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Stakeholders' Views on Hawaii's Long-Term Care System: Problems, Solutions, and Barriers to Reform

Prepared for

Hawaii Long-Term Care Commission
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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

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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

Name	Position	Organization
Government–Legislature (5)		
Rosalyn H. Baker	Senator	Senate
Les Ihara	Senator	Senate
Marilyn Lee	Representative	House
John M. Mizuno	Representative	House
Suzanne Chun Oakland	Senator	Senate
Government–Governor's Office (1)		
Linda Smith	Senior Policy Advisor	Governor's Office
Government–Executive Administration (9)		
Patricia Bazin	Administrator for the Health Care Services Branch	Med-Quest Division, Hawaii Department of Human Services
Dr. Kenneth S. Fink	Division Administrator	Med-Quest Division, Hawaii Department of Human Services
John Grant	Community Assistance and Grants Management	Hawaii Executive Office on Aging
Susan Jackson	First Deputy to the Director	Hawaii Department of Health
Noreen Moon-Ng	Program Officer of the Policy & Program Development Office	Med-Quest Division, Hawaii Department of Human Services
Noemi Pendleton	Director	Hawaii Executive Office on Aging
Keith Ridley	Chief	Office of Health Care Assurance
Marilyn Seely	Former Director	Hawaii Executive Office on Aging
Audrey Suga-Nakagawa	Former Project Director	Hawaii Aging and Disability Resource Center
Government–County (4)		
Elizabeth Bethea	County Executive on Aging	Elderly Affairs Division, Honolulu County Department of Community Services
Deborah Morikawa	Director	Honolulu County Department of Community Services
Alan Parker	Executive	Hawaii County Office of Aging
Lei Shimizu	Coordinator of Information and Assistance	Elderly Affairs Division, Honolulu County Department of Community Services
Providers and Provider Associations (16)		
Lani Akee	President	Adult Foster Homecare Association of Hawaii
Coral Andrews	Vice President	American Health Care Association of Hawaii
Norm Baker	Vice President, Community Building	Aloha United Way

Sananda "Sandy" Baz	Executive Director	Maui Economic Opportunity
Dr. Patricia Blanchette	Professor, Geriatric Medicine	University of Hawaii
Merlita Compton	Elderly Program Coordinator	Kokua Kalihi Valley
Sandy Freeman	Executive Director	Maui Adult Day Care Centers
Ron Gallegos	President	Alliance of Residential Care Administrators
Fred Horwitz	Chairman and Senior Executive Director	American Health Care Association of Hawaii
Tony Krieg	Chief Executive Officer	Hale Makua
Bernie Ledesma	Administrator	Pearl City Nursing Home
Vince Lee	Regional (Oahu) CEO	HI Health Systems Corporation
Rose Nakamura	Founder	Project Dana
Rebecca Ryan	Executive Director and Chair of the Board	Moiliili Community Center
Valorie Taylor	Program Director	Honolulu Gerontology Program, Child & Family Service
Diane M. Terada	Division Administrator	Catholic Charities Hawaii
Consumer Advocates (6)		
Rita Barreras	Director	Aging with Aloha Coalition
John P. Dellera	Executive Director	Hawaii Disability Rights Center
Stuart Ho	President	AARP Hawaii
Wes Lum	A founder of the Hawaii Family Caregiver Coalition; assistant specialist at the Center on Aging at the University of Hawaii	Worked with the Hawaii Executive Office on Aging to develop support for family caregivers
Laura G. Manis	Advocate for long-term care financing strategies	Private advocate
Barbara Kim Stanton	State Director	AARP Hawaii
Researchers and Others (6)		
Dr. Colette Browne	Professor, Social Work	University of Hawaii
Dr. Anthony Lenzer	Former Director, Center on Aging	University of Hawaii
Bruce McCullough	Former Director	Hawaii Office of the Social Security Administration
Dr. Lawrence Nitz	Professor, Political Science	University of Hawaii
Dr. David Nixon	Assistant Professor, Public Policy Center	University of Hawaii
Dr. Eldon Wegner	Professor Emeritus, Sociology	University of Hawaii

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.***

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 "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.[1] 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

[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.[2] 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[4]

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 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.