, it is a relatively modest change in absolute terms, given the aging of the population. Indeed, between 1999 and 2009, total health care expenditures as a percentage of the U.S. economy increased by 3.8 percentage points, more than is expected for long-term care between 2005 and 2050 (Centers for Medicare & Medicaid Services, 2011).

On the other hand, these projections would mean a very large percentage increase in what state governments pay for long-term care as a proportion of their budgets, which would be a strain. In addition, long-term care will be needed primarily by older people, who will also require
Medicare and Social Security spending. Thus, substantial additional funds will be needed to pay for long-term care services, and many states, including Hawaii, are worried about the long-range impact of an aging population on their budgets.

Medicaid, the major source of funding for long-term care, is a major expenditure for state governments. Although Medicaid expenditures (federal and state shares for all services and populations) accounted for 21.8 percent of total expenditures by states nationally in fiscal year 2010, they accounted for only 13.3 percent of expenditures in Hawaii during that same year (National Association of State Budget Officers, 2010). Long-term care for older people and younger persons with physical disabilities accounted for about 22 percent of Hawaii’s Medicaid spending in 2008, the most recent year for which data are available (Eiken, Sredl, and Burwell, 2009). Medicaid long-term care services accounted for about 2.9 percent of total state expenditures, including the federal match.

How policymakers view these projections partly determines what type of financing reform they propose. Advocates for private sector initiatives view these increases and their implications for public spending to be unacceptably high and worry that they will crowd out other worthwhile public spending, especially for younger people. They are unwilling to consider raising taxes to pay for the increased costs and argue that it is imperative to shift as much long-term care costs as is possible to the private sector.

On the other hand, the implicit assumption of advocates for a greater role for the public sector is that these costs are affordable. From their perspective, long-term care is a small portion of the total health care system and even if its proportion doubled or tripled, it would remain a small portion of the health care system. Moreover, from a macroeconomic perspective, it may matter little in terms of the burden to the economy whether services are financed by the public or private sector (Wiener, Illston, and Hanley, 1994). Advocates of mandatory public long-term care insurance argue that offering additional benefits to the population as a whole is a way of building support for the additional revenues that will be needed to cover existing as well as additional services.

The choice of emphasis between public and private programs also depends on who would benefit and whether they meet specified policy goals. For example, if a large majority of citizens were to purchase private long-term care insurance, then many people would see less need for expanding government programs. Conversely, if private insurance were to prove widely unaffordable or otherwise present barriers—such as medical underwriting—that prevent people from voluntarily purchasing policies, then the case for an expanded public role would be stronger.
Private Sector Initiatives

Private sector approaches are appealing because they reflect the American tradition of individuals taking responsibility for themselves and their families. The classic virtue of the competitive market is its flexibility to adapt to individual needs and wants and to local conditions, a virtue that is mitigated for long-term care insurance by the long lead time between purchase and use of insurance. In addition, some private long-term care insurance advocates hope that private sector initiatives can prevent middle class people from having to turn to Medicaid when they have spent all of their assets on long-term care services. In addition, if private sector initiatives could prevent middle-class people from having to depend on Medicaid, they might reduce Medicaid long-term care spending.

Over the last decade, the national policy debate on financing reform has primarily focused on private sector initiatives. The marked improvement in the financial position of the elderly over the last 30 years has made it plausible to argue that private sector financing other than out-of-pocket payments might play a significant role in the future financing of long-term care.

A viable private long-term care insurance market, primarily sold on an individual basis, has existed since the mid-1980s. In 2005, approximately 7 million policies were in force, covering about 3 percent of the total American population aged 20 and older; about 10 percent of older people have some form of private long-term care insurance (Feder, Komisar, and Friedland, 2007), compared to 0.2 percent of people aged 20–49. Most policies have limitations. For example, many policies do not cover lifetime need for services, provide only fixed indemnity benefits rather than payment for all incurred costs, provide benefits that are not inflation-adjusted over time, and do not include a nonforfeiture benefit in case of policy lapse. In recent years, sales have been increasingly to people under the age of 65; in 2009, 81 percent of long-term care insurance purchasers were under age 65 (American Association for Long-Term Care Insurance, 2010).

In some respects, the slow growth of private long-term care insurance is surprising because of the widespread use of automobile insurance, homeowner’s insurance and private health insurance. A major reason that relatively few people have private long-term care insurance is that long-term care insurance is expensive, especially for older people with fixed retirement incomes. In 2008, the average premium for private long-term care insurance policies providing a $150 daily benefit amount, 3 years of coverage, a 90-day elimination period, and 5 percent compound inflation protection, but no nonforfeiture benefit was $2,329 per year if purchased at age 60 (Tumlinson and Aguiar, 2009). In 2009, among people who purchased their policy in the individual market, the average long-term care insurance premium among people age 55-64 and 65 and over, respectively, was $2,200 and $3,250 (American Association for Long-Term Care Insurance, 2010). Using the National Association of Insurance Commissioners’ suitability criteria for purchase of private long-term care insurance (premium not exceeding 7 percent of

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1 For example, 57 percent of policies purchased in 2009 covered 4 years or fewer years of care (American Association for Long-Term Care Insurance, 2010). Similarly, while 91 percent of policies purchased during that same year had some inflation protection, only 53 percent of policies purchased provided inflation protection either through 5 percent compound inflation adjustment or a consumer price index inflation adjustment.
income and financial assets of at least $35,000), only 21 percent of people between age 60 and 79 could afford to buy a “mid-range” policy (Merlis, 2003). Thus, even with generous assumptions about the willingness of people to pay, private long-term care insurance is very expensive for most older people (Wiener, Illston, and Hanley, 1994).

Even if long-term care insurance was more affordable, for many people, there is no point in buying private long-term care insurance because they think they already have coverage through Medicare. This is incorrect. While Medicare covers short-term post acute care, it does not cover long-term care in nursing homes or at home. In a national survey by AARP, almost 60 percent of respondents said that Medicare covered long-term care (GfK NOP, 2006). Medicare coverage rules for skilled nursing facilities and home health care are complex, making benefits difficult to explain to people. One of the goals of the Own Your Own Future awareness campaign sponsored by the U.S. Department of Health and Human Services is to educate people about the lack of Medicare coverage and Medicaid’s financial eligibility requirements.

Although everyone recognizes the risk for use of physician and hospital services, the risk of needing long-term care is much less well known among the general population, and people are unlikely to buy long-term care insurance if they believe it is a low or no risk event. In fact, the lifetime risk of needing long-term care is quite high—69 percent of people aged 65 and older will have some long-term care need before they die and 20 percent of people aged 65 and older will have long-term care needs for more than 5 years (Kemper, Komisar, and Alecxih, 2005/2006).

Because of the risk of adverse selection, individual long-term care insurance policies are medically underwritten—that is, insurance companies will not sell policies to people they deem having a high risk of using long-term care services in the relatively near term because of existing health and other problems. Although underwriting practices differ among companies, one study estimated that 28 percent of people aged 65 to 69 could not pass medical underwriting standards (Merlis, 2003). Among applicants for insurance, 9 percent of persons age 50-59 and 15 percent of persons age 60-69 were declined coverage as a result of medical underwriting (American Association for Long-Term Care Insurance, 2010).

The limitations of the unsubsidized, individual private long-term care insurance market has led to a number of proposals and initiatives to “jump start” it. These include educating the public about their risks of long-term care, encouraging policy makers to enact tax incentives for the purchase of private long-term care insurance and public-private partnerships that combine private insurance with Medicaid coverage.

Exhibit 2 summarizes private sector options and their advantages and disadvantages.
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<th>Option</th>
<th>Advantages</th>
<th>Disadvantages</th>
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<tr>
<td>Establish educational campaign for private long-term care insurance</td>
<td>- Motivates some people to plan for their own long-term care needs</td>
<td>- Does not address affordability of long-term care insurance</td>
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<td>- Can be relatively low cost compared to providing benefits</td>
<td>- Encourages people to purchase products with limitations</td>
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<td>- This approach could be combined with several other options</td>
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<tr>
<td>Strengthen regulation of private long-term care insurance to better protect consumers</td>
<td>- Helps to protect consumers</td>
<td>- Reduces consumer choices</td>
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<td>- Low-cost option</td>
<td>- Raises price of policies by imposing additional requirements, such as inflation protection</td>
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<td>Establish a “public-private” partnership</td>
<td>- Brings private insurance and Medicaid together into integrated program</td>
<td>- Experience in other states suggests that it will motivate few additional people to buy insurance</td>
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<td>- May increase number of people with private insurance</td>
<td>- Asset protection and easier access to Medicaid may not be what people want from long-term care insurance, making it an ineffective incentive</td>
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<td>- Allows people to receive lifetime asset protection (while receiving Medicaid) without buying a long-term care insurance policy that provides lifetime coverage.</td>
<td>- If it does not successfully encourage additional people to purchase insurance, it may result in additional Medicaid costs</td>
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<td>- Reduces price of long-term care insurance by reducing amount of coverage needed</td>
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<td>- If it successfully encourages additional people to purchase insurance, it may reduce Medicaid costs</td>
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<tr>
<td></td>
<td>- Forty-three states are operating or planning to operate “public-private partnerships”</td>
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<tr>
<td>Provide tax incentives for purchase of private long-term care insurance</td>
<td>- Helps to lower the price of insurance a little, making it more affordable for some</td>
<td>- Empirical evidence suggests that typical state tax incentives do not substantially increase number of people with insurance</td>
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<td>- Encourages individuals to take responsibility for their own long-term care needs</td>
<td>- Potential reductions in Medicaid costs likely to be smaller than the cost to the State of the tax incentives</td>
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<td>- Has substantial support among Hawaii state residents</td>
<td>- Empirical evidence suggests that tax incentives will not produce net Medicaid savings</td>
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<td></td>
<td>- Could reduce Medicaid expenditures</td>
<td>- Tax incentives are typically regressive</td>
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<td>- Tax loss must be made up with tax increases or expenditure cuts elsewhere</td>
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Private Sector Option #1: Establish an Education and Marketing Campaign to Promote the Purchase of Private Long-Term Care Insurance

In this option, the State of Hawaii would develop and finance an education campaign that explains the risk and costs of needing long-term care and the available financing options. The emphasis would be on encouraging people to take active steps to plan for their own long-term care needs, including the purchase of private long-term care insurance.

Background

Americans know little about long-term care services, costs, or financing of long-term care and deny their potential risk of needing services. The MetLife Mature Market Institute survey conducted in 2005 and in 2009 demonstrated that most people underestimate the need for long-term care as they age and the majority do not know who pays for it, with few taking action to protect themselves from these expenses (MetLife Mature Market Institute, 2009). Lack of knowledge and low preparedness is widespread: In a survey of California voters, 69 percent of respondents inaccurately believed that Medicare covers long-term nursing home care and 78 percent thought it covers long-term in-home care (Lake Research Partners and American Viewpoint, 2010).

Although recent polls demonstrate low levels of preparedness and knowledge of long-term care costs among the American public, the polls also show that there is a lack of confidence in being able to pay for long-term care. For example, a survey conducted for the SCAN Foundation showed that 66 percent of Californians aged 40 and older worry about being able to pay for long-term care that they or a family member may need in the future (Lake Research Partners and American Viewpoint, 2010). Similarly, in an AARP survey, 59 percent of registered voters in Hawaii expressed lack of confidence in their ability to afford long-term care services (Binette & Dinger, 2008). In the Hawaii Long-Term Care Survey, half of respondents did not know how they would pay for an extended nursing home stay or 24-hour home care (Khatutsky et al., 2010). These findings suggest that the public may be receptive to an educational campaign that provides current and relevant information about long-term care planning options (Life Plans Inc., 2007).

Advantages

- An advertising campaign that educates the people of Hawaii about long-term care risks could motivate them to plan for their own long-term care needs.
- An advertising campaign is relatively low cost, because it does not directly provide services, insurance, or other financing.

Disadvantages

- Education, by itself, does not address the most important barrier to purchasing long-term care insurance: lack of affordability. Education without a viable “action plan” will likely be ineffective in motivating behavioral change.
- Unless private long-term care insurance is better regulated, people may be encouraged to purchase policies that do not meet their needs.
**Private Sector Option #2: Strengthen Regulation of Private Long-Term Care Insurance**

Under this option, Hawaii long-term care insurance regulations would be reviewed for possible revision and strengthening. Major focuses of the review would be inflation protection, nonforfeiture benefits, and premium increases by insurance companies.

**Background**

All states, including Hawaii, regulate private long-term care insurance, usually based, to a greater or lesser extent, on the model statute and regulation of the National Association of Insurance Commissioners. At least three areas are of concern to consumer advocates nationally.

- The first area relates to inflation adjustment (Wiener, Illston, and Hanley, 1994). Unlike health insurance where benefits are typically a fixed percentage of the allowable costs, private long-term care insurance typically pays up to a fixed amount per home care visit or per day in a nursing home or assisted living facility regardless of the cost of care. Unless there is an annual inflation adjustment, the maximum amount stays the same over time. Like virtually all other states, the Hawaii insurance regulations require insurers to offer compound inflation adjustment over time but they allow insurers to sell policies without inflation adjustments. The problem is that long-term care insurance is typically purchased far in advance of using benefits; thus, inflation over time can severely undermine the purchasing power of the policies. For example, assuming a 5 percent annual increase in price, a policy bought at age 60 that pays $4,000 per month for nursing home care needs to pay more than $10,600 per month at age 80 to retain equivalent purchasing power. Without inflation protection, the value of the benefit would drop by 60 percent. Compound insurance protection greatly increases the premium compared to policies without inflation protection. For example, at age 65, policies with 5 percent annual compound inflation protection cost approximately 75 percent more than policies without inflation protection (Coronel, 2004), while the proportion of policies with inflation protection has increased substantially over time. Fully 91 percent of policies purchased nationally in 2009 had some inflation protection, but only 53 percent of policies purchased that year had compound inflation protection or linked increases in benefits to the Consumer Price Index (American Association for Long-Term Care Insurance, 2010).

- The second area relates to lapse rates and nonforfeiture benefits. Long-term care insurance policies are designed to have level premiums; that is, the premiums are supposed to stay the same year after year. Thus, relative to their risk of using long-term care, insureds overpay during the early years of their policy and underpay during the later years of their policy. During the early years of having insurance, individuals contribute to the buildup of reserves which will be used when the individual is older and has a higher risk of needing care. If policyholders terminate or “lapse” their policies, they typically receive no residual benefits even though the insurance company has built up financial reserves during the period of premium payment. The recent dramatic increase in long-term care insurance premiums among many
insurers is expected to result in a large increase the number of lapses. The insurance companies will be able to retain the excess funds for their own use rather than returning the reserves to the policyholders. Observers also note that policies with high lapse rates will have lower premiums, all other things being equal, than policies with low lapse rates, creating an incentive for insurers to assume high lapse rates. If the high lapse rates do not occur, the policy will lose money, causing the insurer to raise premiums, which will increase the lapse rates. Thus, some experts have advocated mandatory residual or nonforfeiture benefits be provided to policyholders when they lapse. Some policies offer “contingent nonforfeiture benefits” which provide a residual benefit if premiums are increased greatly, but the level of required premium increases needed to trigger benefits can be quite large.

- The third area of concern relates to premium increases for existing policyholders. As noted above, premiums are designed to be the same after initial purchase. Although insurance companies may not raise the premiums of individual policyholders, they reserve the right to raise premiums for an entire class of policyholders (e.g., people who bought a certain policy during a particular year) if the policy encounters substantial financial difficulty. Although large, unexpected premium increases have been an ongoing problem in the industry; in the last few months, several well-known insurers, including MetLife, Genworth Financial, and John Hancock, have substantially raised premiums for existing policyholders.²

Insurers have raised premiums partly because they are receiving a lower rate of return on investments than they expected and because fewer people than they anticipated allowed their policies to lapse. A large increase in premiums can cause financial hardship for policyholders and may lead some to lapse their policies, leaving them with no financial protection or may cause them to substantially reduce their coverage. Insurance regulators generally review the insurance premium rates for private long-term care insurance, both initially and for proposed increases to determine appropriateness. Thus, the large premium increases, in some way, reflect a failure both by state regulators and by the insurance companies to accurately price long-term care insurance policies.

Advantages

- Strengthening private long-term care regulations will help to protect consumers by ensuring that the policies that they purchase actually provide the financial protection that they promise, that they will receive some benefits from the financial reserves of the companies if they have to lapse their policies, and that the cost of the policies will be known in advance.

² Genworth Financial is seeking an 18 percent increase on older policies held by about 25 percent of its customers. John Hancock has filed for permission to raise premiums for about 80 percent of its customers by an average of 40 percent and has also temporarily stopped offering new long-term care insurance plans through employers while it recalculates premiums (Lieber, 2010). John Hancock Financial said it would ask state regulators for an average 40 percent increase for about 850,000 of its 1.1 million policyholders (Tergsen and Scism, 2010).
- Regulatory reform is a low-cost option to implement because it does not directly finance services or provide tax benefits.
- Because long-term care insurance is a particularly complex product that few consumers understand, strict regulation is warranted.

**Disadvantages**

- Consumers are already offered compound inflation benefits and some are offered nonforfeiture benefits. If they do not want to purchase policies with this protection, they should not have to incur the extra costs.
- Stricter regulation will raise costs, causing fewer people to purchase policies.
Private Sector Option #2: Establish a “Public-Private” Partnership for Long-Term Care

In this option, private long-term care insurance would be promoted by providing purchasers of state-approved private long-term care insurance policies with easier access to Medicaid. In these public-private partnerships, policyholders are allowed to keep much more of their financial assets than is typically allowed by Medicaid financial eligibility rules.

Background

A number of policy analysts have suggested a public-private partnership for long-term care to promote private long-term care insurance and to align it with Medicaid. These public-private partnerships have been in effect for more than 15 years in California, Connecticut, Indiana, and New York. In determining Medicaid eligibility, these partnership programs generally allow policyholders to keep an extra dollar in financial assets for each dollar that their insurance policies pay in benefits. For example, in Connecticut, persons with state-approved private long-term care insurance policies that pay $150,000 in benefits can keep $152,000 in financial assets and still qualify for Medicaid once the insurance policy has paid all of its benefits. At its core, this approach offers asset protection as its inducement to purchase insurance. Medicaid beneficiaries still must contribute all of their income except for a small personal needs allowance towards the cost of care. However, individuals would still have to use their assets or income to pay for care not covered by insurance, and—once insurance benefits run out—must contribute all of their income to their care before Medicaid will pay.

Although the Omnibus Budget Reconciliation Act of 1993 limited this strategy to the four states mentioned above, the Deficit Reduction Act of 2005 removed those restrictions, opening the approach to all states. The Deficit Reduction Act also lowered the consumer protection standards of the policies that had been set by the original four states. For example, all of the original four states required policies to have automatic compound inflation adjustment to the benefit; the Deficit Reduction Act eliminated that requirement and replaced it with less strict inflation adjustment requirements. As of June 30, 2010, 43 states have adopted the partnership approach, with 228,293 policies in force (Thomson Reuters, 2010).

Advantages

- The partnership brings together the public and private sectors into an integrated system, with the private sector accepting the front-end risk for long-term care and the public sector accepting the back-end risk.
- This approach may increase the number of people who have private long-term care insurance above what might otherwise be the case.
- This strategy allows the insured to obtain lifetime asset protection without having to buy an insurance policy that provides lifetime coverage, thus reducing the price of the private insurance policy needed and increasing affordability for more middle-class people.
- Compared to providing tax incentives, this approach is a relatively low-cost option to promoting private long-term care insurance. If the partnership can induce people who would not have otherwise purchased long-term care insurance to do so, then some Medicaid savings may result in the future.
Disadvantages

- Although this approach is favored by some policy analysts because it melds the public and private sectors, partnerships have not significantly increased the number of people with private long-term care insurance. Only modest numbers of partnership policies have been sold in the four states in which the initiative has been offered, despite more than a decade of active promotion and marketing by the respective states. In 2005, there were approximately 172,000 partnership policies in force in the four states with the longest experience, about 2.2 percent of the older population in the four states (U.S. Census Bureau, 2006; U.S. Government Accountability Office, 2005a). This strategy uses Medicaid to protect the assets of middle- and upper-middle-class insurance purchasers. The majority of purchasers of partnership policies in California, Connecticut, and Indiana had more than $350,000 in assets (U.S. Government Accountability Office, 2005a).

- Asset protection may not be a decisive motivator for the purchase of private long-term care insurance. Most surveys of private long-term care insurance purchasers point to less concrete reasons for buying policies, such as retaining autonomy and independence, not being a burden to one’s children, and having more choice of providers.

- A core component of this approach is to offer easier access to Medicaid, but older people may not want to be on Medicaid. Indeed, most private long-term care insurance is marketed as a way of avoiding Medicaid.

- Depending on who purchases these policies, who eventually needs long-term care, and what services they use, partnership policies may not reduce Medicaid costs, and conceivably could even increase them.
Private Sector Option #3: Provide Tax Incentives for the Purchase of Private Long-Term Care Insurance

This option would provide a Hawaii tax deduction or credit for the purchase of private long-term care insurance. The deduction or credit could be capped and could vary by income.

Background

One strategy to improve the affordability of private long-term care insurance is to provide tax incentives for their purchase, which would reduce the net cost of the insurance. Current federal law allows qualifying long-term care insurance premiums to be deducted from income as part of medical expenses, but only if total out-of-pocket expenses exceed 7.5 percent of adjusted gross income and only for the expenses that exceed the threshold. As a result, fewer than 5 percent of all tax returns report medical expenses as itemized deductions (Ignani, 2006). Even for those able to meet the federal threshold, some policyholders are unable to claim the federal deduction because of other requirements that they do not meet. The recently enacted health reform legislation will increase the threshold for tax deductibility of medical expenses from 7.5 percent to 10.0 percent. Because this provision is a deduction rather than a credit, a deduction is worth more to them than it is for moderate income people who are in lower tax brackets.

Under federal law, employers may deduct their contributions toward the cost of private long-term care insurance as they do health insurance. Despite this incentive, few employers contribute to the cost of private long-term care insurance. The vast majority of employers that offer long-term care insurance to their employees do so on an employee-pay-all basis.

Many states offer some type of tax incentive for private long-term care insurance. In 2006, 23 states and the District of Columbia offered some type of tax incentive: 15 states allowed taxpayers to deduct premiums from income; six states offered tax credits; and two states offered both (Goda, 2010). The credits are not refundable so do not benefit individuals with low incomes who do not pay taxes. Tax incentives in the form of deductions are generally allowable in addition to the standard deduction, not requiring taxpayers to itemize. Because state tax rates are low in absolute terms, the value of the tax incentives is small, generally in the range of $30 to $100 per year on a $1,000 policy (Nixon, 2006). Only three states provide more than a 10 percent subsidy (Goda, 2010).

Advantages

- Tax incentives help some people to buy private long-term care insurance.
- Tax incentives lower the net price of private long-term care insurance. Although responsiveness of consumers to variations in price is not known, standard economics predicts that people will buy more of a good or service when prices are lower.
- Tax incentives are easy to administer through the tax system.

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3 These states were Alabama, Colorado, the District of Columbia, Idaho, Indiana, Iowa, Kansas, Kentucky, Maine, Maryland, Minnesota, Missouri, Montana, Nebraska, New Mexico, New York, North Carolina, North Dakota, Ohio, Oregon, Utah, Virginia, West Virginia, and Wisconsin.
Private long-term care insurance encourages individuals to take responsibility for financing their own care.

Private long-term care insurance increases the amount of funds available for the long-term care system.

Some advocates of tax incentives argue that, if properly targeted, they can reduce Medicaid expenditures and save state government money.

Tax incentives for private long-term care insurance have substantial support among people in Hawaii. In the Hawaii Long-Term Care Survey, 80 percent of respondents favored tax incentives for purchasing long-term care insurance (Khatutsky et al., 2010). This was the highest level of support of any option assessed. When asked to choose the single option they most favored, 33 percent of respondents chose tax incentives for private long-term care insurance, which made it the most popular option by a small margin.

Disadvantages

The limited empirical evidence suggests that tax incentives will increase the number of people with private long-term care insurance only slightly, although the tax loss will be significant. In one of the first analyses of the impact of tax incentives, using a microsimulation model, Wiener, Illston, and Hanley (1994) found that a 20 percent nonrefundable federal tax credit would only increase the relatively small number of people with private long-term care insurance by about a third compared to the number of people with private long-term care insurance without a tax subsidy 25 years into the future. In a cross-sectional multivariate analysis, Nixon (2006) did not find that offering a state tax incentive was a significant predictor of private long-term care insurance market penetration.

Using a price elasticity of private long-term care insurance of –0.75 to –1.25, Feder, Komisar, and Friedland (2007) calculated that a tax deduction for private long-term care insurance might increase the number of people with private long-term care insurance by 11 to 19 percent. In an unpublished paper, Kim (2010) found that the estimated price elasticity of long-term care insurance demand is –0.08, implying that tax subsidies will have a very small impact on the number of people with insurance.

Similarly, Goda (2010) found that the average state tax subsidy increased private long-term care insurance coverage rates by only 2.7 percentage points, mostly among higher income and asset-rich individuals. Because tax subsidies are unlikely to substantially increase the proportion of people with private long-term care insurance, most of the tax subsidy will go to people who would have bought insurance without the incentive. As a result, the cost per additional person with insurance is likely to be high. Feder, Komisar, and Friedland (2007) calculated that each additional policy purchased would cost $1,308 to $2,125 in lost revenue, a high proportion of the cost of the policies.

The tax loss is not likely to be offset by Medicaid savings. Wiener, Illston, and Hanley (1994) found that the 20 percent tax subsidy in their simulation would not be
offset by Medicaid savings within their 30-year simulation period. Goda’s simulations of state tax subsidies found that a dollar of state tax expenditure produces approximately $0.84 in Medicaid savings, about half of which in Hawaii would result in savings to the federal government. As a result, tax incentives are expenditures as surely as direct spending. The tax loss would need to be offset either with other tax increases or expenditure cuts.

- Tax deductions are regressive, providing more benefits to higher income than lower and moderate income people. Unless refundable, many older people do not qualify for deductions because they pay no federal income taxes because of the exclusion of some or all of their Social Security benefits from taxation.
Public Sector Initiatives

Private sector initiatives can play a bigger role than they do today, but none of the options described above is likely to result in private long-term care insurance or similar initiatives replacing public financing of long-term care without very substantial public subsidies for its purchase. An alternative approach is to rely more heavily on the public sector. For advocates of a greater role for public sector programs, four factors are important:

- Long-term care services are already extensively financed by the public sector. Public sector spending for persons of all ages and types of disabilities (including intellectual and other developmental disabilities) accounted for about two-thirds of all national long-term care spending in 2008 (O’Shaughnessy, 2010). In addition, a large portion of out-of-pocket payments are, in fact, contributions toward the cost of care required of Medicaid beneficiaries in nursing homes and not purchases of services by private payers. A heavy role by the public sector in financing long-term care is typical of all developed countries (Organization for Economic Co-operation and Development, 2006).

- The public sector originated or played an important role in many innovations in long-term care, including consumer-directed home care, cash and counseling programs and policies, money follows the person policies, case management, capitated approaches to integrating acute and long-term care, and third-party funding for residential care facilities such as assisted living. Thus, it is well positioned to lead future innovations.

- The public sector is more likely to be able to address the needs of younger people with disabilities, who accounted for 36 percent of people with long-term care needs in 2000 (Komisar and Rogers, 2003). Medical underwriting for private long-term care insurance products excludes people with existing disabilities and working-age adults are less likely to purchase private long-term care insurance because the risk seems small and far away.

- Tax incentives are expensive and are likely to be regressive or at least not targeted to working- and lower-middle class families who most need the help in purchasing insurance. On the other hand, Medicaid targets a relatively low-income population and Medicare covers virtually all older people regardless of financial status. The relatively low incomes and assets of people with substantial disabilities (Johnson and Wiener, 2006) means that most additional spending, even under most social insurance programs, would be spent primarily on lower- and moderate-income people with disabilities (Wiener, Illston, and Hanley, 1994).

Opponents of expansion of the public sector in long-term care argue the following:

The financial burden of existing public long-term care programs, let alone additional ones, will be significantly greater in the future (U.S. Government Accountability Office, 2005b). Although spending for Medicare post-acute and short-term skilled long-term care and Medicaid long-term care is small in comparison to Social Security and overall Medicare expenditures, all of these programs primarily benefit the older
population and are mainly financed by people in the working population. Additional public spending for long-term care may crowd out expenditures for children, higher education, and health care for the uninsured, among other worthy programs.

- Medicaid already provides a safety net for people who cannot pay the costs of long-term care. People who can pay for their own long-term care should do so.

- Americans have a low tolerance for additional taxation, and will not support higher taxes for long-term care. Higher taxes are already likely to support the existing Social Security and Medicare programs.

*Exhibit 3* summarizes public sector options and their advantages and disadvantages.
### Exhibit 3. Public Sector Financing Options

<table>
<thead>
<tr>
<th>Option</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase funding for Kupuna Care and similar programs</td>
<td>▪ Provides funding for people not eligible for Medicaid, but not high income</td>
<td>▪ Might increase fragmentation of financing system</td>
</tr>
<tr>
<td></td>
<td>▪ Focuses on home and community-based services</td>
<td>▪ Funding for appropriated programs less likely to increase over time than entitlement programs</td>
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<tr>
<td></td>
<td>▪ Has broad support among people in Hawaii</td>
<td>▪ Program not eligible for a federal match, as with Medicaid</td>
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<tr>
<td></td>
<td></td>
<td>▪ Would require additional government spending; additional spending would require additional taxes or expenditure cuts elsewhere</td>
</tr>
<tr>
<td>Liberalize Medicaid financial eligibility</td>
<td>▪ Reduces level of catastrophic out-of-pocket costs that people must incur before receiving government help</td>
<td>▪ Does not prevent people from incurring catastrophic out-of-pocket costs</td>
</tr>
<tr>
<td></td>
<td>▪ Easy to implement because it builds on existing system, which dominates long-term care financing</td>
<td>▪ Increases number of people dependent on public means-tested system</td>
</tr>
<tr>
<td></td>
<td>▪ Targets people in great financial need</td>
<td>▪ Would require additional government spending; additional spending would require additional taxes or expenditure cuts elsewhere</td>
</tr>
<tr>
<td>Help federal government to market the CLASS Act</td>
<td>▪ Provides additional resources for CLASS Act to help make it a success</td>
<td>▪ Hawaii has too few people to make much impact on overall success or failure of CLASS Act</td>
</tr>
<tr>
<td></td>
<td>▪ Relatively low-cost option compared to actually providing services</td>
<td>▪ Private insurers will object to favoring public sector option</td>
</tr>
<tr>
<td></td>
<td>▪ CLASS Act likely to be main focus of expanding long-term care insurance over next several years</td>
<td>▪ Marketing not likely to overcome affordability problems of CLASS Act insurance product</td>
</tr>
<tr>
<td>Provide tax incentives for enrolling in CLASS Act</td>
<td>▪ Reduces the net cost of enrolling in CLASS Act, increasing the number of people with insurance</td>
<td>▪ Unless tax incentive is quite large, unlikely to significantly increase number of people with insurance</td>
</tr>
<tr>
<td></td>
<td>▪ Easy to administer</td>
<td>▪ Lost revenue per additional person with insurance could be large</td>
</tr>
<tr>
<td></td>
<td>▪ CLASS Act likely to be main focus of expanding long-term care insurance over next several years</td>
<td>▪ Would require additional government spending; additional spending would require additional taxes or expenditure cuts elsewhere</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Private insurers object to favoring public plan</td>
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</tbody>
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(continued)
<table>
<thead>
<tr>
<th>Option</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Establish a Hawaii-specific wraparound policy for CLASS Act</td>
<td>▪ Addresses perceived limitations in CLASS Act benefits</td>
<td>▪ Limitations of CLASS Act benefits overstated; CLASS benefits adequate for most people</td>
</tr>
<tr>
<td></td>
<td>▪ Would have lower overhead costs than private sector policies</td>
<td>▪ CLASS Act premiums likely to be too high to enable the creation of supplemental insurance market</td>
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<tr>
<td></td>
<td>▪ Private insurers unlikely to offer competing policies</td>
<td>▪ Premature in that key elements of CLASS Act insurance product unknown at this time</td>
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<td></td>
<td>▪ Has substantial support among people in Hawaii</td>
<td>▪ State of Hawaii would have to bear financial risk</td>
</tr>
<tr>
<td>Mandatory public long-term care insurance, similar to CarePlus</td>
<td>▪ Would provide additional revenue for long-term care</td>
<td>▪ Because of the difficulty in establishing premiums for long-term care insurance, the state of Hawaii would be exposed to substantial financial risk</td>
</tr>
<tr>
<td></td>
<td>▪ Premiums would be low and more affordable than pure private insurance or CLASS because all working people would contribute</td>
<td>▪ Mandatory premiums are taxes, which are opposed by most people in Hawaii</td>
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<tr>
<td></td>
<td>▪ With no medical underwriting, this option would provide coverage for people who are already disabled</td>
<td>▪ Largely duplicates the existing private long-term care insurance market</td>
</tr>
<tr>
<td></td>
<td>▪ Would provide near universal coverage</td>
<td>▪ Benefit is too low to pay for nursing home care</td>
</tr>
<tr>
<td></td>
<td>▪ Would reduce the number of people who depend on Medicaid to pay for their long-term care</td>
<td>▪ Benefit is too short (1-year lifetime maximum) to cover risks of long-term care for substantial number of people</td>
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<tr>
<td></td>
<td>▪ Because benefit is limited, leaves substantial role for private insurance</td>
<td>▪ Unrestricted cash benefit might be abused</td>
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<td></td>
<td>▪ Flexible benefit would expand home and community-based services, reducing institutional bias</td>
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</tr>
<tr>
<td></td>
<td>▪ Because the insurance is mandatory, administrative costs would be lower than private insurance (fewer marketing costs or profit)</td>
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</table>
**Public Sector Option #1: Increase Funding for State-financed Long-Term Care Programs, Such as Kupuna Care**

In this option, spending levels would be increased for Kupuna Care and other state-financed long-term care programs.

**Background**

Apart from Medicaid, the federal government funds long-term care through a number of appropriated programs, including the Older Americans Act, the Social Services Block Grant, and the Department of Veterans Affairs. The Older Americans Act programs are generally offered without a means test, while services funded through the Social Services Block Grant and the Department of Veterans Affairs are typically subject to limitations on income and assets.

Similarly, Hawaii funds operates some state-only funded long-term care programs, of which Kupuna Care is the most important. Kupuna Care is an entirely state-financed program designed to meet the needs of frail older adults who cannot live at home without adequate help from family or formal services. The program was developed by the Executive Office on Aging in partnership with the Area Agencies on Aging to address the growing number of older persons with long-term care needs who are not eligible for Medicaid. The Area Agencies on Aging administer the program.

Kupuna Care provides the following:

- personal care
- adult day care
- assisted transportation
- attendant care (volunteer companion)
- case management
- chore services
- home delivered meals
- homemaker-housekeeper

The four services that account for the bulk of Kupuna Care spending are personal care (28%), home-delivered meals (22%), case management (20%), and transportation (15%) (Executive Office on Aging, 2008).

The program has no financial eligibility criteria and services are free to clients, although consumers are asked to make voluntary donations to the service provider. Nonetheless, the program is focused on lower-income individuals. Donations are used to provide services to additional clients.
To be eligible for Kupuna Care, individuals must be

- 60 years or older;
- not eligible for services from another public program, such as Medicaid, or already receiving private pay services;
- living in an apartment or house (not an institution, residential care facility, or foster home); and
- impaired in two or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs) or have significantly reduced mental capacity, and have one or more unmet ADL or IADL need.

Clients receiving a single service are assessed by the service provider. Clients receiving more than one service are assessed by case managers. In State Fiscal Year 2009, Kupuna Care expenditures were $4.7 million (Hawaii Executive Office on Aging, 2008).

**Advantages**

- Because programs are funded through direct appropriations, they would be subject to direct fiscal control, unlike Medicaid, which is an entitlement program.
- The program provides funding for services to populations who are not eligible for Medicaid, but cannot afford services or insurance on their own. If targeted to people at high risk of institutionalization, the marginal public cost might be reduced because nursing home use may be lessened.
- The focus on home and community-based services would help to address the institutional bias of the current financing system.
- Because the programs are entirely state funded, they are free of federal rules and regulations. Thus, they can be designed to more fully meet the needs of individual consumers and the traditions of Hawaii.
- In the Hawaii Long-Term Care Survey, 61.4 percent of respondents favored increasing funding for state programs, such as Kupuna Care (Khatutsky et al., 2010).

**Disadvantages**

- Because the program is not an entitlement, expenditures do not automatically increase as the population in need increases. Funding for appropriated programs tend not to increase with need and inflation over time. Thus, initial gains could be eroded over time.
- Because no federal matching is available, the state would incur 100 percent of the cost.
- Because these programs only fund home and community-based services, they do not help people finance nursing home services.
- Expanding the role of these programs could increase the fragmentation of the financing and delivery system because they are separate from other, larger sources of financing.
- In the Hawaii Long-Term Care Survey, when asked to choose their single preferred option, only 11.7 percent of respondents chose expanding state programs, such as Kupuna Care.

- Without new sources of revenue, expansion of state long-term care programs may squeeze funding for other state priorities. In the Hawaii Long-Term Care Survey, 57.8 percent of respondents said they opposed raising taxes to pay for expanding access to long-term care services.
Public Sector Option #2. Liberalize the Financial Eligibility Criteria for the Medicaid Program to Allow More Working- and Lower Middle Class People to Participate

In this option, Medicaid financial eligibility standards would be raised to allow people with higher income and assets to become eligible for Medicaid.

Background

An incremental approach to long-term care reform would be to liberalize financial eligibility for the Medicaid program by raising the level of protected assets and increasing the amount of income that nursing home and community-based beneficiaries can retain. For example, currently, $2,000 is the maximum amount of financial assets that single Medicaid beneficiaries may retain in Hawaii (Walker and Accius, 2010). An expansion of Medicaid eligibility could be implemented through Section 1902(r)(2) of the Social Security Act, which allows states to “disregard” certain income and assets in determining Medicaid eligibility. Exhibit 4 presents some examples of provisions that can reduce countable income or resources for determining Medicaid eligibility, thus increasing the maximum level of income and assets that beneficiaries could retain. In addition, Hawaii’s “personal needs allowance” for nursing home residents is $50 per month, which is below the level in 12 other states and the District of Columbia.

Exhibit 4. Examples of Provisions That Can Reduce Countable Income or Resources for Determining Medicaid Eligibility

- Allow more than the standard SSI income disregard of $20.
- Disregard higher amounts of work earnings.
- Disregard all or part of certain types of resources that are limited under SSI; for example, income-producing property essential to self-support, burial funds, and the cash value of life insurance.

Advantages

- Raising Medicaid financial eligibility standards reduces the level of catastrophic out-of-pocket costs that people incur paying for long-term care services.
- Raising Medicaid financial eligibility standards is easy to implement and builds on the existing system. Implementation of this provision merely requires establishing new levels of protected assets.
- Raising Medicaid financial eligibility standards targets people in great financial need. The main beneficiaries would be people with somewhat more income and assets than current Medicaid beneficiaries, but not people who are wealthy.

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4 Minnesota and North Dakota have a resource limit of $3,000 (Walker and Accius, 2010).
5 Alaska, Arizona, Connecticut, the District of Columbia, Indiana, Kansas, Maryland, Massachusetts, Minnesota, New Hampshire, New Mexico, South Dakota, and Texas have higher personal needs allowances, ranging from $52 to $101 per month (Walker and Accius, 2010).
In the Hawaii Long-Term Care Survey, 71.5 percent of respondents supported changing Medicaid so that more middle class people would be eligible for government help in paying for long-term care services. When respondents were asked to choose the option that they most supported, 31.4 percent of respondents chose this option, virtually tying with providing incentives for private long-term care insurance.

**Disadvantages**

- Although this strategy would allow those with modestly higher income and assets to become eligible for Medicaid, it would not prevent people from incurring catastrophic out-of-pocket costs for long-term care.
- Liberalizing Medicaid financial eligibility rules would require additional state funding. Higher Medicaid spending may squeeze other state priorities. In the Hawaii Long-Term Care Survey, 57.8 percent of respondents said they opposed raising taxes to pay for expanding access to long-term care services.
- Liberalizing Medicaid financial eligibility rules would increase rather than decrease the number of people dependent on a welfare program, Medicaid.
Public Sector Option #3: Help the Federal Government Market the CLASS Act Insurance Program

This option would support the marketing of the federal CLASS Act insurance product by funding advertising and education that would educate the public about long-term care and encourage enrollment in the CLASS Act insurance program. This option could be broadened to include promoting private long-term care insurance as well.

Background

The Affordable Care Act of 2010 establishes a new voluntary public, long-term care insurance program. Although the legislation gives the Secretary of the U.S. Department of Health and Human Services considerable discretion in designing and implementing the program, Exhibit 5 summarizes the main elements of the CLASS Act insurance program outlined in the legislation. Only working people are eligible to enroll. Unlike most individually purchased private long-term care insurance policies, the CLASS insurance program does not require medical underwriting. Thus, people with disabilities who work will be able to enroll. In addition, benefits are provided on a lifetime basis rather than for a fixed number of years or expenditure level. This feature of the CLASS insurance program will be especially attractive to younger persons with disabilities, who could receive benefits for decades. After paying premiums for at least 5 years, enrollees who meet the disability benefit criteria will receive regular cash payments to help meet their long-term care needs. Average benefit payments must be at least $50 per day. Insurance benefits are entirely financed by premiums paid by the insured; there is no general revenue contribution to benefits.

Exhibit 5. Main Characteristics of the CLASS Act Insurance Program, Section VIII of the Patient Protection and Affordable Care Act (P.L. 111-148)

The CLASS insurance program is designed to provide insurance benefits for people with disabilities who need long-term care.

- The CLASS insurance program is a government plan. It is a “public option” for long-term care.
- Enrollment is voluntary. However, for people who work for participating employers, everyone is automatically enrolled unless they choose not to participate.
- There is no medical underwriting, but there is a 5-year waiting period before individuals can receive benefits.
- Enrollment is limited to people who are employed. Children, retirees, and people who are not working are not eligible (including spouses).
- To receive benefits, individuals must have fairly severe disabilities.
- Benefits will vary by level of disability as determined by the Secretary of the Department of Health and Human Services, but average benefit payments will be at least $50 per day.
- Insurance premiums are the sole source of financing. Deep premium subsidies for full-time students and people with incomes below the federal poverty level will be financed by premium payments by other policyholders.
- No more than 3 percent of premiums may be used for administrative costs. Additional administrative expenditures may be financed from other appropriated government funds.
Unlike public long-term care insurance programs in Japan, Germany, and the Netherlands and Medicare Part A, the CLASS insurance program does not require that everyone enroll. Thus, the program is potentially subject to adverse selection that could drive up the cost of premiums and potentially create an insurance death spiral. In other words, without medical underwriting to exclude them, people with disabilities who need long-term care may disproportionately enroll in the program. To the extent that people with disabilities disproportionately enroll, the program’s ability to spread the costs of people using benefits across a broad population will be limited and premiums will be high. High premiums may reduce the number of nondisabled people who enroll or cause them to disenroll. Thus, a high level of enrollment by people without long-term care needs is critical to establishing premiums affordable to a large percentage of the working population. A vigorous marketing campaign is likely to be necessary to achieve a high level of enrollment.

This marketing initiative could build on the Long-Term Care Campaign, a federally funded project started in January 2005, to increase consumer long-term care awareness and planning. The Campaign’s core activities are state-based direct mail campaigns supported by each participating state’s governor and public service announcements targeted to households with members between the ages of 45 and 70. Campaign materials include a Long-Term Care Planning Kit. As of January 2010, 25 states have participated in the Long-Term Care Campaign. (Further information is available at http://www.longtermcare.gov/LTC/Main_Site/Planning_LTC/Campaign/index.aspx/.)

Advantages
- Low enrollment is one of the biggest risks to the success of the CLASS Act insurance program. By providing additional marketing, Hawaii would help ensure the success of the overall program. Federal funds for marketing may be limited as a result of resistance by opponents of health reform in the new Congress. Thus, outside funds will probably be necessary to ensure the success of the program.
- Funding advertising is relatively low cost compared to increasing funding for existing long-term care programs or starting a new program. After the initial rollout, funding levels could be reduced.

Disadvantages
- Hawaii has too few people to make a major contribution to either the success or the failure of the overall CLASS Act enrollment campaign. Although it has not been decided, it is likely that premiums will be set nationally and will not vary by state. Thus, a high enrollment in Hawaii will not materially affect future premiums.
- Unless they are included, private insurers will object to the promotion of the CLASS Act insurance product, which competes with their products.
- Marketing is unlikely to be able to overcome the high cost of the CLASS Act insurance product or private long-term care insurance. As a result, enrollment is likely to remain low.
Public Sector Option #4: Provide Hawaii Income Tax Incentives for Purchase of CLASS Act Insurance Product

Under this option, people who enroll in the CLASS program would be entitled to a Hawaii income tax deduction or credit, which would increase affordability. The amount of the deduction or credit could be tailored to the amount of funds available.

Background

A key barrier to expanding private long-care insurance and to a high rate of enrollment in the CLASS program are the high premium costs, which limit the number of people who can afford to enroll (Wiener, Illston, and Hanley, 1994). Although they have not yet been set, premiums for the CLASS Act insurance product are expected to be expensive. Premium estimates developed during the health reform debate assumed low levels of enrollment, resulting in average premiums ranging from $123 to $240 per month (American Academy of Actuaries, 2009; Foster, 2009; U.S. Congressional Budget Office, 2010). Premiums will vary by age and these premiums assume a fairly high average age of enrollment. In calculating these premiums, actuaries and other cost estimators note that voluntary enrollment in private long-term care insurance policies in employment settings is usually low, with generally only about 5 to 7 percent of workers enrolling.

Aside from the general substantial cost of long-term care, these premiums are expected to be high for several reasons. First, unlike public long-term care insurance programs in other countries where premiums rise with income, financing is expected to be regressive with everyone except for low-income working people and students paying the same premiums. Moreover, there is no tax subsidy for low- and moderate-income people to moderate the cost. Instead, all financing for the program must come from the premium.

Second, to encourage enrollment of full-time students and people with incomes below the federal poverty level who work, premiums for these groups will initially be only $5 per month, far below the expected premiums for unsubsidized groups. These premium subsidies, however, are financed by other insurance enrollees, not by federal general tax revenues, which may substantially raise the premium for people who are not low income or students. The SCAN Foundation/Avalere Health premium simulator estimates that average premiums for a voluntary long-term care insurance program with a low-income subsidy to be about 50 percent higher than the premiums would be without a low-income subsidy (SCAN Foundation/Avalere Health, 2010).

Third, because the program is voluntary, the CLASS Act is subject to adverse selection, which raises premiums. The SCAN Foundation/Avalere Health premium simulator estimates average premiums for a voluntary long-term care insurance program with some features similar to the CLASS Act to be three times what they would be for a mandatory program.
Advantages

- Providing a tax incentive could decrease the net cost of enrolling in the CLASS insurance product and increase the number of people who could afford coverage. However, to substantially increase affordability, the tax benefit would need to be large.
- A tax incentive would be relatively easy to administer because it could be added to the existing Hawaii income tax system.
- This option could be combined with the initiative to help the federal government market the CLASS Act.

Disadvantages

- Depending on how the tax incentive is structured, the tax loss could be large, which would require new taxes to compensate for the lost revenue. In the Hawaii Long-Term Care Survey, 57.8 percent of respondents said they opposed raising taxes to pay for increased access to long-term care services.
- Most tax incentives are regressive (Wiener, 2000); that is, they provide more tax benefits to upper-income people than to lower-income people. Deductions usually are more regressive than tax credits, but even these can be regressive unless they are refundable because many lower-income people do not pay any income taxes.
- Unless the tax incentive is quite large, it is unlikely to substantially change the affordability of the CLASS Act insurance premium.
- Many tax incentives subsidize people to do what they would have done without the tax incentive. As a result, the incremental cost per additional person with the CLASS Act insurance may be high.
- Proponents of private long-term care insurance oppose the creation of a new public long-term care insurance program and do not favor anything that would increase its market share. Furthermore, they argue that private long-term care insurance should receive a similar tax incentive subsidy, which would increase the cost.
**Public Sector Option #5: Develop, Market, and Manage a Hawaii-specific Wraparound Product to the CLASS Act Insurance Plan**

In this option, the state of Hawaii would develop, market, and manage a Hawaii-specific public long-term care insurance product that would supplement the CLASS Act insurance plan. The plan could have many different designs, including higher benefit levels or specific coverage for higher cost nursing home care. The insurance policy could provide lifetime coverage or coverage for a shorter period of time. The policy could also be limited to a less expansive set of beneficiaries.

**Background**

The legislation enacting the CLASS Act outlines some broad insurance coverage parameters, but it leaves a great deal to the discretion of the Secretary of the Department of Health and Human Services. Persons eligible to receive benefits are persons needing help with two or more ADLs, substantial cognitive impairment, or an equivalent level of disability (which is meant to include some persons with intellectual disabilities/developmental disabilities and severe mental illness). The legislation specifies that the benefits will (1) be a cash payment, with the average value of not less than $50 per day; (2) consist of between two and six benefit levels, which will vary by disability level; (3) be provided on a lifetime basis; and (4) increase with inflation over time. Thus, hypothetically, people with deficits in two ADLs could receive a benefit of $30 a day, while people with deficits in four ADLs could receive an average benefit of $70 a day, so long as the average of all payments was estimated to be $50 a day.

Some observers have criticized the benefit and eligibility structure. First, the benefit amount will not be enough to cover the costs of nursing home care, especially in a state like Hawaii, which has higher costs than the national average. The law does not preclude that the benefit levels vary by geographic area, but it does not require that they do so. Second, some critics argue that the benefit level is not adequate for home and community-based services, covering only about 2 hours a day of home health aide service on average. Third, some observers note that private long-term care insurance policies do not generally provide benefits to people with intellectual disabilities or severe mental illness and that doing so will greatly increase premiums if individuals with these disabilities enroll in large numbers.

**Advantages**

- A public supplemental policy that fills in the gaps on the CLASS Act insurance product might be attractive to people who enroll in the CLASS program.
- A public long-term care insurance policy might have lower overhead costs than private long-term care insurance. However, if the policy is not mandatory, substantial marketing costs will have to be incurred to sell the wraparound policy.
- Although it is not known for sure at this time, it seems unlikely that private long-term care insurance companies will offer supplemental policies. The current conventional wisdom is that private insurers will market against the CLASS program and not work with the government to create wraparound policies.
Insurance policies that take a similar approach, such as Medicare supplemental insurance policies, have been very successful. The vast majority of Medicare beneficiaries have some type of supplemental insurance.

A supplemental public insurance policy would build on the public insurance approach passed by the Hawaii legislature a decade ago.

A supplemental public insurance policy would bring additional revenue into the long-term care financing system on a voluntary basis.

A supplemental policy has substantial support among residents of Hawaii. In the Hawaii Long-Term Care Survey, 56.6 percent of respondents supported a public long-term care insurance program sponsored by the state of Hawaii that would offer benefits additional to the CLASS Act federal insurance program.

Disadvantages

- The limitations of the CLASS benefit structure may be overstated. Although the average $50 per day benefit payment level has been criticized as inadequate, it is paid every day that the individual qualifies for benefits, regardless of whether the individual uses services on that day. Many people receiving paid home care do not receive it every day. Moreover, $50 a day ($18,250 a year) is about twice what Medicaid spends per year on participants in home and community-based services waiver programs for people aged 65 and older and nonelderly persons with physical disabilities (Ng, Harrington, and O’Malley, 2009).

- The premiums for the CLASS Act have not yet been determined, but the premiums estimated during the debate over health reform were quite high. As a result, enrollment may be low. In the Hawaii Long-Term Care Survey, while about a fifth of working respondents said that they wanted to enroll in the CLASS insurance plan, only about 3 percent of working respondents said that they were willing to pay the level of premiums previously estimated for the CLASS Act. Thus, the market for long-term care insurance policies in addition to the CLASS Act insurance product may be extremely small.

- Although certain aspects of the CLASS Act insurance plan are set by the legislation, many features are not. Preliminary and unverified information on the CLASS Act development process suggests that the U.S. Department of Health and Human Services is considering several innovative approaches to structuring the insurance product. No information is available about what those approaches are. Thus, designing a wraparound product may be premature for the next few years.

- Depending on how it is designed, a public long-term care insurance plan could require the state of Hawaii to bear substantial financial risk if premiums are too low to pay benefits.
**Public Sector Option #6: Establish a Mandatory Public Long-Term Care Insurance Program in Hawaii, Such As That Envisioned in CarePlus**

This option would establish a mandatory public long-term care insurance program in Hawaii financed by premiums. The program would provide a basic level of coverage to which private insurers could offer supplemental coverage. It would be modeled on the insurance plan passed by the legislature in 2003 but vetoed by Governor Linda Lingle.

**Background**

The 2003 CarePlus Financing Program (HB 1616 and SB 1088) had the following features:

- Everyone age 25 or over with income above a minimum threshold would have to pay a $10 monthly premium for the CarePlus public long-term care insurance program. This requirement would include retirees and homemakers. Payment of the premium through payroll deduction would be available; self-employed persons would contribute on their own. The premium would increase with the Consumer Price Index. Administrative costs would be kept low by having the tax department collect the premium and having the same premium for everyone.

- Individuals would have to pay premiums for 10 years before they could receive full benefits, although a partial benefit would be available earlier. The benefit would be portable if the insured moves away from Hawaii.

- Eligibility to receive benefits would be limited to people who need assistance with two or more ADLs or who have substantial cognitive impairment.

- The benefit would be $70 per day which could be used for any purpose. Benefits would be available for a total of 365 days, which need not be consecutive. The benefit amount would increase annually with the Consumer Price Index.

- An independent Board of Trustees would be appointed by the governor, which would be responsible for the administration of the program and the management of the trust fund.

**Advantages**

- This approach would raise additional revenue for long-term care in a way that spreads the risk over the entire population. Because the vast majority of workers will participate and benefit, the premium will be low enough to be affordable to the vast majority of workers in Hawaii.

- Because this option does not require medical underwriting, it would allow people with disabilities to obtain insurance coverage.

- This option would provide basic long-term care insurance to the vast majority of people in Hawaii. It would provide benefits to people with a wide range of income and assets.

- By providing an additional source of financing for long-term care, the program would reduce the number of people dependent on Medicaid.
The broad flexibility in the use of benefits would encourage the expansion of home and community-based services.

Because the program provides only a limited benefit, it leaves a significant role for private insurance.

Because the program is mandatory and public, administrative costs will be lower and no profit is needed. Thus, a higher percentage of the premium would be spent on benefits than is spent under private long-term care insurance.

Disadvantages

- Given the difficulty in predicting future long-term care use and expenditures, this public insurance option would represent a substantial financial risk for the state of Hawaii. If premiums are set too low, there will be substantial pressure on state government to pay benefits through increased taxes.

- The premium may be viewed as an additional tax by many people. In the Hawaii Long-Term Care Survey, 57.8 percent of respondents said they opposed raising taxes to pay for improved long-term care services (Khatutsky et al., 2010).

- This new program duplicates the existing long-term care insurance market.

- The limited benefit leaves substantial numbers of people who need long-term care for more than 1 year with no coverage. This will be a particular problem for younger people with disabilities who will live for a long time.

- The $70 benefit is too low to pay for nursing home care in Hawaii. The cost of private pay nursing home care in Hawaii is more than $200 per day (MetLife Mature Market Institute, 2010).

- The unrestricted granting of $70 per day might be abused in some instances by people who do not use the money for long-term care services.
Options for Long-Term Care Delivery System Reform

Long-term care is supplied by many different providers, including nursing homes, home health agencies, home care agencies, homemaker agencies, personal assistants, adult day health programs, assisted living facilities, and many more. Three of the main critiques of the long-term care delivery system are that (1) the system is biased toward institutional care, (2) home and community-based service providers sometimes ignore consumer preferences, and (3) the needs of informal caregivers are not met.

Balance the Long-Term Care System

Probably the most common critique of the long-term care delivery system is its institutional bias. Despite the fact that the overwhelming majority of people with disabilities are at home and want to stay there (AARP, 2003), spending for long-term care for older people is overwhelmingly for nursing home rather than home care. Over the last 10 years, states, in part encouraged by the federal government, have expanded home and community-based services.

Despite improvement in the balance of expenditures, long-term care financing in the majority of states remains heavily tilted toward institutional services, especially nursing home care, although it is becoming less so (Wiener and Anderson, 2009). Although Medicaid home and community-based services for older people and younger persons with physical disabilities have been increasing, only 34 percent of national Medicaid long-term care expenditures for this population were for noninstitutional services in 2009 (Eiken et al., 2010). To achieve their goal of increasing home and community-based services, states have relied largely on Medicaid home and community-based services waivers, which give states much greater fiscal control and allow coverage of a much broader range of services than is possible under the standard Medicaid program. However, waivers require states to limit services to a relatively severely disabled population, i.e., those who meet Medicaid requirements for an institutional level of care.

Consumer Empowerment

Over the last 10 years, states have used the flexibility of Medicaid home and community-based services waivers to experiment with a variety of new service delivery models. A new paradigm of home and community-based services has taken hold drawing heavily on the long-term care systems in Oregon, Washington, and Wisconsin, among others (Wiener et al., 2009). This new paradigm emphasizes consumer choice and empowerment and is embodied in federal and state initiatives to give program participants greater choice of and control over their services, including participant-directed programs, some with individual budgets; nursing facility transition/money-follows-the-person initiatives; and providing services in residential care facilities, including assisted living facilities.

Traditional public home care programs rely on public or private agencies to hire and manage home care workers, schedule and direct services, monitor quality of care, discipline and dismiss workers if necessary, and pay workers and applicable payroll taxes. In the agency-directed model, clients can express preferences for services or workers, but have no formal control over them. This approach to care is based on the assumption that professional expertise
and accountability are critical to the provision of good quality care at reasonable cost. At its extreme, a “medical model” is imposed and individuals with disabilities are considered to be “sick,” as opposed to needing compensatory services, such as help with bathing.

Programs that allow participants to direct their services represent the opposite end of the management continuum from agency-directed services. These programs give participants control over who provides services, when they are provided, and how these services are delivered. Typically, participant-directed programs allow the consumer to hire, train, supervise, and dismiss the home care worker. In some programs, participants have flexible individual budgets with which they purchase the goods and services they need.

Residential care facilities, such as assisted living facilities and smaller board and care or personal care homes, are an important and growing component of the long-term care service system. State interest in funding services in residential care settings through Medicaid, through both home and community-based services waivers and the Medicaid personal care benefit, is fueled by a desire to offer a full array of home and community services, reduce nursing home utilization, and achieve the economies of scale of nursing home care without the undesirable institutional characteristics. A recent study estimated that in 2009 there were 39,635 residential care facilities (with at least four beds) nationally serving older people and younger persons with disabilities; these facilities had an estimated 1,073,043 beds (Wiener et al., 2010). In contrast, during that same year, there were 15,691 nursing facilities certified for participation in Medicare or Medicaid with 1,708,784 beds (American Health Care Association, 2009).

**Informal Caregivers**

Family caregivers are the main source of long-term care in the United States and virtually all other countries (Nixon, 2008; Wiener, 2003). It is commonly estimated that family caregivers provide 80 percent of the care of disabled older persons in the United States (Curry, Walker, and Hogstel, 2006). Nationally, in 2004, about 90 percent of older people with disabilities received care from family members (Houser, Gibson, and Redfoot, 2010). Nationally, the economic value of this caregiving was valued at $350 billion in 2006 (Gibson and Houser, 2007), which dwarfs spending for nursing homes and home care. In the Hawaii Long-Term Care Survey, about 5 percent of respondents reported that they provided care for a younger family member with disabilities and about 8 percent of respondents reported that they provided care to an older family member (Khatutsky et al., 2010).

Caregiving can impose substantial burdens on family members, including financial expenses for medical and long-term care services not covered by insurance, reduced hours of work and opportunities for advancement, reduced retirement savings and Social Security income, limitations on the ability to pursue one’s own goals, depression, and health and psychological strain (Nixon, 2008). On average, Hawaii caregivers report spending 22.0 hours per week caring for their parents—more than a half-time job—and spending $11,656 per year on various expenses. Several trends in society, including high levels of labor force participation by women (who have been the traditional caregivers), high divorce and lower marriage rates, reduced number of children per family, and family mobility are all potential threats to the provision of informal care.
Although informal caregivers provide the overwhelming majority of long-term care to people with disabilities, they receive little financial or government program support. Public programs focus on services to the eligible participant, and generally do not address the needs of family caregivers. The U.S. Administration on Aging’s National Family Caregiver Support Program is a relatively rare exception, but was funded at only $154 million in Fiscal Year 2010 (U.S. Administration on Aging, 2010). In addition, the U.S. Administration on Aging’s Alzheimer’s Disease Supportive Services Program (previously known as the Alzheimer’s Disease Demonstration Grants to States program) focuses on demonstrating innovative programs for caregivers of people with dementia; it is funded at $11 million per year. Limited federal and state tax deductions are available for informal caregivers, but they are very restricted in terms of who can qualify and how large a benefit is provided.
Delivery System Reform Options

*Exhibit 6* summarizes the delivery system reform options and their advantages and disadvantages.

### Exhibit 6. Delivery System Options

<table>
<thead>
<tr>
<th>Option</th>
<th>Advantages</th>
<th>Disadvantages</th>
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| Cover the optional personal care benefit under Medicaid | - Would help to reduce institutional bias  
- Builds on current system of home and community-based services waivers  
- Expands the range of people eligible for Medicaid personal care by including people who do not need nursing home level–care | - Would increase Medicaid spending and thus require a tax increase of reductions in other areas of the State budget  
- Because the personal care option is an entitlement in Medicaid, expenditures might be hard to control  
- Provides only one of many benefits needed by people with disabilities  
- Under QUEST Expanded Access, many people who receive chore services receive personal care from family providers (although they are not paid to do so) |
| Increase the supply of nursing home beds          | - Would increase supply of long-term care services in Hawaii  
- Could reduce number of Medicaid and uninsured people in hospitals waiting for placement  
- Would increase Medicaid expenditures for nursing home care | - Would increase institutional bias  
- Would increase Medicaid expenditures  
- May not reduce hospital backlog, which may be better addressed through changing Medicaid reimbursement |
| Provide tax incentives for informal caregivers    | - Would provide social recognition for efforts by caregivers  
- Would reduce economic strain on caregivers  
- Hawaii Long-Term Care Survey suggests strong support among the population | - Unlikely to change behavior of caregivers to provide more informal care or to provide care for longer periods of time  
- Unless tax incentive is very large, not likely to make major difference to caregiver finances  
- Tax loss could be substantial, requiring offsetting tax increases or cuts in other government programs |
| Reform regulation of domiciliary care facilities  | - Would rationalize fragmented regulation of diverse facilities, improve quality, and make regulation more effective | - Reorganization and more regulation could be time consuming and does not guarantee improved quality |
Delivery System Option #1: Cover the Optional Personal Care Benefit Under Medicaid

In this option, the Hawaii Medicaid program would cover personal care services as an optional benefit part of the regular Medicaid program, not just through Medicaid home and community-based services waivers. As a result, disabled Medicaid beneficiaries needing personal care services who do not need a nursing home level of care would be eligible for those services.

Background

Personal care services include help with the activities of daily living, such as eating, bathing, dressing, transferring, and going to the toilet. Medicaid programs can cover personal care through three different mechanisms. Most states use at least two of these mechanisms. First, states can cover personal care as one of many optional benefits allowed by the federal statute. Indeed, in 2009, 34 states and the District of Columbia covered personal care services as an optional benefit as part of their regular Medicaid program (Eiken et al., 2010). As a regular optional benefit, services must be available to all Medicaid beneficiaries who qualify for the benefit; it is an open-ended entitlement. Using this option, states cover personal care services for people who are disabled, but who do not necessarily need a nursing home level of care. Beneficiaries qualifying for services using this approach must qualify for Medicaid using standard financial eligibility requirements. Prior to QUEST Expanded Access, Hawaii’s Medicaid program did not cover personal care as an optional benefit.

Second, all states cover personal care through their Medicaid home and community-based services waivers. Beneficiaries qualifying for participation in Medicaid home and community-based services waivers must need institutional-level care (i.e., hospital, nursing home, or intermediate care facilities for the intellectually disabled). For the older population, people who do not need nursing home level of care are not eligible for waiver services. Under home and community-based services waivers, states may provide services to people with more income and assets than is typically allowed; people may qualify for Medicaid if they need nursing home–level care if they have up to 300 percent of the federal Supplemental Security Income level. Under the Medicaid home and community-based services waivers, states may also cover a wide range of social and support services not typically allowed to be covered in the Medicaid program, such as homemaker and chore services. Prior to QUEST Expanded Access, Hawaii’s Medicaid program covered personal care services through its Medicaid home and community-based services waivers.

Third, the federal Medicaid statute allows states to apply for research and demonstration waivers (known Section 1115 waivers after the section of the Social Security Act that authorizes the demonstrations) to test new approaches to financing and delivery. QUEST Expanded Access is operating under a Section 1115 waiver. Under this research and demonstration waiver, Medicaid is covering personal care services for people who need an institutional level of care. The Centers for Medicare & Medicaid Services also allowed Medicaid to cover chore services for up to 1,600 persons. Hawaii recently reached the cap on the allowable number of people receiving chore services and created a waiting list. Thus, the state was allowed to fold state-funded chore services for Medicaid beneficiaries into the Medicaid program, receive a federal match, and increase the number of Medicaid beneficiaries receiving chore services at no
additional cost to the state. People who are not Medicaid eligible continue to receive chore services through the state-funded program. Chore workers are not allowed to provide personal care as part of their official duties, but it is believed that many family members who are paid to provide chore services provide personal care as part of their unofficial functions.

Advantages

- This option would help to meet the unmet need for personal care services among people who are disabled but do not need a nursing home level of care. Most states use this approach to covering personal care.
- Covering personal care through the regular Medicaid program would help to reduce the institutional bias of the long-term care delivery system.
- Because personal care is already being provided as part of the Medicaid home and community-based services waivers, implementation of this provision would be fairly easy. It would merely require offering the benefits to a larger number of individuals with a broader range of need.
- Although optional services under Medicaid are open-ended entitlements, the experience of other states suggests that expenditures need not increase dramatically.

Disadvantages

- Covering personal care as a Medicaid-covered service would likely increase Medicaid spending. Without additional revenue, this might squeeze other state priorities.
- Changing coverage would require negotiations with the Centers for Medicare & Medicaid Services to change the research and demonstration waiver.
- Because a large proportion of people with disabilities do not receive paid home care services, expenditure levels might increase substantially and be hard to control.
- Personal care is only one of many services that people with disabilities need. The personal care option is a fairly narrow service compared to the array of services available through the Medicaid home and community-based services waiver.
- Some people receiving Medicaid chore services who do not need a nursing home level of care are receiving personal care informally from family members.
- Given limited resources, the state should focus any additional spending on a more disabled population.
Delivery System Option #2: Increase the Supply of Nursing Home Beds

In this option, the state would work to increase the supply of nursing home beds.

Background

Compared to the rest of the country, Hawaii has an exceptionally low supply of nursing home beds per 1,000 population aged 75 and over. In 2009, Hawaii had 43.4 nursing home beds per 1,000 persons aged 75 and older, compared to the national average of 88.9 nursing home beds per 1,000 persons aged 75 and older (American Health Care Association, 2010; U.S. Census Bureau, 2010). Between 1997 and 2009, the nursing bed/population ratio declined, both nationally and in Hawaii. It is not known why the nursing home bed ratio is so much lower in Hawaii than in the nation as a whole. Possible explanations include that the high level of three-generation households in the state combined with a strong tradition of informal caregiving has resulted in lower demand for nursing home care. Another explanation is that the high cost of real estate and construction constrains the number of nursing home beds.

The relatively low supply of nursing home beds in Hawaii has several consequences. First, the state’s nursing facility occupancy rate is very high—92.8 percent in 2010 compared to the national average of 83.6 percent (American Health Care Association, 2010). Second, because of high occupancy rates, some stakeholders contend that some individuals with a high level of impairment and extensive nursing needs cannot be discharged from acute care hospitals because no nursing home will take them. Third, with so few beds, nursing homes tend to serve a more severely disabled population than the national average. The average nursing home ADL Index—a measure of the need for assistance with ADLs—is 4.52 for Hawaii compared to the national average of 4.02; Hawaii’s index is the highest of any state.

Advantages

- Increasing the nursing home bed supply could increase access to institutional care by older disabled people in Hawaii.
- Increasing the nursing home bed supply might reduce hospital backlog.

Disadvantages

- Hawaii already has one of the highest percentages among states of Medicaid long-term care spending for nursing home care. Increasing the supply of nursing homes would exacerbate Hawaii’s institutional bias.
- The problem of hospital backlogs by people waiting for nursing home placement can be addressed more efficiently by increasing the Medicaid reimbursement for high-need nursing home residents.
- Increasing the bed supply is likely to increase Medicaid expenditures for nursing home care, squeezing funds for other long-term care services and improvements.
Delivery System Option #3: Provide Income Tax Incentives for Family Caregivers

In this option, people who provide a substantial amount of personal care or supervision to disabled relatives would receive a tax credit or could deduct expenses related to care of the relative from their income when calculating their Hawaii income tax.

Background

Some policymakers are concerned about the burdens on family caregivers, the economic consequences of their caregiving, and the potential impact on Medicaid and other public programs should they stop or reduce providing care. Older people with disabilities who receive informal care are less likely to use nursing homes (Lo Sasso and Johnson, 2002).

To encourage people to continue to provide informal care and to compensate them for some of their expenses and burdens, a number of states provide limited caregiver tax incentives. As of 2006, 24 states and the District of Columbia provided some type of dependent care tax credit or caregiver tax credit or deduction (Alzheimer’s Association, 2006).

Nixon (2008) analyzed the Hawaii caregiver tax credit proposed in S.B. No. 1199, S.D. 2 (2007). This incentive provided a tax credit toward the caregiver’s state income tax, regardless of actual expenses. Because the credit would be refundable, it would be available regardless of whether the resident owed any state income taxes. This legislation limited the credit to individuals caring for an older adult who is at least 60 years old and is targeted to lower-income caregivers (the value of the credit varies from $100 to $1,000, depending on the caregiver’s income). Care recipients must require substantial supervision because of cognitive impairment or need help with at least two ADLs. In addition, the care recipient must have lived with the caregiver for at least 6 months of the year and received at least half of his or her financial support from the caregiver. The estimated cost of the caregiver tax credit in terms of lost revenue was approximately $37 million a year, and the likely consumer benefit was estimated to be slightly more, approximately $38 million. If the credit was extended to care of people of all ages, the tax loss would be considerably higher.

Advantages

- Family caregivers will receive societal recognition of their support for their disabled relatives. In addition, they will receive some financial compensation for the costs that they incur caring for people with disabilities.
- As a cash payment, it provides maximum flexibility to caregivers on how to use the money.
- As a tax incentive rather than direct public program, it minimizes the amount of government bureaucracy needed to administer the program.
- If a refundable tax credit rather than a deduction, it can be structured to be progressive rather than regressive in its tax effects.
- Tax incentives for informal caregivers have broad support in Hawaii. In the Hawaii Long-Term Care Survey, 73.5 percent of respondents said that they favored reducing state income taxes for people who provide a lot of care to their disabled relatives (Khatutsky et al., 2010).
Disadvantages

- Although the tax payment provides social recognition, it is unlikely to change behavior unless the incentive is much larger than those commonly offered by states. For example, people are unlikely to decide to leave the labor force to care for their disabled relatives or not place their relative in a nursing home based on the receipt of a $1,000 tax credit. Given the current high level of informal caregiving, a tax incentive is likely to provide funds to people who are already providing informal care at no cost to the government. Given the costs of providing informal care in Hawaii, the tax incentive would have to be much larger to come close to compensating caregivers for their costs.

- The tax loss would be large. Direct service programs have the advantage over tax incentives in that they can target resources to people most in need rather than providing funds to all persons who qualify.

- Monitoring whether care recipients have the required level of disability could be difficult and expensive and viewed as intrusive by taxpayers. On the other hand, without it, substantial numbers of people may claim the benefit to which they are not entitled.

- Tax incentives are expenditures just as much as direct public spending. Without new sources of revenue to compensate for the tax loss, increases in tax incentives may squeeze other government priorities. In the Hawaii Long-Term Care Survey, 57.8 percent of respondents said they opposed raising taxes to pay for expanded access to long-term care services (Khatutsky et al., 2010).
Delivery System Option #4: Reform the Regulation of Domiciliary Care Facilities, Including Adult Residential Care Homes, Extended Care Adult Residential Care Homes, Community Care Foster Homes, and Assisted Living Facilities

Reform of the system of domiciliary care facilities would include (1) ensuring that all of the state’s information outlets—particularly the Aging and Disability Resource Center (ADRC) website—provide clear and consistent information about all of the residential care options available; (2) improving the quality of care in domiciliary care facilities by assessing state allocation of responsibilities for quality assurance across departments; and (3) reviewing the standards and inspection processes for residential care facilities.

Background

Hawaii has a very complex system of community-based residential care settings—broadly called domiciliary care homes—which can be very confusing for service providers and consumers alike (O’Keeffe and Wiener, 2010). The state lacks a source of accurate, comprehensive, and comparative information about residential care options, making it very difficult to ensure optimal use of residential care by people with long-term care needs. A clear written description of the system is unavailable on any of the state’s websites—including the ADRC websites. The information available about various components of the system on various websites is incomplete and unclear.

Many stakeholders express concerns about the quality of care provided in residential care settings—particularly Adult Residential Care Homes and Extended Care Adult Residential Care Homes—which they believe is the result of division of responsibility for regulation and oversight by two agencies, inadequate licensing and certification requirements, and insufficient oversight (O’Keeffe and Wiener, 2010a). Responsibility for regulating Hawaii’s residential care facilities is divided between the Department of Health and the Department of Human Services, which have significantly different regulatory and service philosophies.

Community Care Foster Homes, which serve individuals with a nursing home level of care, are certified by the Department of Human Services, using a social model of care. Assisted living facilities, which may also serve individuals who need a nursing home level of care, are licensed by the Department of Health. Adult Residential Care Homes (ARCHs), which serve individuals who do not need a nursing home level of care, are licensed by the Department of Health, which uses a medical model.

Several stakeholders noted that some of the requirements for ARCHs are more stringent than for foster care homes even though the latter serve Medicaid waiver clients and the former are not permitted to (O’Keeffe and Wiener, 2010a). The 2002 auditor’s report concluded that the additional stringency was appropriate because ARCHs are facilities that serve a larger number of people than foster homes. However, many ARCHs serve five or fewer individuals in what were private homes. Extended Care Adult Residential Care Homes (EC-ARCHs), which may also serve individuals who need a nursing home level of care, are licensed by the Department of Health but the Department of Human Services oversees placement and case management services to Medicaid-eligible clients in these settings. EC-ARCH operators must meet additional
Department of Health staffing and other requirements to be allowed to offer expanded services and accept residents who need nursing home–level care.

The Hawaii Department of Health and the Department of Human Services employ different approaches for ensuring quality of care and dealing with complaints. Some stakeholders believe that having two different state agencies regulating residential care facilities leads to inconsistencies in oversight that fail to protect residents. Nonetheless, a 2002 state auditor’s report recommended against consolidating oversight into a single agency for a variety of reasons. One reason was that the overlap in responsibilities between the agencies would continue because the single state agency responsible for administering the Medicaid program (the Department of Human Services) would inevitably continue to have some oversight responsibility for Medicaid clients in the three types of settings in which they are served as required by federal law—even if all three were licensed/certified by the Department of Health.

Advantages

- Residential care facilities are difficult to regulate because they have some characteristics of nursing homes and some characteristics of private homes. A careful review of the allocation of responsibilities and standards and procedures for quality assurance could result in better quality care.

Disadvantages

- Reorganizations are time consuming and disruptive to the organizations involved. Merely shifting responsibilities may not result in better quality assurance. Likewise, the state is unlikely to devote substantial additional resources to monitoring these facilities.
Conclusions

This paper discusses the background and advantages and disadvantages of a large number of financing and delivery system options for reform of long-term care in Hawaii. None of the options are perfect and all require weighing of the costs and benefits and their distributional impact. It is hoped that this analysis will help the Hawaii Long-Term Care Commission choose the options that will be most beneficial to the people of the state.
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American Association for Long-Term Care Insurance. (2010). The 2010 Sourcebook for Long-Term Care Insurance Information. Westlake Village, CA: American Association for Long-Term Care Insurance.


Appendix C: Overview of Long-Term Care System in Hawaii (2011), Janet O’Keeffe and Joshua M. Wiener, RTI International
An Overview of Long-Term Care in Hawaii

Final Report

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Long-Term Care Services and Funding in Hawaii

Introduction

This report provides a “primer” or overview of long-term care services in Hawaii and the public programs that pay for those services. It aims to provide a basic understanding the state of long-term care in Hawaii. It relies mostly on publicly available information, which is limited. *Exhibit 1* defines long-term care. Long-term care services for persons with serious mental illness are discussed only in passing in this overview.

Like every other state, Hawaii has a range of long-term care services. Although these services could be considered to make up a state long-term care “system,” with few exceptions they are standalone services and are not integrated into a coherent whole.

*Exhibit 1. What Is Long-Term Care?*

<table>
<thead>
<tr>
<th>Long-term care includes a wide range of services and supports:</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Assistance with activities of daily living (ADLs). ADLs include eating, bathing, dressing, transferring from bed to chair, controlling bowel and bladder function, and moving about the house safely.</td>
</tr>
<tr>
<td>▪ Assistance with instrumental activities of daily living (IADLs). IADLs include preparing meals, shopping for food and personal items, managing medications, managing money, using telephones, doing housework, and using public transportation.</td>
</tr>
<tr>
<td>▪ Assistance with other activities needed to maintain community living, such as heavy chores.</td>
</tr>
<tr>
<td>▪ Supervision to safeguard health and safety.</td>
</tr>
<tr>
<td>▪ Skilled and unskilled nursing services and rehabilitation services such as physical and occupational therapy to maintain or improve functioning.</td>
</tr>
<tr>
<td>▪ A range of other services and supports needed to function in community settings, such as habilitation and supported employment for persons with developmental disabilities or serious mental illness.</td>
</tr>
</tbody>
</table>

The first section of this report provides basic information on the size of the elderly population in Hawaii and how it is projected to increase in the future. It also includes an estimate of the number of people who need long-term care. The second section describes the types of long-term care services available in Hawaii. The third section describes the public programs that pay for these services for some individuals under certain circumstances, primarily those with low income and few assets. The fourth section of this report very briefly describes the developmental disabilities services system. Finally, the report concludes with a brief summary of the long-term care system in Hawaii.
Demographic Characteristics of Older People

The elderly population in Hawaii is projected to increase significantly over the next two decades (Exhibit 2).\(^1\) The increase in the population aged 65 and older—and particularly people aged 85 and older—will lead to an increase in the number of people needing long-term care because older people have a higher prevalence of disability than younger people.

### Exhibit 2. Elderly Population in Hawaii, 2007 and 2030

<table>
<thead>
<tr>
<th>Population</th>
<th>2007</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population 65+</td>
<td>185,622</td>
<td>326,957</td>
</tr>
<tr>
<td>Percent of Overall Population</td>
<td>14.0</td>
<td>22.3</td>
</tr>
<tr>
<td>Total Population 85+</td>
<td>26,294</td>
<td>48,254</td>
</tr>
<tr>
<td>Percent of Overall Population</td>
<td>2.0</td>
<td>3.3</td>
</tr>
</tbody>
</table>


Adjusting earlier estimates of the number of people with disabilities in Hawaii, Nixon estimated that there were 21,789 people needing long-term care in Hawaii in 2007 (Exhibit 3).\(^2\) The criteria for needing long-term care were that individuals had (1) two or more ADL limitations lasting 90 days or more or (2) a cognitive impairment (including Alzheimer’s and senility).

### Exhibit 3. Estimated Number of People Requiring Long-Term Care in Hawaii, 2007

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Total Population in Age Range</th>
<th>Total Persons Requiring Long-Term Care in Age Range</th>
<th>Percent of Population Requiring Long-Term Care in Age Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>25+</td>
<td>783,372</td>
<td>21,789</td>
<td>2.8</td>
</tr>
<tr>
<td>25–64</td>
<td>639,597</td>
<td>5,097</td>
<td>0.8</td>
</tr>
<tr>
<td>65+</td>
<td>143,775</td>
<td>16,692</td>
<td>11.6</td>
</tr>
</tbody>
</table>


---


Long-Term Care Services

Long-term care comprises a range of services—from licensed skilled nursing services to homemaking and chore services. The major service types discussed below are used primarily by older people and younger persons with physical disabilities. Long-term care services and supports for persons with developmental disabilities are discussed separately.

Nursing Homes

In 2010, Hawaii had 48 nursing homes with 4,191 beds certified to participate in Medicare or Medicaid. A total of 3,889 individuals resided in these nursing facilities. Nursing homes provide medical, nursing, and health-related care in a residential setting. Hawaii differentiates between skilled nursing facilities (SNFs) and intermediate care facilities (ICFs), indicating that the state operates two types of nursing facilities. However, federal law abolished the distinction between Medicaid SNFs and ICFs in the Omnibus Reconciliation Act of 1987, and requires states to provide both a skilled and an intermediate level of care in a single nursing facility.

Hawaii has a much lower supply of nursing home beds relative to its elderly population than other states. As shown in Exhibit 4, in 2009, Hawaii had 43.4 nursing home beds per 1,000 persons aged 75 and older, compared to the national average of 88.9 nursing home beds per 1,000 persons aged 75 and older. Between 1997 and 2009, the nursing bed/population ratio declined, both nationally and in Hawaii. It is not known why the nursing home bed ratio is so much lower in Hawaii than in the nation as a whole. One possible explanation is that the high level of three-generation households in the state combined with a strong tradition of informal caregiving has resulted in low demand for nursing home care. Another explanation is that the high cost of real estate and construction needed to expand existing facilities or build new ones constrains the number of nursing home beds.

The relatively low supply of nursing home beds in Hawaii has several consequences. First, the state’s nursing facility occupancy rate is very high—92.8 percent in 2010 compared to the national average of 83.6 percent. Second, because of high occupancy rates, some individuals with a high level of impairment and extensive nursing needs cannot be discharged from acute care hospitals because no nursing home will take them. Third, with so few beds, nursing homes tend to serve a more severely disabled population than the national average. The average nursing home ADL Index—a measure of the need for assistance with ADLs—is 4.52 for Hawaii compared to the national average of 4.02; Hawaii’s index is the highest of any state.


4 Ibid.

Exhibit 4. Nursing Home Beds per 1,000 Persons Aged 75 and Older, Hawaii and U.S., 1997 to 2009


Reflecting the high cost of nursing homes in Hawaii, in 2010, 70.0 percent of Hawaii’s nursing home residents were eligible for Medicaid compared to the national average of 63.6 percent. Moreover, fewer Hawaii nursing home residents have their care covered by Medicare: 9.2 percent of residents in Hawaii compared to 14.2 percent for the nation as a whole. A total of 20.9 percent of residents in Hawaii paid out of pocket or through another payer compared to 22.2 percent of residents for the country as a whole. Exhibit 5 presents the distribution of payment sources by nursing home residents over time, demonstrating that the percentages have been quite stable, going back to at least 1997.

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6 Ibid.
Exhibit 5. Nursing Home Resident Payment Sources, 1997–2010


**Residential Care Homes/Facilities**

Hawaii has a very complex system of community-based residential care settings. These include Adult Residential Care Homes (ARCHs), Extended Care Adult Residential Care Homes (EC-ARCHs), Community Care Foster Family Homes (CCFFHs), and assisted living facilities. Unless specifically licensed or certified to provide a higher level of care, these homes provide room and board, supervision, and limited assistance with personal care and health-related needs.7

Prior to 2009, Medicaid paid for services in these residential care settings through two home and community-based services waiver programs. In February 2009, the Section 1115 Medicaid

7 The complexity of Hawaii’s system stems in part from the use of a single term to describe multiple residential care settings and the use of different terms to describe the same setting. For example, even though some ARCHs and EC-ARCHs are large facilities serving 20 or more residents, the Hawaii Department of Human Services’ website uses the program name “Adult Foster Care Program” to cover services provided in ARCHs and EC-ARCHs, as well as CCFFHs. The website also states that the Department of Human Services’ Adult and Community Care Services Branch licenses adult foster homes through its Residential Alternatives Community Care Program. Yet ARCHs—which are part of Department of Human Services’ Adult Foster Care Program—are licensed by the Department of Health.
research and demonstration program QUEST Expanded Access (QExA) was implemented and Medicaid residential care services are now paid through the managed care programs established under the demonstration.

Adult Residential Care Homes
ARCHs are licensed by the Hawaii Department of Health. In addition to room and board, ARCHs provide limited assistance with ADLs, custodial care, and supervisory oversight. Type I ARCHs care for up to 5 residents in a private home; Type II ARCHs care for 6 or more residents in larger, more institutional settings that may care for as many as 50 to 60 residents. Medicaid does not pay for services provided in ARCHs. Residents either pay privately or turn over their Supplemental Security Income (SSI) federal benefit plus state supplement payment (minus a $50 personal needs allowance) to the provider. In 2011, the state had 248 Type I ARCHs with 1,135 beds and 4 Type II ARCHs with 92 beds.

Extended Care Adult Residential Care Homes
EC-ARCHs are licensed by the Department of Health but the Department of Human Services oversees placement and case management services to Medicaid-eligible clients in these settings. To receive these services, individuals must be eligible for SSI, Medicaid, or other financial assistance from the Department.

EC-ARCH operators must meet additional Department of Health staffing and other requirements to be allowed to offer expanded services and accept residents who need nursing home level care. EC-ARCHs serve both private pay residents and those who are Medicaid eligible. Type I EC-ARCHs may serve up to two residents (out of five) who need a nursing home level of care. In Type II EC-ARCHs, only 20 percent of the residents can need a nursing home level-of-care. In 2011, the state had 225 Type I EC-ARCHs with a capacity of 1,109 beds and 20 Type II EC-ARCHs with a capacity of 306 beds.

Community Care Foster Family Homes
CCFFHs are certified by the Department of Human Services to serve both private pay residents and Medicaid-eligible residents who meet the state’s nursing home level-of-care criteria as certified by a physician. Medicaid-eligible and private pay individuals entering a CCFFH must have a case manager from a Department of Human Services–licensed Case Management Agency.

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12 Hawaii Department of Health, Office of Health Care Assurance, op.cit.
coordinate their health and long-term care services and ensure that their health care needs are met.

CCFFHs are certified for one, two, or three individuals and are required to serve at least one Medicaid-eligible resident. If a CCFFH is certified for two or three persons, the home is allowed to have one private-pay, non–Medicaid-eligible individual in addition to the Medicaid-eligible resident. A CCFFH may accept a second private-pay individual if certain conditions are met.\(^\text{13}\)

As of January 2011, there were 1,053 facilities with a capacity of 2,444 beds.\(^\text{14}\) Monthly Medicaid reimbursement rates differ by the level of care required: $724.48 for Level I clients and $1,222.92 for Level II clients. The monthly room and board payment for Medicaid-eligible residents was $1,278.90—the amount of the SSI federal benefit payment plus the state supplement. Residents turn over their SSI payment to the facility to pay for room and board, except for a small personal needs allowance. Thus, facilities serving Level I facilities received $724.48 plus $1,278.90 or $2,003.38 per month minus the personal needs allowance.

**Assisted Living Facilities**

Assisted living facilities are licensed and regulated by the Department of Health. As noted above, they are one of three types of residential care settings permitted to serve individuals who meet the state’s nursing facility level-of-care criteria. Assisted living facilities differ from other types of residential care facilities in that they are required to provide apartment units with cooking facilities (which may be removed if the resident cannot safely use them). These facilities provide room and board, health care services, and personalized supportive services to meet individual residents’ needs. In 2010, Hawaii had 11 assisted living facilities with 1,872 units.\(^\text{15}\) Some independent living retirement facilities are converting a section of their buildings to assisted living to accommodate individuals who need assistance.

According to a recent study, the state agency responsible for enforcing building codes is requiring assisted living facilities that meet the R-1 (residential apartment) code to serve only residents who are ambulatory and can evacuate in an emergency.\(^\text{16}\) Providers contend that enforcement of this requirement limits their ability to implement other aspects of the regulations that support aging in place.

Residents of assisted living facilities who are Medicaid eligible and meet the state’s nursing home level of care criteria can receive home and community-based services through the QExA program. Medicaid covers services in three of these settings for individuals who need a nursing

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\(^\text{13}\) Community Care Foster Care Family Homes, Act 13, Session Laws of Hawaii (SLH) 2009. For additional information, see [http://hawaii.gov/dhs/protection/social_services/adult_services/CCFFH%20Factsheet%201.6.10.pdf](http://hawaii.gov/dhs/protection/social_services/adult_services/CCFFH%20Factsheet%201.6.10.pdf).


home level of care: CCFFHs, EC-ARCHs, and assisted living facilities. In accordance with federal law that limits certain reimbursement to institutions, Medicaid does not cover room and board in these settings.

**State Supplemental Payments**

Residents of all domiciliary care homes in the state who are current SSI recipients; state-funded aid to the aged, blind, and disabled; or general assistance payments are eligible for “state supplemental payments.” These payments are provided through general fund appropriations to provide payments for special care needs individuals. Exhibit 6 presents the combined monthly federal and state supplemental payment levels for various residential care facility settings.


<table>
<thead>
<tr>
<th>Category</th>
<th>2010 Total Monthly Payment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Independent living status</strong></td>
<td></td>
</tr>
<tr>
<td>Eligible person</td>
<td>$674.00</td>
</tr>
<tr>
<td>Eligible couple</td>
<td>$1,011.00</td>
</tr>
<tr>
<td><strong>Living in a foster care home</strong></td>
<td></td>
</tr>
<tr>
<td>Eligible person</td>
<td>$1,325.90</td>
</tr>
<tr>
<td>Eligible couple</td>
<td>$2,651.80</td>
</tr>
<tr>
<td><strong>Domiciliary care (five people or fewer)</strong></td>
<td></td>
</tr>
<tr>
<td>Eligible person</td>
<td>$1,325.90</td>
</tr>
<tr>
<td>Eligible couple</td>
<td>$2,557.80</td>
</tr>
<tr>
<td><strong>Domiciliary care (more than five people)</strong></td>
<td></td>
</tr>
<tr>
<td>Eligible person</td>
<td>$1,433.90</td>
</tr>
<tr>
<td>Eligible couple</td>
<td>$2,867.80</td>
</tr>
</tbody>
</table>

Note: The amounts include both federal and state supplemental payments combined. Not all SSI recipients receive the maximum amount. Individual payments may be lower if the beneficiary has other income.


**Adult Day Care and Adult Day Health Centers**

In addition to directly assisting participants, both adult day care and adult day health centers provide respite for caregivers. All-day programs can enable family caregivers to continue working at paid employment.

**Adult Day Care Centers**

The Department of Human Services licenses adult day care centers providing supportive services to four or more adults with physical or mental disabilities. These centers provide a sheltered setting and activities to promote functioning and the ability to remain safely in their homes or a relative’s home. If specifically licensed to do so, they provide meals and snacks.

“All adult day care services” are defined as services provided through an organized program of personal care, supervision, social services, therapy, and group and leisure activities. Centers also provide family consultation or referral services to appropriate community resources and assistance to clients to learn about, apply for, and receive income entitlements such as Social Security Income (SSI).
Security and SSI benefits, Medicaid, the Supplemental Nutrition Assistance Program (i.e., food stamps) and state supplemental payments. In 2010, the state had 35 adult day care centers with the capacity to serve 830 clients.\(^{17}\)

**Adult Day Health Centers**

Adult day health centers are licensed by the Department of Health; they provide a more medical service than adult day care centers. Adult day health centers provide medical services, nursing services, dietetic services and planned therapeutic and social activities, social services, speech therapy, physical therapy, occupational therapy, and psychiatric or psychological services in a group setting. In 2010, the state had 10 adult day health centers.\(^{18}\)

**Case Management Services**

Case managers assess individuals to identify unmet needs, explore service options, develop service plans, and coordinate services in home and community-based settings for both private pay and Medicaid clients. They assist in the placement of individuals who meet Medicaid nursing home level-of-care criteria to CCFFHs and EC-ARCHs and oversee their care to ensure that their medical and other needs are met. The Department of Human Services licenses Community Case Management Agencies.

**Licensed Nursing Services**

Registered nurses and Licensed Practical Nurses provide unskilled and skilled nursing services. Licensed nurses who provide services in private homes are generally the employees of home health agencies. However, they may also be hired as independent contractors. The state has 26 Medicare certified home health agencies, which are licensed by the Department of Health.\(^{19}\)

**Nurse Aides, Home Health Aides, Personal Assistants/Personal Care Aides**

Nurse aides, certified nurse assistants, home health aides, personal assistants, and personal care aides provide assistance with ADLs and IADLs. These individuals can be employees of an agency or may provide services as independent contractors. Home health agencies employ home health aides and nurse aides and nursing homes employ certified nurse assistants who provide health-related and unskilled nursing services in addition to assistance with the ADLs. All of these workers may be allowed to provide some nursing care tasks, functions, and activities if

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they are specifically delegated—and their performance supervised, monitored, and evaluated—by a licensed nurse.20

**Homemakers, Companions, and Attendants**

Some individuals may not need assistance with ADLs, but need assistance with IADLs such as meal preparation, shopping for grocery or personal items, housework, or laundering. (Hawaii state agencies consider some of these activities to be “chores.”) Some people—such as persons with Alzheimer’s disease—may need supervision to ensure personal safety, but not hands-on care. Although nurse aides, home health aides, personal care aides, and personal assistants are also capable of providing these services, it may be less expensive to hire homemakers, companions, or attendants to provide them—either through a home care agency or as independent contractors.

Home care agencies provide a variety of nonmedical personal, housekeeping, and other services. Until 2008, having a General Excise Tax I.D. number was the only requirement for operating a home care agency. In 2008, the Legislature passed a law requiring that such agencies be licensed by the Department of Health. As a result of budget shortfalls, however, the Department of Health has not implemented these requirements.

**Other Home and Community-Based Services**

Other services are available to help people with long-term care needs to remain in their homes, including assistance with heavy chores—such as washing windows and yard work—home-delivered meals, and transportation services.

**Public Funding for Long-Term Care Services**

Long-term care services can be very expensive—particularly when needed for more than a few months—and are unaffordable to many if not most individuals and families. Long-term care services in Hawaii are substantially more expensive than in the nation as a whole (Exhibit 7).

**Exhibit 7. Cost of Private-Pay Long-Term Care Services in Hawaii, 2010**

<table>
<thead>
<tr>
<th>Type of Care</th>
<th>Average Hawaii Cost</th>
<th>Average National Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year in nursing home care (private room)</td>
<td>$132,860</td>
<td>$83,585</td>
</tr>
<tr>
<td>Year in assisted living facility</td>
<td>$50,676</td>
<td>$39,512</td>
</tr>
<tr>
<td>Home health aide (per hour)</td>
<td>$22</td>
<td>$21</td>
</tr>
</tbody>
</table>


For individuals who need but cannot afford long-term care services, the state pays for these services through a variety of programs; the two most important are Medicaid (known as QUEST in Hawaii) and Kupuna Care. Additional public funding for long-term care services is available through other state-funded programs and the federal Older Americans Act (OAA), which supports programs administered by the U.S. Administration on Aging.

**Medicaid**

Medicaid is a federal- and state-funded program and the largest public funding source for long-term care. For example, as shown in Exhibit 5, approximately 70 percent of nursing home residents have their care paid by Medicaid. Hawaii’s Department of Human Services administers the Medicaid program through its Med-QUEST division. **Exhibit 8** presents Hawaii Medicaid expenditures for long-term care services for 2008.²¹

**Exhibit 8. Medicaid Long-Term Care Expenditures for Older People and Younger Persons With Physical Disabilities in Hawaii, by Service, 2008**

<table>
<thead>
<tr>
<th>Service</th>
<th>Expenditure ($)</th>
<th>Percentage of Total Long-Term Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing Homes</td>
<td>$221,667,411</td>
<td>80.9</td>
</tr>
<tr>
<td>Personal Care</td>
<td>$0</td>
<td>0.0</td>
</tr>
<tr>
<td>Home Health</td>
<td>$654,464</td>
<td>0.2</td>
</tr>
<tr>
<td>Home and Community-Based Services Waiver</td>
<td>$50,945,892</td>
<td>18.6</td>
</tr>
<tr>
<td>Targeted Case Management</td>
<td>$782,226</td>
<td>0.3</td>
</tr>
<tr>
<td>Total Long-Term Care</td>
<td>$274,049,993</td>
<td>100.0</td>
</tr>
</tbody>
</table>


Under federal law, nursing home and home health care are mandatory services that all states must cover. In addition, states may cover a number of optional services. The Hawaii Medicaid program does not cover the optional state plan personal care benefit, but it does operate several Medicaid home and community-based services that cover personal care. Under the QExA research and demonstration program (discussed below), chore services are covered up to a maximum of 1,600 persons. Hawaii recently reached the maximum allowed number of chore beneficiaries under the demonstration program and now maintains a waiting list for these services.

²¹ Starting in 2009, detailed service-specific expenditure data are no long available because payment to managed care plans under QExA is made on an overall capitated basis and not on the basis of services actually provided.
Prior to the implementation of QExA, the proportion of Hawaii’s long-term care expenditures spent on home and community-based services for older people and younger persons with physical disabilities was about a third less than the national average—18.8 percent compared to 31.6 percent in 2008 (Exhibit 9). In addition, Hawaii spent much less per person on home and community-based services than the national average. The proportion of expenditures for home and community-based services was stable in Hawaii between 2004 and 2008, while it has increased nationally. In 2008, Hawaii spent about half the amount per person on Medicaid home and community-based services for older people and younger persons with physical disabilities as the national average—$526,206 per 1,000 older people aged 75 and older in Hawaii versus $1,213,298 per 1,000 older people aged 75 and older nationally (Exhibit 10). Similarly, expenditure levels per person in Hawaii were stable between 2004 and 2008, while they have increased nationally.

Exhibit 9. Percentage of Medicaid Long-Term Care Expenditures for Older People and Younger Persons With Physical Disabilities for Home and Community-Based Services, 1995 to 2008


Exhibit 10. Medicaid Home and Community-Based Services Expenditures for Older People and Younger Persons With Physical Disabilities per 1,000 People Aged 75 and Over, 1997 to 2008

Note: Expenditures adjusted for inflation by the national Consumer Price Index-All Urban Consumers to 2008 levels established by the U.S. Bureau of Labor Statistics.


**QUEST Expanded Access**

In 2007 Hawaii decided to shift the Medicaid aged, blind, and disabled population from fee-for-service Medicaid into managed care plans in an effort to achieve cost savings, improve quality of care, and increase coordination across acute and long-term care.23 In the Medicaid program, the “aged” population includes persons aged 65 and older and the “disabled” population includes

persons under age 65 with severe disabilities. Hawaii received a federal Section 1115 research and demonstration waiver to operate the new program.

In February 2008, a competitive bidding process led to the awarding of a $1.5 billion contract to subsidiaries of two for-profit health plans: UnitedHealth Group’s Evercare subsidiary and WellCare Health Plans, Inc.’s Ohana Health Plan. The state has two QExA health plans: Evercare and Ohana. Both plans are available on five islands. Only Ohana is available on Molokai. Together the plans serve more than 41,000 aged, blind, and disabled Medicaid clients. Since February 2009, all Medicaid primary, acute, and long-term care services for aged, blind, and disabled Medicaid populations have been provided through the managed care QExA program. Medicare services are not included.

Enrollment is mandatory for aged, blind, and disabled beneficiaries and includes all Medicaid beneficiaries who are eligible at 100 percent of the federal poverty level, at the SSI and SSI plus State Supplement levels. Enrollment is also mandatory for all aged and disabled clients in nursing homes, including those eligible through spend down/medically needy rules.

QExA covers all Medicaid long-term care services, including nursing home care, home health services, and all home and community-based services that were formerly covered by the two Medicaid home and community-based services waiver programs, such as service coordination, adult day care, personal care, attendant care, and services in residential care settings. The managed care program replaced two Medicaid home and community-based services waiver programs: Nursing Home without Walls and Residential Alternative Community Care. Self-direction is an option for personal care, respite, and attendant services.

The goals for QExA include the following:

- Improving the health status of seniors and people with disabilities
- Establishing a “provider home” through the use of primary care providers
- Empowering beneficiaries by promoting independence and choice
- Ensuring access to high-quality, cost-effective care that is provided, whenever possible, in beneficiaries’ homes and communities
- Coordinating care, including primary, acute, behavioral health, and long-term care supports and services
- Ensuring that beneficiaries are able to receive needed care in their choice of settings

Preliminary data from QExa suggest that the program has been very effective in increasing the number of people receiving home and community-based services. QUEST reports that the

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number of Medicaid beneficiaries receiving home and community-based services increased from 2,110 in February 2009 to an average of 3,876 in the second quarter of 2010, an 84 percent increase. Moreover, almost all of the increase was a result of people receiving care in their own homes rather than in residential care facilities. During this same period, the number of nursing facility residents declined from 2,840 to 2,650, a 7 percent decline. As a result, home and community-based services beneficiaries increased from 43 percent of long-term care beneficiaries in February 2009 to 59 percent in the second quarter of 2010.

Programs of All-inclusive Care for the Elderly

Programs of All-inclusive Care for the Elderly (PACE) are managed care programs that include all Medicare and Medicaid services for older people who need nursing home-level care. QExA only includes Medicaid services; it does not include Medicare services. Hawaii implemented two PACE programs in the past 10 years. However, as a result of low enrollment, both closed.

Medicaid Home and Community-Based Services (HCBS) Waiver Programs

Under Section 1915(c) of the Social Security Act, states may apply to the U.S. Department of Health and Human Services for Medicaid HCBS waivers designed to give states greater flexibility to meet the needs of community-dwelling persons with disabilities. Unlike personal care offered through the regular Medicaid program, states must limit waiver programs to beneficiaries who need nursing homes, ICFs for people with intellectual disabilities, or hospital services. The federal government imposes this requirement because the waivers services are intended to substitute for institutional care. In addition, under the waivers, states must establish in advance how many people they will serve during the course of a year. In contrast to the regular Medicaid program, states may establish waiting lists for these waiver programs; thus, the waivers are not entitlements, although they operate within a program that is normally an entitlement. States may also provide Medicaid eligibility to persons in the community with incomes up to 300 percent of the federal SSI level, which far exceeds regular Medicaid income eligibility limits.

A major advantage of these waivers is that states may cover a very wide range of services, including case management, homemaker, home health aide services, personal care services, adult day health care, habilitation, respite care, nonmedical transportation, home modifications, adult day care, and other services approved by the Secretary of the Department of Health and Human Services. As noted above, although services in congregate residential facilities such as assisted living facilities may be covered, room and board may not be covered. Room and board may only be covered by Medicaid in nursing homes, ICFs for people with intellectual disabilities, and hospitals.

To ensure cost neutrality of providing these additional services, average Medicaid expenditures for waiver beneficiaries must be the same as or less than they would have been without the waiver. As a practical matter, for older people and younger adults with physical disabilities, this

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means that average expenditures have to be equal to or less than the average cost of Medicaid nursing home care.

In addition to QExA, the state operates three Medicaid HCBS waiver programs—a program for people with HIV/AIDS, a program for people less than 21 years of age who are medically fragile, and a waiver program for individuals with developmental disabilities. The QExA managed care program folded in two HCBS waiver programs: Nursing Home without Walls and Residential Alternative Community Care.

**HIV/AIDS Community Care Waiver Program**

The HIV/AIDS Community Care Waiver Program provides services to persons who are eligible for Medicaid, HIV positive, and needing a nursing home level of care. The program offers an array of services, including case management, nonmedical transportation, personal assistance, home-delivered meals, adult day health care, counseling and training, private duty nursing, personal emergency response, respite care, home maintenance, environmental accessibility, adaptations, moving assistance, and specialized medical equipment and supplies. In 2006, Hawaii’s Medicaid HIV/AIDS Community Care program served 54 participants. The average per participant cost was $7,573 for a total of $408,917. FY 2009 spending for this waiver was $550,452.

**Medically Fragile Community Care Waiver Program**

The Medically Fragile Community Care Waiver program provides services to Medicaid eligibles under 21 years old who are determined to be medically fragile and in need of a hospital or nursing home level of care. The targeted medical condition must be expected to last longer than 12 months. The participant also must have at least two caregivers trained to provide needed care in a home that is able to accommodate the necessary equipment and personnel. The program offers an array of services, including habilitation, respite, home modifications, special equipment, day health services, nursing, transportation, medical day care, attendant care, family training, and case management. In 2006, Hawaii’s Medically Fragile Community Care waiver program served 48 participants. The average per participant cost was $37,394 for a total of $1,794,915.

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State Programs

Hawaii has several non-Medicaid programs that provide long-term care services, which are administered through the Department of Human Services and the Department of Health.

Department of Human Services

The Department of Human Services administers several long-term care programs.

Chore Services for Community Long-Term Care Program

The Chore Services program provides essential housekeeping services to enable eligible adults to remain in the community. Services may include housecleaning, laundering, shopping, and meal preparation. To receive services, an individual must be eligible for SSI, financial or Medicaid assistance from the Department, and must meet other program requirements. Individuals receiving services from Medicaid’s QExA are not eligible for this service. Services may be provided without regard to income in adult protective service situations. Most providers are family members.

Senior Companion Program

The Senior Companion Program is a part-time volunteer program that recruits low-income seniors to provide in-home companionship and limited personal care to frail elders and respite to caregivers in exchange for a small stipend. The program is funded by the federal Corporation for National and Community Service. To be a Senior Companion, individuals must be at least 55 years of age, physically able to volunteer 20 hours per week, and have relatively low incomes.

Department of Health, Executive Office on Aging

Chapter 349 of the Hawaii Revised Statutes establishes the Executive Office on Aging (EOA) 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 Hawaii. The EOA works with four Area Agencies on Aging (AAAs) to administer various programs for older people, including Kupuna Care and programs funded by the U.S. Administration on Aging.

Kupuna Care

Kupuna Care is an entirely state-funded program designed to meet the needs of frail older adults who cannot live at home without adequate help from family or formal services. The program was developed by the EOA in partnership with the AAAs to address the growing number of older persons with long-term care needs. The AAAs administer the program.

Kupuna Care services include the following:

- adult day care

- assisted transportation
- attendant care (volunteer companion)
- case management
- chore services
- home delivered meals
- homemaker-housekeeper
- personal care

The bulk of Kupuna Care spending is for personal care (28%), home-delivered meals (22%), case management (20%), and transportation (15%).

The program has no financial eligibility criteria and services are free, although priority is given to lower-income older people. Clients are asked to make voluntary donations to the service provider for any service provided. Donations are used to provide services to additional clients.

To be eligible for Kupuna Care, an individual must be

- 60 years or older;
- not eligible for services from another public program, such as Medicaid, or already receiving private pay services;
- living in an apartment or house (not an institution, residential care facility, or foster home); and
- impaired in two or more ADLs or IADLs or have significantly reduced mental capacity, and have one or more unmet ADL or IADL need.

Clients receiving a single service are assessed by the service provider. Clients receiving more than one service are assessed by case managers. In State Fiscal Year 2009, Kupuna Care expenditures were $4,708,816.

**U.S. Administration on Aging-funded Programs**

The federal OAA provides funding for elderly support services, nutrition services, preventive health services, elder rights protection, and family caregiver support services. The OAA created a network of federal, state, and local agencies to plan and provide services that enable older adults to live independently in their homes and communities, and also to provide family caregiver support services; this infrastructure is known as the “Aging Network.” The EOA is designated as the State Unit on Aging for Hawaii. The EOA is the designated lead agency for the

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33 Ibid.
coordination of a statewide system of aging and caregiver support services, as authorized by federal and state laws.

Each of the state’s four counties has an AAA, which is responsible for planning, developing, and administration of services to older adults and family caregivers residing in their distinct geographic planning and service area. Each AAA contracts with service providers in their geographic area. Services include chore services, adult day care respite, homemaker/housekeeping services, assisted transportation, legal assistance, attendant care, case management, congregate meals, personal care assistance, transportation, home-delivered meals, and family caregiver services.

The federal and state funding for services is available to assist older adults and family caregivers regardless of income. However, because of limited funding, special considerations are given to those older adults and family caregivers who have the greatest economic and social needs, focusing particularly on low-income minorities, limited English-speaking populations, and people with disabilities.34

The Family Caregiver Support Program, one of the programs funded by the OAA, provides caregiver support services to help people with disabilities to remain in their homes. Services are available to adult family members or other individuals who are informal, unpaid providers of in-home care to older adults aged 60 and older.35 Caregiver support services are also available to grandparents or relatives (not parents) aged 55 or older who are taking care of a child aged 18 and younger or a relative 18 and older with a disability.

Aging and Disability Resource Center

The Aging and Disability Resource Center (ADRC) program is a collaborative effort of the U.S. Administration on Aging and the Centers for Medicare & Medicaid Services (CMS). The purpose of ADRCs is to simplify and streamline access to long-term care services. ADRCs provide states with an opportunity to integrate the full range of long-term supports and services into a single, coordinated system.36 The target population for ADRCs includes individuals of all ages with all incomes and types of disabilities, including serious mental illness and developmental disabilities. Although Hawaii has been working to develop a fully functioning ADRC for several years, it currently provides only limited services and information, primarily through toll-free telephone numbers and a website.

ADRCs provide information and assistance to individuals in need of services, to professionals seeking assistance on behalf of their clients, and to individuals planning for their future long-term care needs. ADRCs also serve as the entry point to publicly administered long-term supports including those funded under Medicaid, the OAA, and state revenue-funded programs.

34 Pendleton, op. cit.
In 2005, an ADRC development grant funded by the U.S. Administration on Aging and CMS was awarded to the Hawaii Executive Office on Aging in partnership with the Hawaii County Office of Aging and the City and County of Honolulu Elderly Affairs Division on Oahu. These two counties served as the original ADRC pilot sites. Hawaii’s ADRC is a collaborative project funded by the U.S. Administration on Aging; CMS; the State of Hawaii, the counties of Kauai, Maui, and Hawaii; and the City and County of Honolulu. All four counties have operational ADRCs.

Hawaii’s ADRC has a website—www.hawaiiadrc.org—which is a one-stop source for long-term care information and services for older adults, people with disabilities, and caregivers who need assistance.37 The website was developed by the City and County of Honolulu Elderly Affairs Division in conjunction with Kaua’i County Agency of Elderly Affairs. Additional state funding expanded the website to include all four counties. The website’s main page directs users to information for four counties: Hawaii, Honolulu, Kauai, and Maui. In addition to this website, individuals can contact any local ADRC site operated by the county AAAs by phone or in person for further assistance. Although the website provides limited information to individuals who are computer literate and have access to a computer, it cannot address the needs of people with limited English language skills and those who cannot use computers.

The Hawaii County ADRC is a physical location where people can go to receive help in person. With additional funding support from Hawaii County, a physical site in Hilo was renovated to co-locate the Hawaii County Office of Aging and other aging and disability agencies onsite. The ADRC brings together several county and private programs serving seniors and individuals with disabilities, including the Adult Community Care Services Section of the State Department of Human Services, the ARC of Hilo, Services for Seniors, Hawaii County Nutrition Program, Coordinated Services for the Elderly Program, the Senior Employment and Training Program, the Legal Aid Society of Hawaii, the State Department of Health’s Adult Case Management Program, the Alzheimer’s Association, and the University of Hawaii at Hilo School of Pharmacy.

The Hilo site is open to the public to obtain information about and assistance to obtain a wide range of services such as adult day care, transportation, Medicaid services, legal aid, respite care, and other community programs for elders and people with disabilities. Additional ADRC sites are planned for the Hamakua district of the Big Island, and the rural communities of Waianae, Hauula, and North Shore on Oahu.

Adult Mental Health Division, Department of Health

The Adult Mental Health Division promotes, provides, coordinates, and administers the mental health system for individuals aged 18 and older who have serious and persistent mental illness and who do not have access to services or the resources to purchase supports. Although the mental health system provides primarily treatment services, it also provides some community supports for persons who would otherwise be institutionalized.

Developmental Disabilities System

The Department of Health administers services for persons with developmental disabilities. The Department ensures the provision of an array of individually appropriate services and care to persons with developmental disabilities through the utilization of existing resources within the community; coordination with supports and services provided under other federal, state, or county acts; and through specific funding when no other resources are available within the limits of state and federal resources allocated for the purpose. These services include but are not restricted to case management; residential, developmental, and vocational support, including supported employment; training; habilitation; residential habilitation; active treatment; day treatment; day activity; respite care; domestic assistance; attendant care/personal assistance; skilled nursing; speech, physical, occupational, and recreational therapy; recreational opportunities; counseling, including counseling to the person’s family, guardian, or other appropriate representative; development of language and communications skills; interpretation; transportation; and equipment.

The Department funds services through state matching funds for Medicaid programs, other governmental programs, and private programs. For example, through its Partnership in Community Living program, the Department’s Developmental Disabilities Division provides up to $2,000 per year to fund services or learning materials to increase independence and functional living for persons with intellectual disabilities and other developmental disabilities.

Only individuals eligible for community services, but not eligible for Medicaid waiver services or other federally reimbursed programs, or for whom such services are not appropriate or not available based on their individual service plan, receive services and supports with solely state funds.

The Department of Health’s Office of Health Care Assurance licenses developmental disabilities domiciliary homes (DDDHs) and ICFs for people with developmental disabilities.

Intermediate Care Facilities for Persons With Intellectual Disabilities

Intermediate Care Facilities for People with Intellectual Disabilities (ICF/IDs) are an optional Medicaid benefit created to fund institutions (four or more beds) for people with developmental disabilities. These facilities provide room and board and “active treatment” for individuals with developmental disabilities.

Hawaii has 18 ICF/IDs. All but one facility, which serves nine residents, are “Community ICF/IDs” serving four or five residents. Four facilities are on Maui and 14 are on Oahu. In 2009, the state Medicaid program spent $9.9 million for ICF/IDs.38

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Residential Care Settings for Persons With Developmental Disabilities

DDDHs provide services to adults with intellectual disabilities and other developmental disabilities. These settings provide services and supports to promote normalization, community and social integration, and personal development to the fullest potential. These facilities must also protect the health and ensure the safety of their residents. Only 79 individuals out of 2,600+ served in the development disabilities waiver program live in a licensed home such as Development Disabilities Domiciliary homes. The Department of Health’s Developmental Disabilities Division Certification Section recruits, orients, and certifies foster homes and foster caregivers for the community placement of adults with developmental disabilities.

Developmentally Disabled Medicaid Home and Community-Based Services Waiver Program

Although the Department of Human Services is the designated Medicaid State Agency, the Department of Health’s Developmental Disabilities Division is mandated by state law to lead initiatives to develop a comprehensive system of supports and services for persons with developmental disabilities. This responsibility includes administration of the Medicaid home and community-based services waiver for people with developmental disabilities and for the provision of case management services for this population.

Persons who are Medicaid eligible and certified as requiring an ICF/IID level of care are eligible for the intellectual disabilities/developmental disabilities HCBS waiver. In 2006, this waiver had 2,242 participants. Total Medicaid spending for the waiver was $83 million with an average of $37,202 per participant. In 2009, total Medicaid spending for the waiver was $113 million. The mental retardation/development disabilities waiver program provides supports and services to enable participants to live as independently as possible in the least restrictive environment. More than 600 individuals use a consumer direction option. This option is very important—particularly in places where there are labor shortages, such as rural areas—because it allows Medicaid waiver participants to hire relatives, friends, and neighbors to provide direct care.

Waiver services include the following:

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39 The term “residential” in the developmental disabilities service system encompasses all types of living arrangements, from family homes to institutions. In this report, the terms “residential care setting” or “residential care facility” refers only to settings/facilities that are provider-operated.
41 In 2006, the most recent year for which data are readily available, the developmental disability waiver served 2,242 people, the HIV waiver served 54 people, and the Medically Fragile waiver served 48 people. Ng and Harrington, op. cit.
42 Eiken et al., op. cit.
Summary

This paper provides a basic summary of the long-term care system in Hawaii. Long-term care includes helping people with daily activities, such as getting dressed, bathing, preparing meals or eating, or taking medications, over an extended period of time. Providers of long-term care include nursing homes, residential care facilities, adult day care centers, and home care agencies. The report’s primary focus is on services and financing for older people and younger people with physical disabilities, but it also briefly addresses the system for people with intellectual disabilities/developmental disabilities.

Demographic Characteristics of Older People

- Like the rest of the country (indeed, the world), the population of Hawaii is getting older. Between 2007 and 2030, the population aged 85 and older, which has the greatest need for long-term care, will increase by almost two-thirds.
- There are approximately 22,000 adults aged 25 and older in Hawaii with significant disabilities.

Long-Term Care Services

- Compared to the rest of the country, Hawaii has many fewer nursing home beds per older population. The ratio of nursing home beds per 1,000 people aged 75 and older in Hawaii is about half the national average. Possible reasons for this lower bed supply include the high cost of land and the tradition of three-generation households. As a result of the relatively low bed supply, occupancy rates are high, some high-need patients in hospitals have difficulty
obtaining placements, and Hawaii nursing home residents are more disabled than in other states.

- A possible consequence of the limited nursing home supply has been the growth of a complicated and confusing system of residential care facilities, including Adult Residential Care Homes, Extended Care Adult Residential Care Homes, Community Care Foster Homes, and assisted living facilities. Some of these facilities serve people who need a nursing home level of care and receive Medicaid reimbursement for services but not room and board. These facilities are regulated by the Department of Human Services and the Department of Health; some facilities are regulated by both agencies.

- Home and community-based services in Hawaii include a wide range of services including case management, licensed nursing services, licensed nursing services, nurse aides, adult day care and adult day health centers, home health aides, personal attendants/personal care aides, homemakers, and other community services. The Department of Health is authorized to license home care agencies, but lacks the funds to implement these requirements.

Public Funding for Long-Term Care Services

General Cost

- Long-term care services are expensive everywhere, but are particularly costly in Hawaii. For example, the private-pay price for the average private room in a nursing home is almost 50 percent higher in Hawaii than in the country as a whole.

Medicaid

- Medicaid is the primary payer for long-term care services. In FY 2008, the state spent approximately $274 million on long-term care for older people and younger persons with physical disabilities.

- Compared to other states, Hawaii’s Medicaid long-term care spending has historically been much more oriented toward institutional services. In 2008, the most current year for which data are available, only 19 percent of Medicaid long-term care services spending in Hawaii for older people and younger persons with physical disabilities, compared to 32 percent nationally. Not surprisingly, then, Medicaid spending for home and community-based services per capita aged 75 and older in Hawaii was half of what it was nationally.

- Medicaid long-term care services in Hawaii underwent a radical change in 2009 with the introduction of QUEST Expanded Access, which combined Medicaid primary, acute, and long-term care services for aged, blind, and disabled beneficiaries into a managed care program. Enrollment is mandatory, with beneficiaries able to choose between two managed care plans. By combining medical and long-term care, policymakers hope to create a more efficient and seamless integrated care system, which will have much greater flexibility in meeting the needs of older and younger people with disabilities. Very little public information is available about how the program is performing. However, preliminary data suggests that the demonstration has substantially increased the number of people receiving home and community-based services and modestly reduced the number of people receiving nursing home care.

- In addition to the Medicaid HCBS waivers absorbed into QExA, Hawaii Medicaid operates HCBS waivers: the HIV/AIDS Community Care Waiver program, the Medically Fragile
Community Care Waiver program, and the Developmentally Disabled Medicaid Home and Community-Based Services Waiver program.

State Programs

- Similar to other states, Hawaii also operates several other long-term care programs focusing on home and community-based services, which are much smaller than Medicaid home and community-based services. These programs are managed by the Department of Human Services and Department of Health.

- The largest of these non-Medicaid programs, including the entirely state-funded Kupuna Care and those programs funded by the U.S. Administration on Aging, are run by the Executive Office on Aging of the Department of Health.

- The Aging and Disability Resource Center Program is a collaborative effort of the U.S. Administration on Aging and CMS. The purpose of ADRCs is to simplify and streamline access to long-term care services. ADRCs provide states with an opportunity to effectively integrate the full range of long-term supports and services into a single, coordinated system. Although the state has been working to develop a fully functioning ADRC for several years, it currently provides only limited services and information, primarily through toll-free telephone numbers and a website. The state currently has a contract with a consultant to upgrade these services.

Intellectual Disabilities/Developmental Disabilities System

- The Hawaii Department of Health administers programs for people with intellectual disabilities/developmental disabilities.

- Like other states regarding services for people with intellectual disabilities/developmental disabilities and unlike services for older people and younger persons with physical disabilities, Hawaii has radically shifted services for people with intellectual disabilities/developmental disabilities from institutions to home and community-based services. For example in 2009, Medicaid’s expenditures for the Developmentally Disabled Home and Community-Based Services Waiver were more than 11 times the expenditures for ICFs for people with intellectual disabilities.
Appendix D: Stakeholders’ Views of Hawaii’s Long-Term Care System: Problems, Solutions, and Barriers to Reform (2010), Janet O’Keeffe and Joshua M. Wiener, RTI International
Stakeholders’ Views on Hawaii’s Long-Term Care System: Problems, Solutions, and Barriers to Reform

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We would like to thank the many individuals who took time to speak with us about their views of the problems with Hawaii’s long-term care system, needed reforms, and barriers to reform. This report would not have been possible without their insights and knowledge.
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Executive Summary

Act 224, Session Laws of Hawaii 2008, established the Hawaii Long-Term Care Commission in 2008. The Commission is charged with identifying needed reforms of the long-term care system, researching program changes and resources needed to meet the State’s long-term care goals, and exploring funding options that may help support the provision of long-term care services. Long-term care includes helping people with daily activities, such as getting dressed, bathing, preparing meals or eating, or taking medications, over a long period of time. Providers of long-term care include nursing homes, home health agencies, home care agencies, adult day care programs, meals-on-wheels programs, and community-care homes.

Every state’s long-term care system has groups that are affected by and can influence the way in which services are organized and financed and quality assured. As part of the Long-Term Care Commission’s analysis of Hawaii’s long-term care system, RTI International conducted interviews with stakeholders—including providers, consumer advocates, government officials, and researchers—to obtain their views about the problems of the State’s long-term care system, what changes they believe are needed to reform the system, and what they believe are the major obstacles to reform and how to overcome them. In summarizing their opinions, we sought to capture the range of views, identifying areas of consensus and areas where there was diversity of opinion.

This report summarizes the views of the individuals interviewed for the report. Although they were selected for participation based on their knowledge and expertise, the contents of this report should not be viewed as findings of fact. In addition, they do not necessarily represent the views of the report’s authors, RTI International, or the Hawaii Long-Term Care Commission. Nonetheless, given the importance of stakeholders in any reform effort, their views provide important perspectives that should be considered in designing initiatives to reform the State’s long-term care system.

Problems With the Current Long-Term Care System

All stakeholders thought that the aging of the population would place great additional strain on the current long-term care system. Most respondents identified the main problems of the current long-term care system as the following:

- **Insufficient third-party financing.** Most stakeholders believed that not enough Medicaid and long-term care insurance financing is available to pay for long-term care services. For most people, services are too expensive to be paid out of pocket. Although a longstanding issue, the strong downturn in the economy has severely exacerbated this problem.

- **Inability of informal caregiving to meet need.** Historically, unpaid care by informal caregivers has been a particularly important component of care of people with disabilities of all ages. But informal care cannot be counted on to meet the growing need for care because of geographic mobility, people living longer, the high cost of living in Hawaii, and the lack of interest among some of the younger generation. The strain on informal caregivers of helping disabled relatives and the lack of support for caregivers may result in an increased demand for paid services.
- **Lack of long-term care service capacity.** Going hand in hand with inadequate financing and strained informal caregivers, stakeholders said that there is an across-the-board shortage of nursing home, community care home, and home care service capacity, especially for people with complex medical needs. The new Medicaid QUEST Expanded Access program has substantially changed service arrangements, but few stakeholders knew much about the impact of the program.

- **Fragmentation of the long-term care and health systems.** Many older people and persons with disabilities have both long-term care and medical needs and must navigate complex and fragmented service delivery and financing systems. Respondents emphasized that there are issues both within long-term care and health care systems and between the two systems. Some stakeholders questioned whether one could even refer to a long-term care “system” because the service and financing components were so “siloed” and disconnected.

- **Poor quality/insufficient monitoring of home and community-based services.** Unlike other states, stakeholders did not identify the quality of nursing home care as a major problem. Rather, respondents focused on the regulation of community care homes and, to a lesser degree, home care. Given severe levels of disability and complex medical/nursing needs among many community care home residents, stakeholders expressed concerns about the lack of staff training, case management, and fragmented oversight of these facilities.

**Reforms Needed to Address the Problems**

Although considerable consensus exists among stakeholders about the problems of the long-term care system, there is much less agreement about the solutions to the problems. Proposed solutions include the following:

- **Solve the financing problem.** Stakeholders were strongly divided about whether the public or the private sector needed to expand to solve the financing problem. Some respondents believed that long-term care is fundamentally a social responsibility of government and that either taxes will need to be increased to pay for Medicaid or a new public long-term care insurance program will need to be established, financed by premiums and general revenues. Other respondents believed that long-term care is ultimately an individual responsibility and that the goal should be to reduce the role of government programs in financing long-term care. Advocates of this view tended to support education on the financial risks of long-term care and tax incentives for purchase of private long-term care insurance policies.

- **Increase service capacity.** Several respondents stressed the need to increase the availability of all types of long-term care services (nursing homes, community care homes, and home care), particularly for people who are not eligible for Medicaid and to provide respite for informal caregivers. While recognizing the need for institutional care, they stressed that the State should not rely only on nursing homes to address long-term care needs. Other stakeholders, however, cautioned that home care does not necessarily lead to cost savings, particularly when individuals need extensive care and supervision.

- **Reform components of the service delivery system.** Stakeholders had a variety of highly specific recommendations, including revising the eligibility determination and service allocation approach for Kupuna Care and increasing the use of consumer-directed services. Some observers stressed the importance of understanding the
current system and designing solutions to its problems before adding new funding, which would just expand the current inadequate system.

- **Reduce system fragmentation and improve service coordination.** At the policy level, some stakeholders advocated consolidating long-term care policy and regulation into one agency, as is done in Oregon and in Washington. Many stakeholders believed that strengthening the Aging and Disability Resource Center could help consumers receive the services they need.

- **Address quality problems with community care homes.** Stakeholders proposed a number of initiatives to improve the quality of care in community care homes, including increasing training and case management, implementing uniform and systematic screening of community care home applicants to ensure appropriate placement, and developing specialized licensing for facilities that serve residents with severe disabilities and complex medical/nursing needs. Some observers thought that regulatory consolidation was particularly needed for oversight of community care homes, which is currently split between the Department of Health and Department of Human Services.

- **Develop adequate reimbursement rates.** Some stakeholders proposed better linking reimbursement for nursing homes and care homes to residents’ needs, a major goal of which would be to pay more for severely disabled and medically complex residents. In their view, the current rates are inadequate and have a negative impact on the quality of care provided to residents. One stakeholder dismissed providers’ concerns about reimbursement, noting that they manage to stay in business with the current rates.

- **Change the State’s decision-making process.** In addition to possibly reorganizing state government to consolidate decision-making on long-term care in a single organization, several stakeholders recommended making decision-making more inclusive and transparent. In particular, respondents said that long-term care stakeholders should be more involved in the decision-making process.

### Obstacles to Reforming the Long-Term Care System

Stakeholders identified several barriers to reforming Hawaii’s long-term care system:

- **Opposition to new or higher taxes.** Both advocates for and opponents of increased government spending identified opposition to additional taxes as a major barrier to increasing government revenues for long-term care. Some stakeholders believed that the public would view a social insurance premium differently than a tax, but not all respondents held this view. Most stakeholders did not think it was politically realistic to propose any tax increase until the economy improves.

- **Opposition to expansion of the public sector.** The appropriate role of government was an area of disagreement among stakeholders, with some wanting a larger role and others wanting a smaller role. This is a philosophical difference that is very difficult to bridge.

- **Lack of knowledge about long-term care issues.** Most stakeholders expressed frustration concerning the lack of knowledge by government officials, the legislature, and the general public about long-term care issues. Bold initiatives are not possible if policymakers are unaware of the issues and the problems underlying them.

- **Leadership lacks the will.** Most stakeholders did not believe that top government policymakers are committed to addressing long-term care issues. The strong division
between the underlying philosophies of the current governor and the current legislature make it hard to argue for investment of time and energy in long-term care reform at this time. Some observers saw the election in November as an opportunity to bring the governor and the legislature into closer ideological alignment.

- **Lack of effective advocacy.** Although stakeholders faulted government policymakers, they also faulted long-term care providers and consumer advocates for being largely ineffective in advancing the cause of long-term care reform. According to observers, this lack of effectiveness breeds indifference because advocates do not see successes on which to build.
Introduction

Act 224, Session Laws of Hawaii 2008, established the Hawaii Long-Term Care Commission in 2008. The Commission is charged with identifying needed reforms of the long-term care system, researching program changes and resources needed to meet the State’s long-term care goals, and exploring funding options that may help support the provision of long-term care services. Long-term care includes helping people with daily activities, such as getting dressed, bathing, preparing meals or eating, or taking medications, over a long period of time. Providers of long-term care include nursing homes, home health agencies, home care agencies, adult day care programs, meals-on-wheels programs, and community-care homes.

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This report summarizes the views of the individuals interviewed for the report. Although they were selected for participation based on their knowledge and expertise, the contents of this report should not be viewed as findings of fact. In addition, they do not necessarily represent the views of the report’s authors, RTI, or the Hawaii Long-Term Care Commission. Nonetheless, given the importance of stakeholders in any reform effort, their views provide important perspectives that should be considered in designing initiatives to reform the State’s long-term care system.

This report begins with a description of the study’s methodology, including selection of stakeholders and the discussion guide. The following sections discuss the views of the stakeholders regarding the problems of the long-term care system in Hawaii, their recommendations for reform, and the barriers to implementing reforms. The report concludes with a summary of the findings.

Stakeholder Selection

To ensure that we would obtain a wide range of perspectives, with input from staff and commissioners of the Hawaii Long-Term Care Commission, we compiled a list of key stakeholders: aging and long-term care advocacy groups; state provider associations; state legislative and executive branch policymakers; public and nonprofit program administrators; and individual long-term care providers, researchers, and other expert and knowledgeable individuals. In the course of our interviews, some respondents suggested that we speak with certain individuals and we asked the Healthcare Association of Hawaii to recommend knowledgeable service providers to include in our interviews. In all, we interviewed a total of 47 individuals (Exhibit 1).
### Exhibit 1. Individuals Interviewed

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organization</th>
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<tbody>
<tr>
<td><strong>Government–Legislature (5)</strong></td>
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</tr>
<tr>
<td>Rosalyn H. Baker</td>
<td>Senator</td>
<td>Senate</td>
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<tr>
<td>Les Ihara</td>
<td>Senator</td>
<td>Senate</td>
</tr>
<tr>
<td>Marilyn Lee</td>
<td>Representative</td>
<td>House</td>
</tr>
<tr>
<td>John M. Mizuno</td>
<td>Representative</td>
<td>House</td>
</tr>
<tr>
<td>Suzanne Chun Oakland</td>
<td>Senator</td>
<td>Senate</td>
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<tr>
<td><strong>Government–Governor’s Office (1)</strong></td>
<td></td>
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</tr>
<tr>
<td>Linda Smith</td>
<td>Senior Policy Advisor</td>
<td>Governor’s Office</td>
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<tr>
<td><strong>Government–Executive Administration (9)</strong></td>
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</tr>
<tr>
<td>Patricia Bazin</td>
<td>Administrator for the Health Care Services Branch</td>
<td>Med-Quest Division, Hawaii Department of Human Services</td>
</tr>
<tr>
<td>Dr. Kenneth S. Fink</td>
<td>Division Administrator</td>
<td>Med-Quest Division, Hawaii Department of Human Services</td>
</tr>
<tr>
<td>John Grant</td>
<td>Community Assistance and Grants Management</td>
<td>Hawaii Executive Office on Aging</td>
</tr>
<tr>
<td>Susan Jackson</td>
<td>First Deputy to the Director</td>
<td>Hawaii Department of Health</td>
</tr>
<tr>
<td>Noreen Moon-Ng</td>
<td>Program Officer of the Policy &amp; Program Development Office</td>
<td>Med-Quest Division, Hawaii Department of Human Services</td>
</tr>
<tr>
<td>Noemi Pendleton</td>
<td>Director</td>
<td>Hawaii Executive Office on Aging</td>
</tr>
<tr>
<td>Keith Ridley</td>
<td>Chief</td>
<td>Office of Health Care Assurance</td>
</tr>
<tr>
<td>Marilyn Seely</td>
<td>Former Director</td>
<td>Hawaii Executive Office on Aging</td>
</tr>
<tr>
<td>Audrey Suga-Nakagawa</td>
<td>Former Project Director</td>
<td>Hawaii Aging and Disability Resource Center</td>
</tr>
<tr>
<td><strong>Government–County (4)</strong></td>
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</tr>
<tr>
<td>Elizabeth Bethea</td>
<td>County Executive on Aging</td>
<td>Elderly Affairs Division, Honolulu County Department of Community Services</td>
</tr>
<tr>
<td>Deborah Morikawa</td>
<td>Director</td>
<td>Honolulu County Department of Community Services</td>
</tr>
<tr>
<td>Alan Parker</td>
<td>Executive</td>
<td>Hawaii County Office of Aging</td>
</tr>
<tr>
<td>Lei Shimizu</td>
<td>Coordinator of Information and Assistance</td>
<td>Elderly Affairs Division, Honolulu County Department of Community Services</td>
</tr>
<tr>
<td><strong>Providers and Provider Associations (16)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lani Akee</td>
<td>President</td>
<td>Adult Foster Homecare Association of Hawaii</td>
</tr>
<tr>
<td>Coral Andrews</td>
<td>Vice President</td>
<td>American Health Care Association of Hawaii</td>
</tr>
<tr>
<td>Norm Baker</td>
<td>Vice President, Community Building</td>
<td>Aloha United Way</td>
</tr>
<tr>
<td>Name</td>
<td>Title</td>
<td>Organization</td>
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<tr>
<td>Sananda &quot;Sandy&quot; Baz</td>
<td>Executive Director</td>
<td>Maui Economic Opportunity</td>
</tr>
<tr>
<td>Dr. Patricia Blanchette</td>
<td>Professor, Geriatric Medicine</td>
<td>University of Hawaii</td>
</tr>
<tr>
<td>Merlita Compton</td>
<td>Elderly Program Coordinator</td>
<td>Kokua Kaliihi Valley</td>
</tr>
<tr>
<td>Sandy Freeman</td>
<td>Executive Director</td>
<td>Maui Adult Day Care Centers</td>
</tr>
<tr>
<td>Ron Gallegos</td>
<td>President</td>
<td>Alliance of Residential Care Administrators</td>
</tr>
<tr>
<td>Fred Horwitz</td>
<td>Chairman and Senior Executive Director</td>
<td>American Health Care Association of Hawaii</td>
</tr>
<tr>
<td>Tony Krieg</td>
<td>Chief Executive Officer</td>
<td>Hale Makua</td>
</tr>
<tr>
<td>Bernie Ledesma</td>
<td>Administrator</td>
<td>Pearl City Nursing Home</td>
</tr>
<tr>
<td>Vince Lee</td>
<td>Regional (Oahu) CEO</td>
<td>HI Health Systems Corporation</td>
</tr>
<tr>
<td>Rose Nakamura</td>
<td>Founder</td>
<td>Project Dana</td>
</tr>
<tr>
<td>Rebecca Ryan</td>
<td>Executive Director and Chair of the Board</td>
<td>Moiliili Community Center</td>
</tr>
<tr>
<td>Valorie Taylor</td>
<td>Program Director</td>
<td>Honolulu Gerontology Program, Child &amp; Family Service</td>
</tr>
<tr>
<td>Diane M. Terada</td>
<td>Division Administrator</td>
<td>Catholic Charities Hawaii</td>
</tr>
</tbody>
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**Consumer Advocates (6)**

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Organization</th>
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</thead>
<tbody>
<tr>
<td>Rita Barreras</td>
<td>Director</td>
<td>Aging with Aloha Coalition</td>
</tr>
<tr>
<td>John P. Dellera</td>
<td>Executive Director</td>
<td>Hawaii Disability Rights Center</td>
</tr>
<tr>
<td>Stuart Ho</td>
<td>President</td>
<td>AARP Hawaii</td>
</tr>
<tr>
<td>Wes Lum</td>
<td>A founder of the Hawaii Family Caregiver Coalition; assistant specialist at the Center on Aging at the University of Hawaii</td>
<td>Worked with the Hawaii Executive Office on Aging to develop support for family caregivers</td>
</tr>
<tr>
<td>Laura G. Manis</td>
<td>Advocate for long-term care financing strategies</td>
<td>Private advocate</td>
</tr>
<tr>
<td>Barbara Kim Stanton</td>
<td>State Director</td>
<td>AARP Hawaii</td>
</tr>
</tbody>
</table>

**Researchers and Others (6)**

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Colette Browne</td>
<td>Professor, Social Work</td>
<td>University of Hawaii</td>
</tr>
<tr>
<td>Dr. Anthony Lenzer</td>
<td>Former Director, Center on Aging</td>
<td>University of Hawaii</td>
</tr>
<tr>
<td>Bruce McCullough</td>
<td>Former Director</td>
<td>Hawaii Office of the Social Security Administration</td>
</tr>
<tr>
<td>Dr. Lawrence Nitz</td>
<td>Professor, Political Science</td>
<td>University of Hawaii</td>
</tr>
<tr>
<td>Dr. David Nixon</td>
<td>Assistant Professor, Public Policy Center</td>
<td>University of Hawaii</td>
</tr>
<tr>
<td>Dr. Eldon Wegner</td>
<td>Professor Emeritus, Sociology</td>
<td>University of Hawaii</td>
</tr>
</tbody>
</table>
Interview Process

To focus the discussion with stakeholders, we developed an open-ended discussion guide to elicit their views on four major topics (Exhibit 2):

- Does the State’s long-term care system have any problems that need fixing?
  What components of the State’s long-term care system most need reform?
- What is needed to reform/fix the problems of the long-term care system to meet current and future service needs?
- What obstacles have prevented past reform efforts from succeeding?
- What are the obstacles to the reforms that are needed?

To encourage respondents to be candid in expressing their views, we assured them that nothing they said would be attributed to them individually in this report. To ensure this confidentiality, we are reporting responses in the aggregate—rather than by type of stakeholder. Additionally, because providers are key stakeholders, and to ensure the confidentiality of their responses, we have combined responses from the stakeholder interviews and the provider survey. When synthesizing stakeholders’ responses and selecting specific responses to illustrate key points and perspectives, we paraphrased them for brevity and to ensure confidentiality. In a few cases, the results of more informal conversations are also included. Most interviews were conducted by telephone in February and March 2010.
Exhibit 2. Discussion Guide

Good afternoon. Thank you for taking the time to speak with us today. As described in the e-mail we sent you, RTI International has a contract with the State of Hawaii to conduct an assessment of the state’s long-term care system and policy options for addressing identified problems.

We are interviewing key stakeholders, including providers (and their trade associations) to obtain their input on a range of long-term care issues in the state and their views on how to address them.

Consent

Because we are obligated to provide the list of persons being interviewed to the state, you cannot participate in this interview anonymously.

However, we will not attribute any information obtained in this interview to you directly, unless you want to be “on the record.” All information obtained through the interviews will be reported in the aggregate; any examples of statements made will be paraphrased and presented without attribution.

Any information that you want to provide “off the record” will be treated confidentially—that is, we will not report it or if we believe it is important, we will write it in a way that it cannot be traced back to you. In this case, we will send what we have written for your review and approval.

If there is any question that you do not wish to answer or that you are not comfortable answering, please let me know and I will move on to the next question.

If you agree with these conditions of participation, we can start our discussion.

Do you agree?

Questions

1. Does the state’s long-term care system have any problems that need fixing? What components of the state’s long-term care system most need reform?

2. What is needed to reform the system/fix the problems to meet current and future service needs?

3. What obstacles have prevented past reform efforts from succeeding?

4. What are the current obstacles to the reforms you believe are needed?
Interview Findings

We have organized stakeholders’ responses into three major categories:

- Problems with the State’s long-term care system
- Reforms needed to address the problems
- Obstacles—past and current—to solving the problems

I. Problems With the State’s Long-Term Care System

The longevity of Hawaii’s population and its rapidly growing elderly population were noted by several respondents as setting the context for the problems of Hawaii’s long-term care system. With few exceptions, stakeholders said that the long-term care infrastructure is inadequate to accommodate this growing population, with many observers noting the failure of both the public and private sector to keep pace with the increased demand for services. Stressing that in 10 years, 25 percent of Hawaii’s population will be age 60 and older, many observers argued that the State needs to develop a plan to meet the needs of the aging population and noted the centrality of solving the problem of insufficient public and private financing. The large amount of unmet need among people who are not eligible for Medicaid and cannot afford to pay for services is a particular problem and some observers reported that persons with severe disabilities who are eligible for Medicaid are not getting enough assistance.

Stakeholders also noted that because of the lack of nursing home beds, care for many individuals who need a nursing home level of care is being provided by family foster care homes and adult residential care homes. While recognizing that many people prefer to be served in these community care homes rather than in a nursing home, several observers expressed concerns about the ability of these homes to provide the intensive level of care needed and about the quality of care provided in those facilities.

A few respondents said that everything about the long-term care system needs fixing, but most mentioned three or four major issues. With a few exceptions, there was a remarkable consensus among respondents regarding the problems that needed to be addressed:

- Insufficient third-party financing
- Inability of informal caregivers to meet need
- Lack of long-term care service capacity, both for nursing homes and home and community-based services
- Fragmentation of the long-term care system
- Poor quality/insufficient monitoring of community care homes

Stakeholder views of the problems of the long-term care system in Hawaii are summarized in Exhibit 3.
All stakeholders thought that the aging of the population would place great additional strain on the current long-term care system. Most respondents identified the main problems of the current long-term care system as the following:

- **Insufficient third-party financing.** Most stakeholders believed that not enough Medicaid and long-term care insurance financing is available to pay for long-term care services. For most people, services are too expensive to be paid out of pocket. Although a longstanding issue, the strong downturn in the economy has severely exacerbated this problem.

- **Inability of informal caregiving to meet need.** Historically, unpaid care by informal caregivers has been a particularly important component of care of people with disabilities of all ages. But informal care cannot be counted on to meet the growing need for care because of geographic mobility, people living longer, the high cost of living in Hawaii, and the lack of interest among some of the younger generation. The strain on informal caregivers of helping disabled relatives and the lack of support for caregivers may result in an increased demand for paid services.

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- **Fragmentation of the long-term care and health systems.** Many older people and persons with disabilities have both long-term care and medical needs and must navigate complex and fragmented service delivery and financing systems. Respondents emphasized that there are issues both within long-term care and health care systems and between the two systems. Some stakeholders questioned whether one could even refer to a long-term care “system” because the service and financing components were so “siloed” and disconnected.

- **Poor-quality/insufficient monitoring of home and community-based services.** Unlike other states, stakeholders did not identify the quality of nursing home care as a major problem. Rather, respondents focused on the regulation of community care homes and, to a lesser degree, home care. Given severe levels of disability and complex medical/nursing needs among many community care home residents, stakeholders expressed concerns about the lack of staff training, case management, and fragmented oversight of these facilities.

### Insufficient Third-Party Financing

With very few exceptions, respondents said that insufficient financing to meet long-term care needs is a major problem and for many, it is the principal problem that the State needs to address, particularly funding for Medicaid and for home and community-based services. As one respondent put it:

> The cost of long-term care is high for individuals and for the State. For most individuals, a need for long-term care means impoverishment. For the State’s long-term care system, the costs will rise dramatically as the population ages.
The key question is: How should these high costs be shared? The current funding sources—including out-of-pocket spending and Medicaid—are inadequate. We have to find a new financing mechanism that will bring in additional funds, one which people will be willing to support.

One respondent observed that although state Medicaid funds are matched by federal dollars, the governor has not budgeted enough Medicaid funds to meet service needs, noting that even the intake and assessment system to determine eligibility for services has a waiting list. Moreover, the State Unit on Aging has been level funded for many years.

There was agreement among a broad range of stakeholders that the demand for services has been increasing over the past years and that state government and the private sector have failed to keep pace with the growth in the elderly population. In particular, many stakeholders said that there is a growing number of people who are not financially eligible for Medicaid but cannot afford to pay for long-term care—even costs incidental to the provision of informal care, such as incontinence supplies. Although this population is eligible for Kupuna Care, the program has a long waiting list (currently 500 individuals) and spends an average of only $800 per year per client. Moreover, few people have private long-term care insurance, which one observer attributed to people waiting to buy it until they are older when policies are more expensive—and thus unaffordable—or the presence of health problems which make them uninsurable.

**Effect of the Current Economic Crisis**

Most stakeholders noted that the long-term care financing problem has been exacerbated by the current economic downturn and the governor’s policy of cutting spending to balance the budget rather than raising taxes. Supporters of the governor’s policy argued that there is no political support to raising taxes and that there is no alternative. Many observers expressed major concerns about the impact of budget cuts on those in need of assistance and noted that because the governor is refusing to spend all of the funds appropriated for Kupuna Care, the program is serving fewer people.

The governor has announced major delays in paying Medicaid providers in FY2010 and some respondents said that similar delays occurred in FY2009 and that the State has not yet completely paid what is owed. Some stakeholders reported that providers have to wait 9 months or more to be paid and some have accounts receivable going back to February 2009. A few providers noted that if lack of payment continues, some adult residential care homes will go out of business because they will not be able to make their mortgage payments.

One stakeholder reported that long-term care providers contacted the Centers for Medicare & Medicaid Services (CMS) regional office to protest the delays in payment. They were told

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1 Kupuna Care is a small state-funded home and community-based services program for people age 60 and older administered by the Hawaii Executive Office of Aging. Services include case management, transportation, attendant care, personal care, homemaker, chore, home delivered meals, and adult day care. Unlike Medicaid, eligibility for Kupuna Care is not limited solely to low-income people with very limited assets.
that Hawaii’s Medicaid Director had informed CMS of the plan to delay provider payments and had assured CMS that no harm would come to any Medicaid recipients as a result of the delay. When the provider coalition went to the legislature to seek a solution to the payment problem, they were told that the executive branch was responsible for the administration, regulation, and monitoring of the Medicaid program.

Many respondents believed that the long-term care system is under siege by the governor, with one stakeholder expressing concerns that the budget cuts were “shredding the safety net.” But one respondent noted that the State’s inability to pay Medicaid providers was affecting not only long-term care providers but also health care providers and was, in part, a consequence of a substantial increase in the number of people eligible for Medicaid during the current economic downturn. Because the State accepted federal stimulus funds to get a higher Medicaid match (now 67 percent), it cannot tighten eligibility criteria.

An unanticipated consequence of the economic downturn is that the nursing home utilization rate has decreased somewhat. Stakeholders were not able to definitely attribute the decrease to particular factors, but some said they believed that the managed care companies are making greater use of home and community-based services to avoid the high cost of institutionalization. One person theorized that because people who are unemployed can stay home and take care of their family members, there is less pressure to place older people into nursing homes.

**Strain on the State’s Finances From the “Compact of Free Association”**

Two respondents mentioned that under the Compact of Free Association, people from the Marshalls and other islands can move freely between their island and the United States to obtain education and health care. Most are enrolled in the Hawaii Medicaid program and many need dialysis. One noted that although the federal government pays states for their care, the payments do not come close to covering Hawaii’s costs and that funding for this group was one of the first items the governor reduced.

**Inability of Informal Caregiving to Meet Need**

Many respondents stressed the cultural traditions in Hawaii of taking care of one’s elders and living in multigenerational households, which facilitates the provision of informal care for aging relatives. Some respondents attributed the State’s low use of nursing homes—compared to the national average—to these traditions. A few observers noted that high housing costs also contribute to multigenerational households. Several respondents contended that these cultural traditions are weakening and that it is now more acceptable to place family members in nursing homes and other residential settings. As one stakeholder put it:

> Asian populations have a long tradition of caring for their elders. We have the highest rate of multigenerational families living in one home in the country. Because we make the assumption that they will continue to do so, this tradition prevents people from thinking about public solutions to the long-term care problem. But the mindset is changing—in part because of high female labor force participation. We’re seeing caregiver burnout. The cultural tradition is starting to break down.
Other reasons offered for the change in these cultural traditions include the following:

- **Geographic mobility.** Adult children move out of state for various reasons, including education and jobs. As a result, many families now have members who live on the mainland. Some providers reported that they increasingly get calls from adult children on the mainland who are worried about their aging parents.

- **Because people are living longer, more people have extensive long-term care needs which place strains on caregivers.** People with disabilities may have special needs that require expensive supplies, such as incontinence pads, and dietary problems that require nutritional supplements. Additionally, the State has high levels of obesity, which greatly increases the physical demands on caregivers. Families may provide care for years, but then face a crisis when care needs increase and they are unable to meet them or to pay for services.

- **The high cost of living in Hawaii,** particularly of housing, means that many households need two or more wage earners, reducing the number of potential caregivers. A few respondents noted that people in their 60s are working and are not able to take care of aging parents. The high cost of housing means that many living units are small and cannot accommodate multigenerational families.

- **Lack of interest among some of the younger generation,** who no longer want to provide care or feel they cannot because of other priorities. One respondent said that the children of residential care home operators—generally a family business—are not interested in this work.

Several stakeholders noted that many caregivers are burning out as their family members’ needs become more complex and that the nonprofit organizations that provide evening, overnight, and weekend respite are cutting back on services because of lack of funding. They particularly noted the pressing need for services to help informal caregivers who are not eligible for Medicaid.

Some respondents expressed major concerns that a weakening of the informal care system will increase the number of people who will need paid services, including those who rely on Medicaid. One respondent noted that a substantial portion of Medicaid home and community-based services funding is spent on residents of adult foster care and expanded adult residential care homes rather than on individuals receiving care in their own homes. Although community care homes are an important part of the long-term care system, this respondent said that assisting informal caregivers is essential to delay or prevent entrance to community care homes and nursing homes.

Other stakeholders said that informal caregivers needed more support from employers in both the private and public sectors, noting that even in state government, although an individual supervisor may have some authority to provide some flexibility in work hours, no formal provisions allow government workers to adjust their schedules to accommodate caregiving responsibilities.

Several service providers felt that weakening of the informal care system has already occurred—evidenced by the extent of unmet needs they encounter in their work. Given this, they noted that the State cannot rely on informal caregivers to address current and especially future needs.
Lack of Long-Term Care Service Capacity

The overwhelming majority of respondents said that lack of service capacity is a major issue, noting shortages for nursing homes, home care, community-based services, and adult residential care homes. The lack of capacity is most acute for nursing home and adult residential care home residents with high needs (e.g., obesity, mental illness, complex medical needs, severe dementia, and combinations of these conditions). Because of excess demand, providers can be selective about who they admit without worrying about vacancies.

Some respondents said that because the State is made up of islands, some of which do not have sufficient services, geographic access barriers present challenges to meeting people’s needs. Some people have to travel to different islands for health and long-term care and some get “stuck” in a particular facility because they need services that cannot be provided where they live. Not surprisingly, one stakeholder noted that islands with larger populations have many service providers compared with others. Contradicting these views, one stakeholder said that there are no major geographic differences in access to Medicaid home and community-based services (possibly with the exception of meals-on-wheels and transportation services) and that each island has “enough” community care homes.

Insufficient Nursing Home Beds

Most stakeholders said that the State lacks sufficient nursing home beds to meet current demand and that the nursing home bed shortage would become even more of a problem as the elderly population increases. A few said that although additional nursing home beds were needed, nursing homes were just too expensive to be viewed as a primary or major solution to the State’s lack of service capacity in the long-term care system. Although some respondents cited the chronic nursing home waiting list as evidence of the nursing home bed shortage, only a few thought the waiting list itself was a major problem for the long-term care system. Some observers saw the waiting list primarily as a problem for hospitals that are not receiving payments for patients on the waiting list who are uninsured or not eligible for Medicare or Medicaid.

One respondent attributed the lack of nursing facility beds to Medicaid reimbursement that is lower than cost, noting that this is particularly a problem for subacute care patients. Moreover, because nursing homes historically have not provided care to these patients with such extensive needs, data are lacking which could be used to calculate more appropriate rates. According to this observer, the Level D Medicaid subacute payment is only for patients who have tracheotomies or who are on ventilators, but it needs to be expanded to include other complex conditions (e.g., a need for skilled services, complex wound care, comorbidity with behavioral issues, or patients who are morbidly obese).

Given the increased demand for services by the subacute/medically complex patient population, this stakeholder argued that the State needs to develop tailored “niche” services (e.g., an eight-bed facility for morbidly obese patients), but providers cannot obtain Medicaid reimbursements to cover such services. Two respondents noted that to care for many of the medically complex and high-need patients on the waiting list, nursing homes have to provide their staff with additional training, which is costly.
When asked why nursing homes would not admit the postacute patients on the waiting list who would be eligible for Medicare reimbursement, one stakeholder replied that these residents would stay in the nursing home after their Medicare coverage ended. If nursing homes admit these individuals, they will have to continue caring for them with much lower Medicaid reimbursement. Thus, it is not in the interest of nursing homes to admit these heavy care patients until Medicaid long-term care reimbursement rates are higher. Until then, hospitals will remain the default care setting for this patient population.

One stakeholder argued that if the State and providers wanted to solve the waiting list problem, they would. Another stakeholder agreed, noting that the State’s Medicaid program has no financial incentive to move waitlisted Medicaid beneficiaries from the hospital to nursing homes. One respondent asserted that the waiting list for nursing homes beds is the result of a deliberate state policy not to certify for Medicaid participation all of the nursing home beds available because the State does not have the money to fund more Medicaid nursing home beds.

**Insufficient Adult Residential Care Homes in Certain Geographical Areas**

Several stakeholders mentioned a shortage of adult residential care home beds, which is particularly acute in certain communities. Many of these homes were geographically “segregated”—located primarily in fairly small ethnic communities on Oahu and Hawaii. Some respondents said that this pattern of service location creates problems for people who want to receive care in these homes but do not want to leave their own communities. Their location also reduces opportunities for community integration. As one respondent put it:

> Family foster care and adult residential care homes are predominantly run by people from the Philippines. This is a good thing when they are located in communities where many people from the Philippines live. It ensures that this population has providers from the same culture with the same language. It is not always a good match when people from other ethnic groups need care in these homes.

The location of community care homes in limited geographic areas is a longstanding problem, observers noted, partly because of the residential location of people who want to provide this care. However, resistance from local communities who do not want these homes in their neighborhoods is also a factor. A family’s proposal to convert its home to a residential care home can generate considerable opposition from neighbors because of concerns about inadequate parking, wandering by residents, and noise caused by ambulances.

Another factor limiting the growth of adult residential care homes is that real estate is expensive and these homes are costly to outfit to meet state requirements. One stakeholder estimated that it usually costs between $100,000 and $150,000 in renovations to meet Department of Health certification requirements. A few respondents noted the difficulty of operating financially sustainable community care homes, noting that because housing is expensive, people with large homes are often better off financially renting out rooms than operating as a foster care or adult residential care home.
Insufficient Home and Community-based Services
Infrastructure and Financing

Home and community-based services are also in short supply, according to many observers, which contributes to a strong institutional bias. Several stakeholders said that most people cannot afford to pay the $25 per hour it costs to purchase services from home care agencies. Many stakeholders said that it was essential for the State to provide additional funding for home and community-based services, in part because failing to do so would increase the need for more expensive health care and increase the demand for nursing home care.

One respondent contended that the State and others support home and community-based services because they are believed to be less expensive than nursing homes, but there are economies of scale in nursing homes. According to one stakeholder:

> The cost of home care can be very high for people who need supervision or the availability of assistance 24 hours a day. In fact, depending on the amount of services required, home care can cost as much as or more than nursing home care. It is important not to take a simplistic view regarding the relative costs of institutional care and home care.

In particular, Medicaid pays an all-inclusive rate for nursing home care. In the community, however, each discrete service (e.g., transportation costs, case management, Registered Nurse, home health aide) is unbundled and billed separately, so costs can be high. One stakeholder contended that some providers own businesses in each of the discrete service lines and "self-refer" from one of their service lines to another.

With the implementation of the Medicaid QUEST Expanded Access (QExA) program for older people and persons with disabilities, use of home and community-based services has reportedly increased by 20 percent and waiting lists for home and community-based services waiver services have ended. Some stakeholders also noted that the program has a consumer-direction option that allows individuals who need personal assistance to hire friends and family members. One respondent expressed concern that the higher capitation rate in QExA for enrollees who need home and community-based services will lead to unnecessary use because of the financial incentives for the health plans to increase the number of people in that payment category. On the other hand, two stakeholders contended that chore services have been cut back drastically since the implementation of QExA, although one person said the change was appropriate because some people receiving services did not need them.

Several stakeholders noted that the state-funded Kupuna Care program has about 500 people on a waiting list and federal Older Americans Act-funded programs also have waiting lists. Specific home and community-based services shortages were noted for respite and adult day health services. Several respondents said that the need for weekend respite care

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2 Medicaid QExA is a Medicaid managed care program for older persons and younger persons with disabilities. It covers both health and long-term care services. Currently, two plans are available—Evercare and the Ohana Health Plan.
for family caregivers is especially great. Maui reportedly has a good adult day care program, but the number of people it can serve is limited and it cannot address the needs of people with complex medical needs.

**Fragmentation of the Long-Term Care and Health Systems**

Many respondents identified fragmentation of the long-term care system as a major problem, noting that there is no real long-term care “system”; every component was designed for a different purpose and they do not work together. Consequently, the system is so confusing that people do not know what resources are available and cannot figure out how to get services. Particularly when caregivers are feeling overwhelmed or are dealing with a crisis, they do not have the time or the knowledge to find and arrange the services that family members need in the most appropriate setting. As one stakeholder put it, “It’s a maze that even professionals acknowledge is convoluted and difficult to sort through.”

In addition to confusion among the general public, some health and long-term care providers also do not understand the system and its various options. When the need for long-term care arises, understanding the eligibility rules for various services and differences among services can be daunting. In particular, according to several observers, Hawaii’s system of foster family care, adult residential care homes, and expanded adult residential care homes, with the different levels of care that they provide, is very difficult for consumers to understand.\(^3\) In a summary judgment by one stakeholder, “The ‘system’ is just a lot of disjointed programs with different eligibility criteria.”

The fragmentation of the delivery and financing system is not limited to long-term care. One stakeholder argued that people served in the long-term care system also need and receive services across the entire health and long-term care continuum and that both systems are fragmented. As one stakeholder summarized it for Medicaid:

> The Medicaid system is not designed to provide cost-effective and high-quality care. There is a lack of coordination and communication among health care providers (mainly due to lack of reimbursement for coordination and communication services), which limits the system’s ability to support individuals in the community and to prevent health and functional decline. More efforts should be focused on how proper coordination and case management of individuals entering the acute care system can be used to promote better outcomes and reduce costs, which would contribute to a decrease in aggregate Medicaid long-term care costs.

Some respondents asserted that transitions between health and long-term care settings could be much better managed. They said that because people are not getting adequate services in the community, they develop health problems and are hospitalized or admitted to a nursing home. This is particularly a problem among lower income older persons and those without informal support networks. Service coordination and follow-up postdischarge

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\(^3\) Foster family care homes and expanded adult residential care homes are allowed to serve a limited number of individuals who need a nursing home level of care, but adult residential care homes are not allowed to serve this population.
to prevent rehospitalizations and nursing home admissions is lacking. One respondent stated that the State’s managed care plans are attempting to address this problem.

In addition, one commenter observed that the system does not deal well with certain subpopulations who are aging—for example, people with developmental disabilities, serious mental illness, and HIV/AIDS. Often the agencies that serve older persons and those that serve discrete populations, such as persons with developmental disabilities or serious mental illness, believe that the “other” agency is responsible for serving older people with these conditions. Reportedly, some providers serving older people are attempting to work with agencies that serve other populations but doing so is difficult because public funding is siloed and services have been cut.

Some stakeholders noted the lack of coordination among the many entities that provide services to older people and their families. Difficulty navigating the system was the reason that the State developed an Aging and Disability Resource Center (ADRC). Although the State received a federal Systems Change grant from CMS in 2001 to begin development of an ADRC and an Administration on Aging/CMS ADRC grant in 2005, the ADRC was described by one stakeholder as having “just been launched” and by another as being “in its infancy.” Additionally, with the exception of one physical office in Hilo, it remains largely a series of Web sites rather than an organization that interacts with consumers on an ongoing basis to provide help navigating the long-term care system. One respondent expressed concern that people using the ADRC are discouraged to learn that there is a waiting list for many publicly funded services. According to several stakeholders, older adults of many different ethnic backgrounds have neither computers nor the language skills to use the ADRC Web site.

Moreover, some long-term care stakeholders had never heard of the ADRC. One provider said she had heard about it but did not know how to contact it, noting:

*If I don’t know about it, how is the general public supposed to know? All they know is that the hospital said to call a particular case manager or case management agency. It’s easier for discharge planners to call a case manager than to call 50 different foster care or adult care providers to find an appropriate placement.*

Compounding the problems of the limitations of the ADRC, several stakeholders noted that the State laid off hundreds of workers in the Department of Health and the Department of Human Services and closed several Medicaid eligibility application centers to address the budget crisis. Currently, there are only two physical offices in the State—one in Honolulu and one in Hilo—where people can apply for Medicaid in person. One respondent said:

*People seeking services now either use the telephone or the Internet to get information but many people need face-to-face contact because they do not have computers, or do not understand English or the bureaucratic process. It is impossible for them to navigate the system by phone, computer, or written communication.*
**Lack of an Effective Referral System Between Hospitals and Long-Term Care Settings**

Several stakeholders said that hospital discharge planning was inadequate, especially in terms of its relationship to community care homes. As one stakeholder put it:

> We can improve the long-term care system by ensuring appropriate placement post-hospital discharge. Not everyone needs to go to a nursing home, or if they do, they may only need postacute care for a short period of time. Some people may be able to be cared for at home or in an adult care home. Individuals should be discharged to the least intensive level of care that meets the individual’s needs. Anything more would be considered waste. However, discharging an individual to a lower intensity of services when more care is required potentially jeopardizes patient health and safety, and can increase the risk of rehospitalization.

Respondents noted that because discharge happens so quickly and nursing home beds are lacking, many people are discharged home too soon without necessary services in place. As a result, they are not able to care for themselves nor are their families adequately prepared to care for them. In addition, some people are discharged too soon to family foster care providers, which is particularly a problem for elderly persons who may not have the cognitive capacity to engage in discussions about their needs postdischarge and thus are at risk for rehospitalization.

Several respondents emphasized the importance of matching individuals who have long-term care needs with the right setting and caregiver, noting that placements are often not based on residents’ desires. One stakeholder contended that discharge planners sometimes collude with the proprietors of particular homes to ensure that their beds are filled, regardless of the client’s needs or preferences. One respondent alleged that hospital employees who are relatives of facility operators steer patients being discharged to their relatives’ facilities.

**Poor Quality/Insufficient Monitoring of Home and Community-Based Services**

Somewhat surprisingly, because it is usually a matter of great concern in other states, none of the stakeholders interviewed raised concerns about nursing home quality. Concerns about the quality of home and community-based services were raised in four areas:

- Competency of long-term care workers generally; language barriers; and cultural differences.
- Low levels of training and the potential for fraud when people hire workers privately rather than through agencies. Some observers stated that many home care workers are paid “under the table,” contributing to the State’s grey economy and decreasing tax revenues.
- Lack of monitoring of some home and community-based services providers. Although a 2009 law requires licensure of home care agencies that primarily serve the private pay market, it has not been implemented because of lack of funding. Home health agencies are licensed.
Insufficient oversight and monitoring of community care homes.

The overwhelming majority of quality concerns voiced by stakeholders related to community care homes. Respondents stressed the importance of ensuring that family foster care and adult residential care home providers are able to provide adequate care because when they cannot address their clients’ complex health issues, they bring them to hospital emergency rooms, which is very expensive and sometimes unnecessary. Some stakeholders said that poor staffing was an issue and others said that low reimbursement made it difficult to provide good quality care.

One respondent contended that monitoring and oversight were generally weak, but that quality monitoring varies across the counties. A few noted some egregious lapses, such as when an operator convicted of criminal activity was allowed to open up a new home. (This incident was also reported in the Honolulu Advertiser in a series of articles running on March 28, 29, and 30, 2010.)

Several stakeholders said that adult residential care homes have successfully opposed additional quality regulations, including rating systems, criminal background checks for workers, and a Web site for complaints. One respondent claimed that in many adult residential care homes, only one person has received training and is qualified to care for residents; the other staff are family or friends of the owner with no training. This lack of training can lead to abuse (e.g., overmedication to solve behavior problems) and a failure to meet residents’ needs. In defense of the industry, one respondent contended that there were only a few instances of poor quality care in adult residential care homes and that similar rare instances occurred in other long-term care settings, but are not reported in the media.

Other quality-related issues respondents raised regarding community care homes include the following:

- **Inability to age in place.** The inability to age in place is an issue when adult residential care homes cannot continue serving residents who need more services as they become more disabled. Although some adult residential care homes are licensed to provide a higher level of care—expanded adult residential care homes—not all adult residential care homes are so licensed.

- **Regulatory inconsistencies.** The Department of Health regulates adult residential care homes using a medical model while the Department of Human Services regulates foster homes using a social model even though foster homes are required to serve at least one individual who needs a nursing home level of care and adult residential care homes are not permitted to serve individuals who need this high level of care. Both the Department of Health and the Department of Human Services oversee individuals in expanded adult residential care homes who need a nursing home level of care. One respondent contended that the overlapping responsibilities meant that neither agency was truly accountable for the quality of care in community care homes and each agency tended to fault the other for problems.

Expanded adult residential care homes have proposed that they be allowed to serve more than two nursing facility level-of-care residents (out of five maximum residents). Although a third resident at this level would help facilities financially because of the higher
reimbursement, some stakeholders questioned whether these homes could provide the level of care needed.

II. Reforms Needed to Address the Problems

Although there was considerable consensus among respondents about the long-term care system’s problems, there was less agreement about what should be done to solve them, primarily as a result of conflicting views regarding financing mechanisms. Respondents generally believed that many, if not most, of the needed reforms could not be accomplished without first addressing the financing issue—the “elephant in the room” as one person called it. Several stakeholders cited the urgency of doing so given the expected increase in the older population. As one person put it:

> With an aging population, the biggest concern is that we need to prepare for future long-term care needs. We need to determine what those needs will be and how to meet them; how we will provide services and most importantly who will pay for them—how the services will be financed.

Several stakeholders stressed that solutions needed to come from both the private and the public sector and one felt strongly that the State needed to make a major shift in thinking about aging and what it means to be old, noting that many older people are active into their 70s and that no one wants to be called elderly when they are 60 years old. Given the longevity of the population in Hawaii, some observers urged the State to take steps to help people adopt healthy lifestyles to prevent chronic illnesses, frailty, and other conditions that can lead to a need for long-term care.

*Exhibit 4* summarizes stakeholders’ views on needed reforms in the long-term care system.

**Solve the Financing Problem**

Virtually all respondents mentioned financing and many focused on it as the key reform needed to address current and future long-term care needs. Several persons interviewed noted that it would not be possible to address financing issues until the recession ended and the legislature and the governor were in more philosophical agreement. One stakeholder felt that fixing the long-term care financing system was part of the government’s overall responsibility to aid the poor, aged, and disabled. This person stated, “The State is going to have to find the funds. Although people don’t want taxes raised, they will have to pay the cost somehow.”

Because Medicaid services are partly financed at the state level with general revenues and must compete with funding for other state services, some respondents argued that the State needed to develop a new source of dedicated funding for long-term care—one that would rise with inflation and with need. Some stakeholders related that consumer advocates are proposing an increase in the sales tax to fund services for seniors and long-term care. Advocates of higher taxes cautioned that the State needs to find ways to raise revenue that do not have a negative economic impact or adversely affect lower-income people.

The first step, some said, in tackling the financing issue would be to compile a comprehensive long-term care budget for the State; currently, funding for programs for
Exhibit 4. Reforms Needed to Address the Problems

- **Solve the financing problem.** Stakeholders were strongly divided about whether the public or the private sector needed to expand to solve the financing problem. Some respondents believed that long-term care is fundamentally a social responsibility of government and that either taxes will need to be increased to pay for Medicaid or a new public long-term care insurance program will need to be established, financed by premiums and general revenues. Other respondents believed that long-term care is ultimately an individual responsibility and that the goal should be to reduce the role of government programs in financing long-term care. Advocates of this view tended to support education on the financial risks of long-term care and tax incentives for purchase of private long-term care insurance policies.

- **Increase service capacity.** Several respondents stressed the need to increase the availability of all types of long-term care services (nursing homes, community care homes, and home care), particularly for people who are not eligible for Medicaid and to provide respite for informal caregivers. While recognizing the need for institutional care, they stressed that the state should not rely only on nursing homes to address long-term care needs. Other stakeholders, however, cautioned that home care does not necessarily lead to cost savings, particularly when individuals need extensive care and supervision.

- **Reform components of the service delivery system.** Stakeholders had a variety of highly specific recommendations, including revising the eligibility determination and service allocation approach for Kupuna Care and increasing the use of consumer-directed services. Some observers stressed the importance of understanding the current system and designing solutions to its problems before adding new funding, which would just expand the current inadequate system.

- **Reduce system fragmentation and improve service coordination.** On the policy level, some stakeholders advocated consolidating long-term care policy and regulation into one agency, as is done in Oregon and in Washington. Many stakeholders believed that strengthening the Aging and Disability Resource Center could help consumers receive the services they need.

- **Address quality problems with community care homes.** Stakeholders proposed a number of initiatives to improve the quality of care in community care homes, including increasing training and case management, implementing uniform and systematic screening of community care home applicants to ensure appropriate placement, and developing specialized licensing for facilities that serve residents with severe disabilities and complex medical/nursing needs. Some observers thought that regulatory consolidation was particularly needed for oversight of community care homes, which is currently split between the Department of Health and Department of Human Services.

- **Develop adequate reimbursement rates.** Some stakeholders proposed better linking reimbursement for nursing homes and care homes to residents’ needs, a major goal of which would be to pay more for severely disabled and medically complex residents. In their view, the current rates are inadequate and have a negative impact on the quality of care provided to residents. One stakeholder dismissed providers’ concerns about reimbursement, noting that they manage to stay in business with the current rates.

- **Change the state’s decision-making process.** In addition to possibly reorganizing state government to consolidate decision-making on long-term care in a single organization, several stakeholders recommended making decision-making more inclusive and transparent. In particular, respondents said that long-term care stakeholders should be more involved in the decision-making process.
older people and persons with disabilities are not examined together. Additionally, although Medicaid is the dominant public funding source for long-term care, it is important to understand how much money is being spent on other programs for younger people with physical and mental disabilities and for Older Americans Act programs. According to this view, the State needs a better sense of the total spending on long-term care and current funding allocations to identify areas that need more funding and to discuss alternatives for financing services. As one person stated, “We need to know how much we’re spending and come up with alternatives for financing it differently. The State must determine what resources are available and what its priorities are for spending them.”

When asked if the State should develop a global long-term care budget that combined all state long-term care funding as is done in Oregon and Washington, one respondent said that the State was not yet ready for this approach because much more needs to be known about current funding. He noted that legislators and even people knowledgeable about long-term care know something about different programs, but not how they are funded. (This view was borne out in the interviews; people who were very knowledgeable about certain aspects of the long-term care system did not always know how specific services were funded.) Some stakeholders stated that to meet the projected increase in long-term care needs, the State needs to stop looking at the old mechanisms for financing and to start thinking about new approaches. One stakeholder insisted:

*If the State is not able to provide the necessary funding, we have to look at other ways to address long-term care needs instead of sitting around and complaining or pointing fingers. If the State has not responded to calls for more money for aging services for the past 20 years, then we need to propose new solutions that might get state support.*

Finally, one respondent said that the current system provides a very poor foundation for expansion and simply adding money to it is not the solution. Rather, the State needs to decide on the specific service delivery model it wants before adding additional funds. It needs a better understanding of the current system of service delivery, its gaps, and its shortcomings to design a model to ensure quality, choice, and cost efficiency. In his view, a good starting point would be to combine the regulatory and administrative infrastructure from multiple organizations into one agency.

Respondents were divided on whether the State should promote “personal responsibility” and encourage individuals to voluntarily purchase private long-term care insurance or implement a mandatory public long-term care insurance program. One respondent noted that fixing the financing problem will be much more difficult than fixing problems with the service delivery systems because what is needed is what is hardest to get: thoughtful conversation about long-term care issues—devoid of partisan politics—and the crafting and enactment of solutions.
**Enact a Public Social Insurance Program**

Several stakeholders said that a mandatory social insurance model that spreads risk across the entire population would be the best solution by providing universal coverage for a basic long-term care benefit. Another respondent thought that a major goal of reform should be to prevent people who have been financially independent all of their lives from becoming impoverished and ending up on welfare in the form of Medicaid.

Those people who supported requiring everyone to participate in a public insurance program believed that spreading the risk across the entire population is the only realistic solution to raise the funds necessary to pay for the growing number of people with disabilities. One stakeholder argued:

> People are more likely to pay premiums that provide benefits to the people enrolled in the insurance program rather than to pay taxes that subsidize “other” people, such as Medicaid beneficiaries. People will be more willing to pay for their own long-term care than for others. Cross-subsidies are hard to sell politically.

This basic program could be supplemented by private long-term care insurance with Medicaid as the safety net. One respondent noted that had the 2002 proposal for a state public long-term care insurance program, Care-Plus, been enacted, the State would currently be reaping its benefits during the current economic crisis because a dedicated funding stream would be available to finance long-term care. Another person said that unless the State mandates insurance coverage, it is unlikely that people will purchase it, and noted that Hawaii has had mandatory health insurance for many years and most people now take it for granted.

Additionally, several observers did not believe that sufficient numbers of people would enroll in a voluntary public insurance program to make it actuarially sound, so enrollment should be mandatory. One stakeholder predicted that enrollment in the CLASS Act would be low because it is voluntary.

When asked about the likelihood of a Hawaii-specific social insurance program being enacted in the coming years, those who thought it would be possible agreed that it would have to wait until the current economic recession was over because mandating payment of premiums would be a “nonstarter.” However, once the recession ends, they believed that the legislature could consider such a program if the new governor supported it. They noted that the State came quite close to enacting this type of program in the early 2000s.

Stakeholders who support a public social insurance program acknowledged that it will be difficult to convince the public of its need because people know little about long-term care. Additionally, some stakeholders seemed unfamiliar with the basic financial underpinnings of

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4 Most of the interviews took place before the enactment of the Community Living Assistance Services and Supports (CLASS) Act as part of the Patient Protection and Accountable Care Act of 2010. These new provisions establish a voluntary, public insurance program for long-term care. Thus, for the most part, the conversation focused on Hawaii-specific rather than national options.
insurance programs—that they must pool the relatively small number of people with high risk of needing services and the large number of people with a low risk of needing services to create an affordable premium. For example, one respondent said that Care-Plus was poorly conceived because everyone would pay into it but not everyone would receive long-term care benefits.

Because most of the public does not know there is a long-term care problem, many people—especially young people—will resist paying even a fairly nominal premium/tax. To gain the public’s support, supporters of a public insurance approach argued that the State and long-term care advocates will have to explain the long-term care financing problem to the public to convince people that the private sector is not an adequate solution.

One respondent noted that a social insurance approach might be needed but that the federal government rather than the State should be responsible for this initiative. One stakeholder noted the importance of the State understanding how the long-term care provisions of the new legislation—particularly the new CLASS program—will affect the State.

Several respondents were opposed to a mandatory public social insurance program, some strongly so. One stated that the government should help those in need, but that a government insurance plan is not the solution. One observer observed that Republicans resist public social insurance because they believe that financing for long-term care is the responsibility of individuals and their families. One stakeholder summarized the opposition by saying, “If the government provides the care, then it reduces personal responsibility. It’s socialism.” Others noted that the insurance industry and the Chamber of Commerce also oppose social insurance programs for long-term care.

**Encourage the Purchase of Private Long-Term Care Insurance**

Several respondents believed that private long-term care insurance is the solution to the financing problem. Just as people understand the need for homeowner’s insurance, they need to understand the need for long-term care insurance. One stakeholder said, “The best way to deal with the long-term care issue is for individuals to plan in advance and use the expert capabilities of the long-term care insurance industry.” One person related that people must learn that if they buy long-term care insurance when they are young, then it will be relatively inexpensive; if they wait until they are older, then it will be much more costly.

Supporters of private long-term care insurance did not believe that the government could mandate its purchase; instead they said that the State had to work to change people’s attitudes so that more people would buy it. Advocates of private long-term care insurance said that people need to be educated to prepare financially for possible long-term care needs, not just for aging parents but for themselves. Others noted that educational campaigns about the risk of needing long-term care have been conducted for years (e.g., by AARP) but have not been effective. In addition, in the current economic climate, it is particularly difficult to convince people to buy a relatively expensive product such as private long-term care insurance.

One respondent said that a major obstacle to getting the public to take responsibility for providing for themselves was that our society expects that the government will take care of them. This person said that this attitude is a particular problem in Hawaii because the State
has many immigrants from other countries, who are used to having government programs support them. One respondent noted: “This is part of their experience and they see little need to do things on their own; they are shocked that we do not provide all the things they are used to.”

Several stakeholders said that long-term care insurance can make a difference for the middle class and that the State should educate the public about the need to plan for their retirement years, including a possible substantial period of needing long-term care. They said that a cultural change is needed so that this middle class recognizes that they have to be responsible for their own long-term care needs. Unless they do, the pressure will be on the Medicaid program. As one respondent argued:

*People need to understand that the State does not have the money to provide long-term care for everyone who is going to need it. Medicaid is not an unlimited source of funds. People need to be able to take care of themselves. States do not have and will never have enough money to care for everyone who needs care.*

One respondent who opposed the Care-Plus legislation said that the tax/premium of $10 a month was “a lot of money for many people.” When it was pointed out that private long-term care insurance policies can cost over $100 a month, this person replied that the cost of private long-term care insurance could be reduced by fostering competition in the insurance industry, getting rid of regulatory barriers, and lowering taxes. In addition, this stakeholder said:

*More competition is needed to drive down costs. In addition, a bigger pool of people buying policies will reduce premiums. One option that could decrease prices would be for insurers to lower premiums for individuals with advance directives stating that they do not want heroic measures at the end of life.*

Several respondents thought that the State needed to provide financial incentives for the purchase of private long-term care insurance. Some advocates suggested that the State should make premiums for long-term care insurance tax deductible and that tax incentives should be aimed at 30- to 40-year-olds—when long-term care insurance will cost less—to further encourage its purchase. Others noted that such tax incentives primarily help those with relatively high incomes, and that even with the incentives, many people would still not be able to afford insurance. Another said that tax incentives primarily would help those who would have purchased insurance without the tax benefit. In the view of one stakeholder, even if actuarially sound products are available for most people, it does not make sense to purchase policies unless they have sufficient assets to protect—at least $100,000.

**Increase Service Capacity**

Several respondents stressed the need to increase the availability of all types of long-term care services, particularly for people who are not eligible for Medicaid and to provide respite for informal caregivers. While recognizing the need for institutional care, however, they stressed that the State could not rely only on nursing homes to address long-term care needs. As one stakeholder put it:
Past studies have shown that we need more acute, subacute, and long-term care beds—we know that. But for the long term, we need more home and community-based services to better balance expenditures between the two settings. We need to strengthen the infrastructure for home and community-based services and deemphasize institutional care.

One respondent recommended that the Hawaii Long-Term Care Commission focus on increasing the proportion of Medicaid long-term care expenditures spent on home and community-based services. Other stakeholders, however, cautioned against expecting cost savings by shifting funding from institutions to home and community-based services. Another stakeholder argued that the goal should be to “level the playing field” between institutional and home and community-based services and then let consumers decide what services they want.

One person stressed the importance of developing the home and community-based services infrastructure on all of the islands so that people are not forced to leave their homes or the State to get services. Another suggested providing incentives to home and community-based services providers to expand services on islands with shortages.

Given the high cost of institutional services and the desire by most people to stay at home, one stakeholder suggested that the State provide more services that help informal caregivers to keep their relatives at home, such as adult day care. One respondent noted that the overwhelming majority of Medicaid home and community-based services funding is spent on residents of family foster care and expanded adult residential care homes rather than on individuals receiving care in their own homes. Although residential care homes are an important part of the long-term care system, this respondent argued for assisting informal caregivers to delay entrance to community care homes and nursing homes.

Other stakeholders said that informal caregivers need more support from employers in both the private and public sectors, noting that even in state government there are no formal provisions allowing government workers to adjust their schedules to accommodate caregiving responsibilities. They proposed that the State work with employers to encourage them to offer benefits to support caregivers, such as flex time, working from home, job sharing, and paid family leave. However, they also noted that the business community has opposed such proposals in the past.

Reform Components of the Service Delivery System

Although some stakeholders felt that it was pointless to discuss reform of the service delivery system in the absence of sufficient funding, many respondents proposed needed improvements, acknowledging that most would require additional financing. Moreover, these observers thought that obtaining additional funding would be easier if there was a clearer vision of what the money would be used for. Some observers believed that the long-term care system could work more effectively and efficiently by addressing service delivery reform, even without additional funding.

Some of the suggested reforms suggested addressed specific problems that stakeholders had raised as problems, such as the waiting list for Kupuna Care services. One stakeholder suggested that Kupuna Care’s current policy of providing services on a first-come first-
served basis, regardless of income, should be changed. Instead, public funds should be used to provide services to those at greatest risk for nursing home placement who do not have the personal resources to pay for them. To implement this approach, the State would need a common eligibility, intake, and assessment process across all points where people enter the Kupuna Care system. However, another stakeholder felt that this approach would divert too much funding from services to an eligibility determination process.

Another stakeholder said that consumer-directed service options should be expanded, not just in Medicaid but in Kupuna Care, because such options offer greater flexibility than agency-delivered service models. They also permit payment of family members—particularly important if relatives quit their jobs to provide care. Paying informal caregivers ensures that they continue to build Social Security retirement credits and continue to pay taxes.

Respondents noted that any solutions to current service delivery problems need to be sensitive to the varied service models currently operating in the islands and to rural/urban differences. One observer said that before undertaking reforms, it is very important to have an overarching policy with respect to the service delivery models that will be promoted. The service options should allow for a balance of choice and the efficient use of Medicaid resources. The State also needs to develop a delivery system that is not based solely on either a social or medical model—but instead on a blended model that addresses both social and medical needs.

**Reduce System Fragmentation and Improve Service Coordination**

Several respondents commented on the need for better coordination within the long-term care system and between the health and long-term care systems. As a strategy to improve coordination and facilitate service implementation, some stakeholders believed that a new department should be created to bring together all state long-term care financing and policy into a single agency, as Oregon and Washington have done.

Some advocates said that the State’s ADRC should be strengthened to bring together all of the different components of the private and public long-term care system, including state agencies, county offices on aging, the state office on aging, service providers, elderly advocacy groups, and the disability community. Stakeholders agreed that there is a need for a “one-stop shop” where social workers and nurses conduct timely assessments to determine what services people need, determine eligibility for different programs, and help them get the support they need.

Several stakeholders proposed that each of the islands have a physical ADRC facility in addition to the Web site. They also said that Area Agencies on Aging are at different stages of development with regard to regard to intake, eligibility determinations, and referral procedures and more uniformity in these procedures is needed. As one observer noted:

> It would be helpful to have a physical site for ADRCs, which is necessary for the population it is supposed to serve. A large island like Oahu needs more than one site. People need to know the sites are available. It is also important to have access to interpretive services. We need to determine if telephonic interpretive services would work because there are so many languages, it would be difficult to ensure that all of them would be spoken at each site. We
know that for some language groups, telephonic interpretive services will not work because it is not culturally appropriate.

One observer noted that the State does not have money to fund case managers for the ADRC. Making the case for these case managers would be especially difficult because the Department of Human Services laid off many Medicaid and other program eligibility workers and has changed to a computer-based, online application system.

To resolve the problem of people waiting in hospitals for nursing home placement, observers said that actions are needed by the Department of Health, the Department of Human Services, hospital CEOs, and the representatives of the community care home industry. As part of this process, the hospitals and community care homes should develop better working relationships and referral systems. Other stakeholders said that certifying all available nursing home beds for Medicaid participation would increase the effective bed supply and ease placement backlogs.

**Address Quality Problems With Community Care Homes**

Several stakeholders proposed strategies for improving the quality of care that they provide, including the following:

- Provide more training for adult residential care homes’ staff and more oversight of the services they provide.
- Improve case management for residents of expanded adult residential care homes and foster care homes who meet nursing facility level-of-care criteria to help ensure that their needs are being met.
- Develop a systematic mechanism to screen adult residential care home and foster care home provider applicants for licensure.
- Consider specialized licensing to address the needs of particular populations and residents with higher acuity.

To address the overlapping oversight of community care homes, some stakeholders recommended revamping the current regulatory system. First, to ensure coordination across levels of care, they recommended that regulation of foster care homes, adult residential care homes, and expanded adult residential care homes be consolidated into a single agency. Second, to end what they saw as artificial distinctions across facilities, they proposed substituting the three current types of residential care with a single model of residential care with multiple tiers to serve residents with low to high levels of need, and reimbursement rates tied to these tiers, allowing for a better match of reimbursement and need.

**Develop Adequate Reimbursement Rates**

A few respondents emphasized the need for Medicaid payment rates to reflect the costs of providing care to residents with different acuity levels. One commenter noted that a reimbursement system based on resident disability and medical needs would make the residential care industry more attractive to potential providers. Another said that such rates should provide an incentive for nursing homes to admit high-need residents. In particular,
they argued that higher Medicaid rates are needed for medically complex medical patients—especially for those in hospitals waiting for discharge to nursing homes.

Currently, the level of care tool (DHS Form 1147) does not acknowledge additional labor requirements that nursing facilities and home and community-based services providers need to care for some residents. As a result, community care home providers find that their residents need many more services than they were assessed for. In their view, the current rates are inadequate and have a negative impact on the quality of care provided to residents. One respondent, however, dismissed concerns about reimbursement, saying that “providers manage to stay in business despite them, so they must be adequate.”

One respondent proposed allowing foster care homes and expanded adult residential care homes to serve a higher number of residents per facility. Specifically, this stakeholder argued that foster homes with sufficient rooms should be allowed to take three to four residents (with up to two private pay residents), and expanded adult residential care homes should be allowed to serve three residents who need a nursing facility level of care rather than just two. This stakeholder argued that these changes are needed to make care homes more financially viable. However, several respondents had reservations about expanding the use of community care homes to care for individuals who need a nursing home level of care because they felt that the homes are not adequately monitored and that quality of care problems are frequent.

**Change the State’s Decision-Making Process**

Several stakeholders made recommendations for changes in the State’s overall decision-making process for long-term care. One respondent said that the State should more systematically include stakeholders in discussions about potential changes, noting that:

> State agencies need to involve those who will be affected by the changes, but they currently do not and this is a problem. Involving stakeholders may require a longer process but the product at the end will be better and it will increase cooperation when it is time for implementation. Much more consumer involvement is needed.

A few respondents said that more effective advocacy is needed to advance long-term care policy and that older people need to be more assertive in their demands. Several observers said that the general public and many policymakers are not well informed about long-term care and need to be educated about issues and options before reforms will be possible.

Several observers felt that that nothing will be done for the aging population without support at the highest policy levels, including the governor, and stressed the need for the new gubernatorial administration to make long-term care a high priority. One participant said that proposals for addressing Hawaii’s long-term care issues over the past 20 years have not been successful because policymakers have not made it a priority. Thus, it is essential to look at other mechanisms, including those that do not necessarily require more state funding, to address long-term care issues (e.g., changing how the culture and state policy views aging and retirement). For example, the Older Americans Act qualifies people for services at 60 years of age, implying that they are old. The State needs to reconsider the age at which people are considered “old.”
According to one respondent, Hawaii is a highly unionized state where many workers can retire at relatively young ages, but many individuals do not need or really want to retire. Retirement benefits planning should include not just financial planning but activity planning as well to keep older people socially connected and engaged, which are factors associated with successful aging and good health. Doing so may help to prevent the physical and mental decline that can lead to a need for long-term care. This observer also felt that the State needs to increase funding for health education, health maintenance, and health promotion programs that are of proven benefit in improving health during later periods in life. Although doing so in tough economic times may seem wishful thinking, this participant thought that possible savings in overall medical care may offset the cost of these services.

III. Obstacles to Reforming the Long-Term Care System

Stakeholders provided many lessons learned on why past reform efforts failed—particularly the effort to enact the Care-Plus program. Respondents said that all of the obstacles that prevented past reform efforts from succeeding still needed to be overcome for future efforts to succeed. In addition, a new obstacle—the current economic recession—had to end before any major financing reforms could occur. Stakeholders specifically mentioned five major obstacles: opposition to taxes, opposition to expansion of the public sector, lack of political will among government policymakers, lack of knowledge and understanding of long-term care issues, and lack of effective advocacy. Stakeholder views of obstacles to reforming the long-term care system are summarized in Exhibit 5.

Opposition to Taxes

Many options for reforming the long-term care system depend on increased tax revenues but the current governor, the business community, the insurance industry, and many legislators oppose tax increases. Some stakeholders highlighted the strong lobbying by the Chamber of Commerce and the insurance industry against past long-term care financing reforms and pointed to their opposition as a major obstacle.

Some respondents thought that cigarette and soda taxes may be raised in the near term, although not to pay for long-term care services. Rather, several stakeholders noted that the State's priorities are education, rail transportation, and green energy jobs. Another said that the governor's priorities are energy, business development, and children, noting that the governor had publicly stated that there is not much she can do for seniors and that it is more cost-effective to provide services to children. Another said that because the economic crisis had led to cutbacks for many services, the first priority when the recession ends will be to restore cuts for children and education and that senior services will be a much lower priority.

Most stakeholders thought that until the State is out of the recession, it is unrealistic to think that any new tax revenue will be possible. Several observers said that the State has to figure out how to pay current long-term care costs and does not anticipate a return to its prerecession budget until 2012. Some observers argued that a public insurance premium that provides benefits to the insured would be viewed differently than a tax and could have more support but others did not agree with this view.
Exhibit 5. Obstacles to Reforming the Long-Term Care System

Stakeholders identified several barriers to reforming Hawaii’s long-term care system:

- **Opposition to new or higher taxes.** Both advocates for and opponents of increased government spending identified opposition to additional taxes as a major barrier to increasing government revenues for long-term care. Some stakeholders believed that the public would view a social insurance premium differently than a tax, but not all respondents held this view. Most stakeholders did not think it was politically realistic to propose any tax increase until the economy improves.

- **Opposition to expansion of the public sector.** The appropriate role of government was an area of disagreement among stakeholders, with some wanting a larger role and others wanting a smaller role. This is a philosophical difference that is very difficult to bridge.

- **Lack of knowledge about long-term care issues.** Most stakeholders expressed frustration concerning the lack of knowledge by government officials, the legislature, and the general public about long-term care issues. Bold initiatives are not possible if policymakers are unaware of the issues and the problems underlying them.

- **Leadership lacks the will.** Most stakeholders did not believe that top government policymakers are committed to addressing long-term care issues. The strong division between the underlying philosophies of the current governor and the current legislature make it hard to argue for investment of time and energy in long-term care reform at this time. Some observers saw the election in November as an opportunity to bring the governor and the legislature into closer ideological alignment.

- **Lack of effective advocacy.** Although stakeholders faulted government policymakers, they also faulted long-term care providers and consumer advocates for being largely ineffective in advancing the cause of long-term care reform. According to observers, this lack of effectiveness breeds indifference because advocates do not see successes on which to build.

**Opposition to Expansion of the Public Sector**

Some approaches to reform—such as a social insurance program—include a larger role for the public sector, which many oppose as a matter of principle. Another respondent said there is no clear cut agreement about the appropriate role of government in long-term care. Conservatives, it was noted, lack trust in the government and assert that because there is so much waste in government, the public has lost faith that their money will be used appropriately. One stakeholder characterized the Republican view of social responsibility as encouraging volunteerism and having the community fix its own problems.

A few respondents said that the problem is political (i.e., that legislators are focused on getting reelected so they do not want to take strong stands that will offend some constituents). Moreover, one observer noted that although Republicans are ideologically united, Democrats include legislators with a wide range of political views, some of which are quite conservative.
Lack of Knowledge About Long-Term Care Issues

The majority of respondents felt that lack of knowledge and understanding about long-term care issues is a major obstacle to reform efforts. One respondent said that some members of the legislature do not know the difference between Medicare—the federal health insurance program for older people and some persons with disabilities, and Medicaid—the federal/state health care program for the low-income population with very few assets and people who are “medically needy” (i.e., they become poor because of the high cost of medical care). As one stakeholder put it, “People are always in denial about long-term care—until they or a family member needs it.”

The lack of understanding underlies the difficulty in gaining public support for major long-term care initiatives. According to stakeholders:

- Many people deny the seriousness of the problem and its implications for the future and do not understand their risk for needing long-term care and the need to plan for it. Others do not want to think about long-term care because it is unpleasant and distasteful to think about being dependent on others.

- Those who work in long-term care know there is a crisis because they see people falling through the cracks and not getting quality care, but neither the general public nor legislators know this.

- Influential people often have the financial resources to provide for their elderly relatives. As a result, they think that every family should and can do the same. They do not understand that not everyone can afford to provide or pay for this care.

- The public may think they can care for relatives at home, but do not understand how expensive paid home care is. They also do not know how expensive community care homes and nursing homes are. Some people rely on “solutions” that are unrealistic (e.g., divesting assets to become eligible for Medicaid without knowing that there is a 5-year look-back period).

- The belief that long-term care is a family responsibility is widespread. Although families certainly have an important role to play, few can handle it alone. When they do not receive support, caregivers burn out and the elder is institutionalized.

- The public does not understand the principle of risk-pooling that is central to insurance. This principle requires everyone to pay a modest amount to cover the high costs of a few, while providing financial protection for all at an affordable cost.

- The public wants services but does not want to pay for them—certainly not through taxes.

- People do not want to go to a nursing home when they are older so they do not want to pay taxes or a premium for insurance that pays for nursing home care.

- Private sector options for financing long-term care, such as reverse mortgages, have lessened perceptions about the urgency of financing reform because it enables some people to pay for services.

Many stakeholders noted that until people have personal experience with long-term care, they do not comprehend the issues. One said that the adult population is getting more concerned as they begin to deal with the long-term care needs of their aging parents and
that this direct experience should make them more supportive of long-term care reform efforts.

A few observers noted that for the past several years, the State has seen a very coordinated effort among advocates for the elderly and people with disabilities to reform the system—but nothing has resulted because the legislature needs to hear from the general public as well. But the general public does not understand that the system is broken. According to one stakeholder: "The public needs to demand changes, but they don’t and won’t until they are personally affected by the burden of long-term care—its costs or as a caregiver."

A few respondents said the State needs to undertake a major education campaign so the public will demand long-term care financing reform but when asked what type of educational efforts would be effective, they had no concrete proposals, noting that past efforts have not been successful.

**Leadership Lacks the Will**

A majority of stakeholders felt that an obstacle to reform is the lack of top-level government leadership on long-term care issues. As one stakeholder put it:

> We have been talking about a range of issues—problems with the long-term care system, the need for more home and community-based services, inadequate Medicaid reimbursements, and workforce development, etc.—for a very long time. The issues have been talked to death but no one is willing to make a move. No one wants to give up the known for the unknown.

Several observers noted that most legislators lack personal experience with long-term care, do not understand how expensive it is, and do not understand the relationship between long-term care and the Medicaid budget. Another commenter said that because legislators need to be educated, long-term care reform will require incremental steps. On the other hand, one stakeholder said that *incremental* reforms could forestall the crises that may be needed to push the State to make the broad changes that are needed.

Because Hawaii has strong gubernatorial powers and a weak legislature, several respondents noted that it is hard to pass a bill if the governor opposes it. Even if the legislature overrides a veto and appropriates funds, the governor can refuse to spend the funds. The legislature can only force the release of funds if two thirds of both houses agree.

**Lack of Effective Advocacy**

A few stakeholders said that advocates for older people are not politically strong or well coordinated, noting that compared with legislative caucuses for children, Native Hawaiians, or Filipinos, those for elderly persons and persons with disabilities do not have the same clout. As one person noted:

> The population in need of long-term care is not a strong advocacy group. They need help to just live. So providers need to advocate, but we’re seen as self-serving even though many of us are nonprofits and care about the people we serve.
One respondent said that long-term care workers cannot participate in rallies because if they do not work they will not get paid. Also, many feel that rallies, letter writing, and other lobbying efforts will not make any difference. Another stated that the islands go to the legislature separately with their requests but what is needed is unified advocacy for a system that will work for the entire state. Similarly, different sectors of the long-term care system do the same (e.g., adult residential care homes have their own lobbying group as do foster care homes).

**Summary**

The purpose of this report is to provide information about the views of long-term care stakeholders in Hawaii on the problems of the State’s long-term care system, proposed reforms, and barriers to implementing the reforms. To that end, this report summarizes interviews that RTI International conducted with 47 long-term care stakeholders in Hawaii, including aging and long-term care advocacy groups; state provider associations; state legislative and executive branch policymakers; public and nonprofit program administrators; and individual long-term care providers, researchers, and other expert and knowledgeable individuals. To encourage candor, stakeholders were promised anonymity and were not quoted by name. Most interviews were conducted in February and March 2010.

Although there is broad agreement among stakeholders on the problems of the long-term care system and on the barriers to adoption of various reforms, there are sharp disagreements on which reforms are desirable. In general, stakeholders were highly critical of the current long-term care system. Of concern to almost all stakeholders is that the population of Hawaii is aging and the State lacks a plan to cope with the expected large increase in need for long-term care services. Most respondents said that the current financing system is inadequate and that the increase in the number requiring long-term care would further highlight its inadequacies. Many stakeholders did not think that Medicaid should be the main source of financing and that other approaches needed to be developed.

At the same time that demands on the financing system are increasing, informal care is also under strain. Moreover, the long-term care system lacks service capacity in all areas—nursing homes, community care homes, and home care—and will be unable to address future needs. Adding to the complexity, stakeholders thought that the long-term care and health care financing and delivery systems are fragmented and consumers are bewildered by their complexity. Finally, as in other states, there are significant concerns about quality of care, but they are primarily about care in community care homes rather than nursing homes.

Stakeholders disagreed about what should be done to solve the identified problems. The greatest divide is on financing, which splits along ideological/political lines. In the short term, because of the economic downturn, most respondents did not think that asking people in Hawaii to pay higher taxes or insurance premiums is politically feasible. In the longer term, after the economy recovers, some stakeholders believed that the government should establish a mandatory social insurance program for long-term care. In contrast, other respondents believed that the government should promote private rather than public long-
term care insurance through education and tax incentives. Underlying this division are major philosophical differences about who is responsible for long-term care.

Other recommendations by stakeholders would increase the availability of all types of long-term care services. For example, some respondents proposed increasing funding for Kupuna Care and approving more nursing home beds and certifying them for participation in Medicaid. Several stakeholders recommended upgrading the Aging and Disability Resource Center so that it could be a true “one stop shop” for consumers looking for access to the system. Some observers suggested consolidating various state agencies responsible for long-term care to make them more accountable and to improve policy and budgeting coordination.

Finally, most stakeholders expressed a high level of frustration about how hard it is to implement long-term care reforms in Hawaii. In the view of many, stakeholders have been talking about the issues for a long time, but little has happened. Fundamentally, opposition to higher taxes and to expansion of the role of the public sector is identified as the main reason that the social insurance approach, exemplified by Care First, has not been enacted. Although some stakeholders thought that an insurance premium would be perceived differently than a tax to support Medicaid, others did not agree. Beyond differences in what reforms should be implemented, stakeholders identified a lack of knowledge about long-term care issues, the fact that long-term care is not a priority issue, and the lack of effective advocacy as reasons for the lack of progress.
Appendix E: Assessing Long-Term Care Policy Options in Hawaii: Results from the Hawaii Long-Term Care Survey (2011), Galina Khatutsky, Joshua M. Wiener, Heather Best, and Joseph McMichael, RTI International
December 2010

Assessing Long-Term Care Policy Options in Hawaii

Results from the Hawaii Long-Term Care Survey

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1. Introduction

Act 224, Session Laws of Hawaii 2008, established the Hawaii Long-Term Care Commission. The Commission is charged with identifying needed reforms of the long-term care (LTC) system, researching program changes and resources needed to meet the state’s long-term care goals, and exploring funding options that may help support the provision of long-term care services. Long-term care includes helping people with daily activities, such as getting dressed, bathing, preparing meals or eating, or taking medications, over a long period of time. Providers of long-term care include nursing homes, home health agencies, home care agencies, adult day care programs, meals-on-wheels programs, and community-care homes.

As part of the Long-Term Care Commission’s analysis of Hawaii’s long-term care system, RTI International conducted a mail survey, the Hawaii Long-Term Care Survey, of state residents aged 18 and over to understand public perceptions, awareness, and attitudes about LTC and to elicit the general public’s views of various options for LTC reform. This report summarizes the results of the Hawaii Long-Term Care Survey.

2. Survey Methodology

This section describes the methodology used for the Hawaii Long-Term Care Survey. In particular, it outlines the following:

- Sample selection procedures
- Participant recruitment procedures
- Survey instrument design
- Data collection procedures
- Control system
- Participant compensation
- Sample weighting

Sample Selection Procedures

The Hawaii Long-Term Care Survey collected data through a mail survey. A random probability sample of 3,002 Hawaii addresses was obtained and matched, where possible, to names via batch tracing. To ensure representation of residents from each county in the state, a predetermined percentage of addresses was selected from each county. Appendix A is a sampling table documenting the distribution of the address sample and respondents across counties in Hawaii.
The first question on the mail survey screened for eligibility based on age and residency status. Persons eligible for participation were 18 years of age or older and had lived at the Hawaii address to which the questionnaire was addressed for 60 days or longer. If no one in the household was eligible, the recipient was asked to indicate that by checking a box and returning the survey to RTI. If at least one household member was eligible, the recipient was instructed that the survey should be completed by the eligible adult in the household who had the most recent birthday.

**Participant Recruitment Procedures**

To increase the response rate, prospective participants were sent a signed cover letter from the Hawaii Long-Term Care Commission along with the questionnaire. The cover letter (Appendix B) described the purpose of the study, and advised them that their participation was voluntary and that their privacy and data would be protected. The cover letter offered a toll-free number for recipients to call if they had questions about the study and also explained that RTI would provide a financial incentive for questionnaire completion. Different cover letters were sent with each wave of the survey.

**Survey Instrument Design**

This survey, which contained 31 items, concentrated on the support of adult Hawaii state residents for different approaches to financing LTC, and included the following domains:

- Understanding the costs of LTC
- Preferences for LTC setting
- Opinions about different payment options for LTC
- Knowledge of Insurance program principles, familiarity with and opinions about the Community Living Assistance Services and Supports (CLASS) Act, which was enacted as part of the health reform law

The survey also asked information about respondent demographics, health status, health insurance coverage, and personal exposure to caregiving. The full survey instrument is included as Appendix C. The six-page mail survey took about 15 minutes to complete.

**Data Collection Procedures**

A total of three waves of questionnaire mailings were sent to the sample. Included with the questionnaire in each of these mailings was (1) a signed cover letter from the Long-Term Care Commission, (2) a business reply envelope with prepaid postage, and (3) an incentive postcard. Participants were instructed to provide their name and mailing address on the incentive postcard and mail it back separately from their questionnaire to protect their privacy. As with the questionnaire envelope, the postcard was preaddressed and postage was prepaid.
A reminder postcard (**Appendix E**) was mailed to the entire sample about a week after the first questionnaire mailing, thanking those who returned a completed survey and prompting those who had not yet done so to complete the survey.

Prior to the second wave questionnaire mailing, the mailing list was updated by removing addresses associated with completed surveys, ineligible households, and vacant or unreachable addresses. The address list was updated again prior to the third wave questionnaire mailing. See **Table 1**.

**Table 1. Mailings of the Hawaii Long-Term Care Survey**

<table>
<thead>
<tr>
<th>Wave</th>
<th>Date</th>
<th>Quantity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial questionnaire mailing</td>
<td>6/30/10 &amp; 7/1/10</td>
<td>3,002</td>
</tr>
<tr>
<td>Postcard reminder</td>
<td>7/9/10</td>
<td>3,002</td>
</tr>
<tr>
<td>Second questionnaire mailing</td>
<td>7/26/10 &amp; 7/27/10</td>
<td>1,935</td>
</tr>
<tr>
<td>Third questionnaire mailing</td>
<td>8/19/10</td>
<td>1,557</td>
</tr>
</tbody>
</table>

**Control System**

An efficient and flexible control system was designed to track the status of each case throughout the data collection process. The control system also generated reports providing updates on data collection progress. Among the case statuses documented and tracked were those indicating that all persons at the sample address were ineligible, the address was vacant, and a completed interview had already been received in association with this address. The control system reduced the likelihood of operational error by automating certain tasks, including those associated with confirming eligibility for incentives and those required to remove addresses from the mailing list for future waves of mailings when warranted.

**Participant Compensation**

A $1 cash incentive was included in the questionnaire mailing in wave 1. The first two waves of the questionnaire mailing offered a $10 incentive for returning a completed survey. The third and final questionnaire mailing offered an incentive of $15 for survey completion to further encourage participation from those who had not responded to previous mailings.

Each incentive postcard and corresponding questionnaire was linked for verification of questionnaire completion via the project’s control system using their unique case number. The use of the control system to record and track unique case numbers enabled project staff to process and track one and only one incentive check for each sample address associated with a participant who both returned a completed survey and requested an
incentive. Incentives for completed surveys were sent in the form of a check and were accompanied by a “thank you” letter (Appendix F).

**Weighting**

Survey respondent data need to be weighted before they can be used to produce reliable estimates of the target population responses. Weighting of responses also attempts to compensate for practical limitations of surveys, such as differential nonresponse and undercoverage. Moreover, by taking advantage of auxiliary information about the target population, weighting can reduce the variability of estimates.

The weighting for this study was a two-step process. First, we assigned initial address weights (or design weight) to the 3,002 sampled addresses. This initial address weight is the inverse probability of selection of the address. It accounts for differing selection probabilities across counties.

The second weighting step required the logical imputation of gender for 24 cases and the use of weighted sequential hotdecking to impute a remaining 8 missing records for gender and 26 for age. Finally we used PROC WTADJUST in the statistical program SUDAAN to apply poststratification adjustment factors to the initial address weight to force them to sum to the 2006–2008 U.S. Bureau of the Census’ American Community Survey 3-year estimates for age, county, and gender. The control totals for this adjustment are in Table 2.

**Table 2. Control Totals for Poststratified Weights by Age, Gender and County**

<table>
<thead>
<tr>
<th>Gender</th>
<th>County</th>
<th>Age</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>18–24</td>
<td>25–34</td>
</tr>
<tr>
<td>Male</td>
<td>Hawaii</td>
<td>8,456</td>
<td>13,500</td>
</tr>
<tr>
<td></td>
<td>Honolulu</td>
<td>51,865</td>
<td>65,938</td>
</tr>
<tr>
<td></td>
<td>Kauai</td>
<td>2,849</td>
<td>4,529</td>
</tr>
<tr>
<td></td>
<td>Maui</td>
<td>5,710</td>
<td>11,688</td>
</tr>
<tr>
<td>Female</td>
<td>Hawaii</td>
<td>7,919</td>
<td>11,542</td>
</tr>
<tr>
<td></td>
<td>Honolulu</td>
<td>40,976</td>
<td>58,415</td>
</tr>
<tr>
<td></td>
<td>Kauai</td>
<td>2,437</td>
<td>3,532</td>
</tr>
<tr>
<td></td>
<td>Maui</td>
<td>5,128</td>
<td>9,545</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>125,340</td>
<td>178,689</td>
</tr>
</tbody>
</table>


**Response Rate**

Response rates were calculated using standard American Association of Public Opinion Research (AAPOR) definitions, specifically RR2, which counts partial interviews as
A total of 1,244 completed questionnaires were returned, yielding an overall RR2 weighted and unweighted response rate of 46.9%. Table 3 presents counts of cases for each data collection status at the end of the data collection.

Table 3. Hawaii Long-Term Care Survey Response Rate, Using AAPOR Disposition Codes

<table>
<thead>
<tr>
<th>AAPOR Disposition Code</th>
<th># of Addresses</th>
<th># of Addresses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unweighted</td>
<td>Weighted</td>
</tr>
<tr>
<td><strong>1.0 Interview (I+P)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.1 Complete interview</td>
<td>1,244</td>
<td>208,070</td>
</tr>
<tr>
<td>1.2 Partial interview</td>
<td>1</td>
<td>258</td>
</tr>
<tr>
<td><strong>1,245</strong></td>
<td>208,328</td>
<td></td>
</tr>
<tr>
<td><strong>2.0 Eligible, Non-Interview (R+NC+O)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.112 Known respondent refusal</td>
<td>62</td>
<td>10,586</td>
</tr>
<tr>
<td>2.333 No interviewer available for language</td>
<td>1</td>
<td>258</td>
</tr>
<tr>
<td><strong>63</strong></td>
<td><strong>10,844</strong></td>
<td></td>
</tr>
<tr>
<td><strong>3.0 Unknown Eligibility, Non-Interview (UH+UO)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.21 No screener completed</td>
<td>1,307</td>
<td>220,507</td>
</tr>
<tr>
<td>3.18 Unable to locate address</td>
<td>33</td>
<td>3,793</td>
</tr>
<tr>
<td>3.20 Housing unit/Unknown if eligible respondent</td>
<td>7</td>
<td>997</td>
</tr>
<tr>
<td><strong>1,347</strong></td>
<td><strong>225,296</strong></td>
<td></td>
</tr>
<tr>
<td><strong>4.0 Not Eligible (NE)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.60 Vacant housing unit</td>
<td>116</td>
<td>20,872</td>
</tr>
<tr>
<td>4.50 Not a housing unit</td>
<td>109</td>
<td>14,069</td>
</tr>
<tr>
<td>4.70 No eligible respondent</td>
<td>34</td>
<td>5,286</td>
</tr>
<tr>
<td><strong>347</strong></td>
<td><strong>53,790</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>3,002</strong></td>
<td><strong>498,259</strong></td>
</tr>
</tbody>
</table>

RR2: \( \frac{(I+P)}{(I+P+R+NC+O+UH+UO)} = 46.9\% \).

---

1 AAPOR’s RR2 is defined as \( \frac{\text{Complete Interviews} + \text{Partial Interviews}}{\text{Complete Interviews} + \text{Partial Interviews} + \text{Refusal and Break Off} + \text{Non-Contact} + \text{Other} + \text{Unknown if Household/Occupied Housing Unit} + \text{Unknown, Other}} \). American Association of Public Opinion Research. (2009). Standard definitions: Final disposition of case codes and outcome rates for surveys. Deerfield, IL: American Association of Public Opinion Research. Available at http://www.aapor.org/AM/Template.cfm?Section=Standard_Derinitions1&Template=/CM/ContentDisplay.cfm&ContentID=1814. Accessed December 13, 2010.
3. Survey Results

This part of the report presents survey findings. All results are presented weighted and adjusted for survey nonresponse.

**Demographics, Health Status, and Caregiving Experience**

This section describes demographic characteristics of the survey respondents. In the survey, respondents were asked about their age, gender, race/ethnicity, total household income, education, employment status, and what type of primary health care coverage they have for their acute medical care. Respondents were also asked about their caregiving experience.

**Demographics**

Overall, **Figure 1** shows that about 45% of respondents were 25 to 44 years of age, about 30% of respondents were 45 to 64 years of age, and almost 17% of respondents were 65 years old and older. Eight percent of all survey respondents were 18 to 24 years of age. **Figure 2** shows the respondent age distribution by county.

**Figure 1. Respondent Age**

![Respondent Age Chart]

- 16.9% 18-24
- 30.2% 45-64
- 44.7% 25-44
- 8.3% 65 or older
Figure 2. Respondent Age, by County

- **Hawaii**:
  - 18-24: 7.7%
  - 25-44: 16.9%
  - 45-64: 35.6%
  - 65 or older: 39.8%

- **Honolulu**:
  - 18-24: 8.9%
  - 25-44: 16.9%
  - 45-64: 28.2%
  - 65 or older: 46.0%

- **Kauai**:
  - 18-24: 8.0%
  - 25-44: 19.6%
  - 45-64: 34.4%
  - 65 or older: 40.0%

- **Maui**:
  - 18-24: 6.1%
  - 25-44: 15.4%
  - 45-64: 34.3%
  - 65 or older: 44.2%
Figure 3 shows that slightly over 47% of all respondents were female and over 52% were male.

Figure 3.  Respondent Gender
Figure 4 shows the race/ethnicity distribution of the survey respondents was as follows: slightly over 42% were Asian, 31% were white, over 17% were native Hawaiian, and 4.5% were other Pacific Islanders. African Americans and American Indians represented less than 3% and 2%, respectively.

Figure 4. Race/Ethnicity
Figure 5 shows that nearly three fifths of respondent families have income below $60,000 a year, 24% have incomes between $60,000 and $99,999, and almost 17% have incomes above $100,000.

Figure 5. Income Distribution
**Functional Status**

The survey elicited information on respondents’ functional status (ability to perform activities of daily living and instrumental activities of daily living) by asking the following question: "Does a physical or mental health problem currently limit your ability to do one or more of the following activities: bathing, dressing, getting around in the house, using the telephone, paying bills, taking medications, or doing laundry?" Figure 6 shows that about 6% of all survey respondents reported physical or mental health problems that interfered with their daily activities. This proportion varied slightly by county from about 5% in Honolulu to about 7% in Maui.

![Figure 6. Respondent Functional Status, by County](image)

**Caregiving Experience**

Because prior studies show that personal caregiving experience affects how much people know and plan for LTC, the survey also asked respondents whether they provide personal care assistance to disabled family members, both young and aged. Overall, about 5% of all respondents reported taking care of a family member between the ages of 18 and 64 who is disabled. Providing such care included help with regular daily activities, such as eating,
bathing, dressing, going to the toilet; using the telephone; or taking medications. **Figure 7** shows that this proportion varied slightly from about 4% in Kauai to about 6% in Honolulu.

**Figure 7.** Respondents Providing Care for Younger Disabled Family Members, by County

![Bar chart showing the proportion of respondents providing care for younger disabled family members by county.](chart)

- **Hawaii**: 4% providing care, 96.6% not providing care.
- **Honolulu**: 5.9% providing care, 94.1% not providing care.
- **Kauai**: 8% providing care, 92.2% not providing care.
- **Maui**: 6.1% providing care, 93.9% not providing care.
A similar question was asked about providing care to disabled family members aged 65 and older. Overall, about 8% of all respondents reported taking care of a family member aged 65 and over who is disabled. Providing such care included help with regular daily activities, such as eating, bathing, dressing, going to the toilet; using the telephone; or taking medications. **Figure 8** shows that this proportion varied slightly from about 5% in Maui to about 9% in Honolulu.

**Figure 8. Respondents Providing Care for Aged Family Members, by County**

<table>
<thead>
<tr>
<th>County</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>HAWAII</td>
<td>4.6</td>
<td>95.2</td>
</tr>
<tr>
<td>HONOLULU</td>
<td>8.7</td>
<td>91.3</td>
</tr>
<tr>
<td>KAUAI</td>
<td>5.0</td>
<td>95.0</td>
</tr>
<tr>
<td>MAUI</td>
<td>5.3</td>
<td>94.7</td>
</tr>
</tbody>
</table>

**Cost of Care**

This survey domain examined respondents’ perception of how much nursing home and in-home care they can afford, given the cost of care in the state of Hawaii and what sources they are planning to use for payment.

To answer this survey question about the affordability of long-term care services, respondents were provided with the average cost of care in the state of Hawaii: A year in a nursing home or a year of 24-hour home care costs between $128,000 and $158,000. Given these costs, **Figure 9** shows that 62% of all surveyed respondents reported that they could not afford to pay any of the costs of care. About a third of all respondents suggested that they could afford to pay less than half of the costs, and 3% of all respondents reported that
they could pay more than half but not all of the costs of care. Three percent of respondents also reported that they could afford to pay all the costs of needed care.

**Figure 9.** If You or Anyone in Your Family Needed Nursing Home Care or Round-the-Clock Home Care for a Year, How Much of the Cost Could You Afford to Pay?
In addition to affordability, respondents were asked what sources they are planning to use to pay for round-the-clock care. **Figure 10** shows that nearly half of respondents (49%) do not know the answer to this question, suggesting that they have done little planning to cover this possible expense. About one third of Hawaii state residents will use their income and savings and about one third are counting on Medicaid to pay for their extensive care. Almost 19% reported that they plan to use private long-term care insurance, a number far higher than the actual number of policies in the state. This suggests that many people mistakenly think that they have long-term care coverage when they do not. Finally, about 13% of Hawaii state residents report that they will depend on their family to pay for the expense.

**Figure 10. If You Needed Nursing Home or 24-Hour Home Care Over a Long Period of Time, How Would You Pay for It?**

Most people receiving long-term care do not need as much care as is provided in a nursing home. Most of those people live at home. Two hours of daily home care costs about $18,200 a year in Hawaii. **Figure 11** shows that, given these costs, 35% of all survey respondents reported that they could afford to pay less than half of the costs. Thirty-four percent reported not being able to afford any of the costs and 13% reported that they could afford to pay more than half, but not all of the costs. Only about 12% of respondents
reported that they are able to afford all of the costs associated with receiving 2 hours of home care daily for a year.

**Figure 11.** If You or Anyone in Your Family Needed 2 Hours of Home Care for a Year, How Much of the Cost Could You Afford to Pay?
In addition to affordability of 2 hours of daily care, respondents were asked what sources they are planning to use to pay for care of this amount. Figure 12 shows that this amount of care is perceived as more affordable, so the great majority of respondents (47%) are planning to use their income and savings. About a third of respondents do not know the answer to this question, suggesting that they have not planned for this possible expense. Twenty-eight percent of Hawaii state residents are counting on Medicaid to pay for the 2 hours of daily care. Almost 17% reported that they plan to use private long-term care insurance, again far more than the number of in-force policies in the state. Finally, about 16% of Hawaii state residents report that they will depend on their family to pay for the expense.

**Figure 12. If You Needed 2 Hours of Home Care Over a Long Period of Time, How Would You Pay for It?**

<table>
<thead>
<tr>
<th>Source of Payment</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use my income and savings</td>
<td>47.4</td>
</tr>
<tr>
<td>Use private long-term care insurance</td>
<td>15.9</td>
</tr>
<tr>
<td>Use Medicaid (known in HI as Quest)</td>
<td>16.9</td>
</tr>
<tr>
<td>Depend on my family to pay for it</td>
<td>28.3</td>
</tr>
<tr>
<td>Do not know</td>
<td>33.8</td>
</tr>
</tbody>
</table>

**Preferences for Care Setting**

Respondents were asked for their preference for LTC setting if they were disabled and needed substantial amounts of long-term care services over a long period of time and about whether the percentage of Medicaid long-term care expenditures that are for nursing home care are appropriate. They were also asked about their support for consumer-directed home care.
care, where consumers rather than agencies hire, supervise, schedule, and fire their direct care workers.

Similar to people in other states, Hawaii residents prefer to receive their long-term care in the community rather than in the institutional setting. **Figure 13** shows that about 41% prefer to receive such care from family and friends and almost 29% prefer to pay a nurse or a personal care assistant to provide such care at home. About 12% expressed a preference for an assisted living facility or a small group home. Nursing home is the setting of last resort: only 4% of Hawaii state residents prefer to be in a nursing home if they require long-term care. Almost 15% of respondents could not choose a setting and responded "Don't Know."

**Figure 13. Preference for Type of Long-Term Care Provider**

Hawaii has one of the highest percentages of Medicaid long-term care expenditures going for nursing home care; compared to other states, the proportion of Medicaid expenditures for home and community-based services is very low. To answer the question about whether respondents thought that the distribution of Medicaid expenditures across service types is appropriate, the survey informed respondents that, "Currently, 81% of Hawaii’s Medicaid spending for long-term care is for nursing home care and 19% is for home and community-
based services, such as personal care (help with eating, bathing, and dressing) and adult day care.” As shown in Figure 14, about a third of all Hawaii state residents do not have an opinion on the service distribution of Medicaid spending in their state. Only 27% think that the proportion of Medicaid spending on nursing homes is too high and about 30% think it is appropriate. Ten percent of all respondents reported that they think that the percentage of Medicaid LTC spending on nursing home care is too low. Given the relatively low levels of LTC service provision in the state compared to other states, respondents may be answering regarding the absolute level of spending instead of the distribution between institutional and noninstitutional services.

Figure 14. Do You Think That the Percentage of Medicaid Long-Term Care Spending for Nursing Home Care is?
Consumer direction is a relatively new model of home and community services where people are allowed to hire and pay their family and friends for providing personal care services. **Figure 15** shows that this option is very attractive to Hawaii residents: almost three quarters of all respondents favor this option. About 13% are against consumer direction and 14% have no opinion about it.

**Figure 15.** Do You Favor or Oppose Allowing Government-Funded Home Care Programs to Pay Family Members and Friends Rather Than Private Agencies to Provide Home Care?

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**Opinion About Financing Options**

Respondents were asked about their opinion of several LTC financing options where their support or opposition were measured. These options were the following:

1. Changing Medicaid so that more middle class people would qualify for help in paying for long-term care services
2. Having the government help pay for long-term care for all persons who need services regardless of how much money they have
3. Reducing state income taxes for people who provide a lot of care to their disabled relatives
4. Tax incentives to help people purchase private long-term care insurance
5. Increasing funding for small home care programs such as Kupuna Care
Medicaid is a joint federal and state program that helps pay for acute and long-term care for people who are poor or become poor because of the high cost of long-term care. Expanding Medicaid eligibility to middle-class individuals is one way to broaden public long-term care programs. As shown in Figure 16, this idea has wide support among Hawaii residents. Over 71% of respondents favor changing Medicaid eligibility to include more middle-class people. Fifteen percent oppose such an expansion and about 14% have no opinion in this matter.

**Figure 16. Do You Favor or Oppose Changing Medicaid so That More Middle-Class People Would be Eligible for Government Help in Paying for Long-Term Care Services?**
Although Hawaii residents favor Medicaid expansion to the middle class, they are more ambivalent about having the government pay for all persons in need of long-term care regardless of their income. As shown in Figure 17, Hawaii residents are almost evenly split between supporting and opposing this option (42% and 47%, respectively). Slightly over 11% expressed no opinion on this subject.

Figure 17. Do You Favor or Oppose Having the Government Help Pay for Long-Term Care for All Persons Who Need Services Regardless of How Much Money They Have?
One way to lighten the burden for caregivers is to reduce their state income taxes. As shown in Figure 18, this idea finds a lot of support among Hawaii residents: almost three quarters of all respondents favor such state income tax reductions. About 12% of respondents oppose it and almost 15% have no opinion.

**Figure 18. Do You Favor or Oppose Reducing State Income Taxes for People Who Provide a Lot of Care to Their Disabled Relatives?**
Purchasing private long-term care insurance is one viable option that people can choose to cover their long-term care expenses. However, few people can afford long-term care insurance because premiums are expensive. Tax incentives to help people defray the costs of premiums is one strategy to promote private long-term care insurance. This approach is quite popular among Hawaii residents. According to Figure 19, over 80% of respondents favor this idea and only 5% oppose it. About 14% have no opinion.

**Figure 19. Do You Favor or Oppose Tax Incentives to Help People Purchase Private Long-Term Care Insurance?**
Many states fund their own home and community-based programs. Kupuna Care is a home care program for older people funded by the state of Hawaii. Figure 20 shows that a great majority of Hawaii residents (over 61%) support Kupuna Care and favor increased funding for the program. About 13% oppose additional funding for the program. About a quarter of all respondents have no opinion about the program.

Figure 20. Do You Favor or Oppose Increasing Funding for Hawaii Programs Such as Kupuna Care?

![Pie chart showing support and opposition to increased funding for Kupuna Care.]

Insurance Options: CLASS Act

The survey solicited opinions from respondents on the newly enacted CLASS Act: whether they favor or oppose it, whether they plan to enroll, and how much they are willing to pay for it. Additional questions were asked about whether respondents think enrollment should be voluntary or mandatory and whether Hawaii should implement a wraparound public program for LTC benefits in addition to CLASS. Because only a few people are aware of the legislation establishing the CLASS option, the following introduction was given to survey respondents to educate them about the CLASS option:

The health reform law includes the Community Living Assistance Services and Supports (CLASS) Act, a national public long-term care insurance program. Working people who want to participate in the program will pay monthly premiums which will cover the cost of the program. People who do not work are not eligible for the program. Enrollment in the program is voluntary.
To qualify for benefits, individuals must be 18 years old, have paid premiums for at least 5 years, and have a fairly severe disability. Disabled people who qualify for benefits will receive a daily cash payment based on their level of disability. The average payment will be $50 per day. The program will provide benefits for as long as the individual qualifies.

A solid majority of Hawaii state residents support the CLASS Act. As shown in Figure 21, more than half of all survey respondents favor the CLASS Act and slightly over 14% oppose it. About 30% of respondents have no opinion of the CLASS Act, probably because they are not familiar with it.

**Figure 21. Do you Favor or Oppose the Newly Enacted CLASS Act?**
Support for and opposition to the CLASS Act varies only slightly across Hawaii’s counties. As shown in Figure 22, more than half of all respondents in each county favor the CLASS act; its support is highest in Maui (58%), followed by Honolulu (55%) and Kauai (54%). Among all counties, the residents in Hawaii expressed the lowest support (51%), although still a majority.

Figure 22. Do You Favor or Oppose the Newly Enacted CLASS Act? Data by County
Support for and opposition to the newly enacted CLASS Act varies by respondent income category. **Figure 23** shows that survey respondents with household income under $19,999 expressed the least support for the CLASS Act (41%), perhaps because they are least able to afford the premiums. The proportion of CLASS supporters was greatest among survey respondents with family income between $20,000 and $59,999 (slightly over 61%) and among those with family income higher than $100,000 (slightly less than 60%).

**Figure 23.** Do You Favor or Oppose the Newly Enacted CLASS Act? Data by Income
To examine the planned CLASS enrollment, we restricted the sample to include only respondents who reported that they are currently employed, because those who are not employed are not be eligible to enroll in the CLASS program. It appears that support for CLASS does not necessarily translate into plans for enrollment. Figure 24 shows that only 20% of respondents reported that they are planning to enroll in CLASS and more than a quarter reported that they are not planning to enroll. More than half of all respondents have not made this decision yet.

**Figure 24. Do You Think You Will Enroll in the CLASS Act Public Long-Term Care Insurance Program When it is Available in 2011? Data for Employed Respondents**
Again, limiting the data to the working population, there are some differences on planned enrollment in CLASS by age. As shown in Figure 25, most people do not know if they will enroll in CLASS. Employed people aged 45–64 are the most likely to report that they are planning to enroll in CLASS—about 30% reported that they plan to enroll in the program. Not surprisingly, the proportion of those planning to enroll is the lowest in the 18–24 age group (10%), followed by 13% among those aged 25–44.

Figure 25. Do You Think You will Enroll in the CLASS Act Public Long-Term Care Insurance Program When it is Available in 2011? Data by Age
To examine the planned CLASS enrollment by income, we restricted the sample to include only respondents who reported that they are currently employed, because those who are not employed are not eligible to enroll in the CLASS program. As shown in Figure 26, planned enrollment in CLASS is lowest among working Hawaii state residents with total household income under $20,000, with only about 11% reporting that they plan to enroll in the program. Other income categories are almost twice as likely to enroll without much variation across categories. More than half of all employed survey respondents in each income category did not know whether they would enroll in the program.

Figure 26. Do You Think You will Enroll in the CLASS Act Public Long-Term Care Insurance Program When it is Available in 2011? Data by Income Among Employed Respondents

Decisions about program insurance enrollment are tied to the amount of money people are willing to pay to participate. During the debate on health reform, different organizations estimated the premiums for CLASS to be between $123 and $240 per month. The U.S. Department of Health and Human Services has not yet established the premiums. The Hawaii survey respondents were asked how much in monthly premiums they would be willing to pay to enroll in CLASS. Limiting the analysis to people who are currently employed and would be eligible to participate in CLASS, Figure 27 shows that, overall, only about 2%
of all survey respondents are willing to pay a premium above $120 per month. About the same proportion of respondents are willing to pay between $80 and $120 a month, and 17% are willing to pay between $40 and $80 a month. The large majority of respondents (57%) are willing to pay under $40 monthly and 23% of respondents are unwilling to pay anything to enroll in CLASS.

Figure 27. How Much Would You be Willing to Pay to Enroll in the CLASS Act?
Data for Employed Respondents

The CLASS insurance program is voluntary; people do not have to participate. This is a departure from public social insurance programs like Social Security and Medicare Part A, but it has precedents in Medicare Parts B and D, which are voluntary. Because the insurance is voluntary, there is a risk of adverse selection that could drive up the cost of premiums and possibly create an insurance death spiral. Without medical underwriting to exclude them, people with disabilities who need long-term care—and those at high risk of needing long-term care—may disproportionately enroll in the program. If few people without disabilities enroll, the program’s ability to spread the costs of people using benefits across a broad population will be limited and premiums will be high, potentially causing nondisabled people to not enroll or to disenroll. Survey respondents were asked about whether they think the enrollment in CLASS should be mandatory for all people; that is, people should be
required to enroll as they will be required to enroll in health insurance or pay a penalty. As shown in Figure 28, which includes all respondents regardless of age or employment status, mandatory enrollment in CLASS did not find much support among Hawaii residents: only one fifth of all survey respondents thought that everyone should be required to enroll in CLASS; 59% did not think people should be required to enroll. About 21% of all respondents did not know how to answer the question on mandatory enrollment.

**Figure 28. Do You Think Everyone Should be Required to Enroll in the CLASS Act Public Long-Term Care Program?**
Disaggregating the data by income, Figure 29 shows that the idea of mandatory enrollment in the CLASS program finds the least support among lower income Hawaii residents; only 10% of those with household income of under $20,000 support the mandatory enrollment of all in the CLASS program. More support for mandatory enrollment exists among Hawaii residents of middle and higher income, but the level of support is still low. For example, 26% of those with total household income between $20,000 and $59,999 and 20% among those total household income between $60,000 and $99,999 with are in support of mandatory enrollment. Eighteen percent of people with family income over $100,000 support making the CLASS program mandatory.

Figure 29. Do You Think Everyone Should be Required to Enroll in the CLASS Act Public Long-Term Care Program? Data by Income
Sponsoring a supplemental State of Hawaii long-term care insurance program around the federal CLASS insurance program is one way to enhance the modest long-term care benefits planned for the CLASS insurance program. As shown in Figure 30, survey respondents expressed support for such a program: almost 57% of Hawaii residents favor an additional public long-term care insurance program sponsored by the state of Hawaii to supplement the CLASS program. Only about 13% of respondents oppose such a program, while about 31% have no opinion on the issue.

**Figure 30.** Do You Favor or Oppose a Public Long-Term Care Insurance Program Sponsored by the State of Hawaii That Would Offer Benefits Additional to the CLASS Act Federal Insurance Program?
As shown in Figure 31, support for an additional public long-term care insurance program sponsored by the state of Hawaii is similar across counties and ranges from 56% in Hawaii to 52% in Maui.

Figure 31. Do You Favor or Oppose a Public Long-Term Care Insurance Program Sponsored by the State of Hawaii That Would Offer Benefits Additional to the CLASS Act Federal Insurance Program? Data by County
Preferred Choice for Long-Term Care Reform

Finally, survey respondents were asked to identify the long-term care reform option that had their greatest support. As shown in Figure 32, providing tax incentives to encourage the purchase of private long-term care insurance was the most popular choice, supported by 33% of Hawaii state residents, followed by allowing middle-class Hawaii residents to qualify for Medicaid services, supported by 31% of respondents. Twelve and a half percent of respondents favored establishing the state wraparound insurance program to supplement the federal CLASS program and about 12% would like to see the state home care program, Kupuna Care, expanded. Eleven percent of respondents did not choose any options to support.

Figure 32. Among the Following Reform Options, Which One has Your Greatest Support?

Options to Increase State Revenues to Finance Expansions of Long-Term Care

Aside from insurance premiums, expansions of long-term care must be financed either by increased tax revenues or by reducing spending on other state services, such as education
and transportation. This section explores the willingness of Hawaii residents to pay increased taxes to improve the long-term care system.

Increasing state taxes is one way to pay for additional long-term care services for state residents. As shown in Figure 33, only about one quarter of all respondents support tax increase to fund improvements in long-term care services; almost 58% oppose tax increase to pay for better long-term care services. About 16% of all respondents do not have an opinion.

Figure 33. Do You Favor or Oppose Higher Taxes to Pay for Improved Long-Term Care Services?

Despite the overall opposition to open-ended tax increases, when specific levels of tax increases were offered, a much higher percentage of respondents were willing to pay something to improve long-term care services. As shown in Figure 34, only 37% of all respondents reported that they are willing to pay nothing, compared to 58% who earlier reported opposing tax increase. About 35% of respondents are willing to pay under $40 a month to improve long-term care services in the state and 7% are willing to pay between $40 and $80 a month. About 1% of all respondents are willing to pay over $80. About one
fifth of all respondents did not know how much they would be willing to pay for improvement in long-term care services.

**Figure 34. How Much More per Month Would You be Willing to Pay in Taxes to Improve Long-Term Care?**
Survey respondents were also asked which tax should be increased if the state made the decision to increase taxes to pay for improved long-term care services. As shown in Figure 35, increasing the state sales tax was the most popular option, chosen by 26% of Hawaii residents, followed by estate tax (17%). Increasing the state income tax was the least popular source for additional funds, favored by 12% of survey respondents. About 35% of survey respondents did not have an opinion on which tax should be increased.

**Figure 35. If You Were Required to Pay Higher Taxes to Improve Long-Term Care in Hawaii, Which Tax Should be Increased?**

4. Conclusions

In summer 2010, RTI International conducted the Hawaii Long-Term Care Survey on behalf of the Hawaii Long-Term Care Commission. State residents aged 18 and over were surveyed to understand public perceptions, awareness, and attitudes about LTC and to elicit the general public’s views of various options for LTC reform. Several important points may be inferred from the results:

- Overall, many people had “no opinion” on many questions, indicating that knowledge about long-term care services is low and that the costs associated with long-term care are not widely understood by the general public. Moreover, many people have no opinion about how these long-term care services should be
improved or what sources of revenue should be used to pay for the improvements. Similarly, about one third of all Hawaii residents do not have any opinion about the newly enacted CLASS program and more than half do not know whether they plan to enroll in it. Such lack of opinion may indicate a substantial need to educate the public about the options and costs of long-term care. In particular, as with the rest of the nation, residents of Hawaii need education about the CLASS program.

- Long-term care is not affordable for the large majority of Hawaii residents, with many people not knowing how they would pay for it. Affordability is perceived as a major problem: more than 60% of survey respondents reported that they could not afford any of the costs for round-the-clock care either at home or in a nursing home and about one third could not afford any costs for 2 hours’ worth of care a day.

- In terms of changing the balance of Medicaid spending between institutional and home and community-based services, which has been the focus of long-term care reform in most states, only about a quarter of respondents thought that the proportion of Medicaid long-term care spending for nursing home spending was too high; about 30% thought it was about right. These results were somewhat surprising because Hawaii has among the lowest percentage of Medicaid long-term care spending for home and community-based services in the country. Moreover, large majorities of Hawaii residents wanted to be cared for at home, either by relatives or paid caregivers; relatively few people wanted to receive care in residential care facilities and almost no one wanted to be cared for in a nursing home. Large majorities of Hawaii residents favored consumer-directed home care by which consumers could hire and fire their own workers.

- Large majorities of respondents favored expanding Medicaid eligibility to the middle class, reducing taxes to informal caregivers, tax incentives for purchase of private long-term care insurance, and increasing funding for Kupuna Care.

- Among those with an opinion, a solid majority of survey respondents favored the CLASS Act. However, most people did not know if they would enroll in CLASS and about one third of all respondents reported that they would not enroll. Additionally, what people are willing to pay for CLASS in premiums if they enroll is significantly less than what was estimated to be an average monthly CLASS premium. About half of all survey respondents said that they would pay less than $40 per month to enroll in CLASS; only a tiny proportion said that they would enroll if premiums were as high as estimated during the health reform debate. A substantial majority of Hawaii residents opposed requiring people to enroll in CLASS, which would dramatically reduce premiums and would protect the program against adverse selection. Instead, respondents preferred to keep enrollment voluntary. A substantial majority of respondents also favored a state-sponsored Hawaii wraparound program to supplement the long-term care services provided by the CLASS program.

- When forced to choose one option for reform to improve long-term care services as having their strongest support, about a third of survey respondents chose allowing the middle class to qualify for Medicaid, about a third of respondents chose tax incentives for private long-term care insurance, about an eighth each chose establishing a Hawaii LTC insurance plan to supplement CLASS and expanding Kupuna Care.
With the exception of the CLASS program, which is self-financed, Hawaii residents generally supported long-term care financing initiatives that either increased government spending or reduced government revenues. However, a substantial majority of Hawaii residents opposed higher taxes to pay for improved long-term care services, but when pressed, two thirds of respondents reported that they would be willing to pay something, but not too much, for improvements to the long-term care system. If taxes had to be increased, the sales tax was the most popular option, followed by estate tax.