HAWAII STATE HEALTH PLANNING AND DEVELOPMENT AGENCY
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Kupuna Advisory Council - Plan Development Committee

DRAFT

Meeting Minutes

October 31, 2025 | 12:30 PM Hawaii Time
Virtually via Zoom and Physical Meeting Location at
The Keoni Ana Building, 1177 Alakea Street, Suite 402

MEMBERS: Melissa Ah Ho-Mauga, Ritabelle Fernandez, Nathan Hokama, Derrick Ariyoshi, Jeanette Koijane, Marilyn Seeley, Brandy Shima, Jinyong Lee, Lawrence Nitz, Kevin Kawamoto, Stephen Kemble, Audrey Suga Nakagawa, Barbara Yamashita, Tani Salazar, Cullen Hayashida
MEMBERS ABSENT: Michelle Cordero-Lee, Mia Taylor, Melvin Sakura, Warren Wong, Lindsey Ilagan
GUESTS: None
SHPDA: John Lewin, Terry Visperas

ATTENDANCE RECORD OF MEMBERS

Date	11/2/23	12/8/23	1/12/24	1/25/24	3/11/25	10/31/25	TBD	TBD	TBD	TBD
Melissa Ah Ho-Mauga	X	X	X	X	X	X				
Derrick Ariyoshi	O	X	O	X	O	X				
Michelle Cordero	X	X	X	O	O	0				
Ritabelle Fernandez	X	X	X	X	X	X				
Nathan Hokama	X	X	X	X	O	X				
Lindsey Ilagan	X	X	O	X	X	0				
Jinyong “Jenny” Lee	X	X	O	O	O	X				
Jeanette Koijane	X	X	X	O	X	X				
Lawrence Nitz	X	X	X	O	X	X				
Melvin Sakurai	X	X	X	X	X	0				
Marilyn Seeley	X	X	X	X	X	X				
Brandy Shima	X	X	O	O	O	X				
Mia Taylor	O	O	O	O	O	0				

Warren Wong	X	X	X	X	X	0				
Stephen Kemble						X				
Audrey Suga-Nakagawa						X				
Kevin Kawamoto						X				

Legend: X=Present | O=Absent | /=No Meeting | *-Chair | **-Vice Chair

Meeting Recording: https://youtu.be/T2G6u9dTUNM

TOPIC	DISCUSSION	ACTION
Call to Order	A quorum was established. The meeting was called to order at 12:34 p.m. by M. Ah Ho-Mauga, Chairperson, Kupuna Advisory Council (KAC) presiding.	
Roll Call	Member roll call.	
Welcome	M. Ah Ho-Mauga welcomed members and staff.	
Minutes	Motion to accept the minutes from the March 11, 2025, meeting. Vote: Unanimous. Motion carried. Call for public testimony – none.	
Melissa Ah Ho-Mauga, Chair	Welcomed new Kupuna Advisory Council members (Dr. Stephen Kemble, Tani Salazar, Kevin Kawamoto, Audrey Suga-Nakagawa). Acknowledged the previous email exchanges and frustration regarding the Permitted Interaction Group (PIG) and the white paper. Chair shared that, everything we do here is guided by the Sunshine Law, which ensures that our discussions and decisions are open, transparent, while respectful of the process. She took a moment to acknowledge the email exchanges and the white paper on long-term care financing. She stated that she knew some of those messages reflected frustration, and completely understood, but it really came from a place of passion and commitment to move things forward quickly. That said, she was grateful to regroup, reconnect, and continue the conversation in a way that reflects the shared purpose and respect that's always been at the heart of this Council. Moved to the review and approval of the previous meeting's minutes. J. Koijane, M. Seely, moved to accept the minutes of the meeting from March 2025.	

M. Seely, presented on the Long-Term Care (LTC) Financing White Paper/PIG Report (105 pages):

Expressed profound thanks and passion for the work of the PIG, noting her 50-year commitment and that this is her fourth attempt to get LTC financing passed.

1. Identified three interrelated issues:
    a. *How to achieve stable, affordable LTC financing (referencing the 1990 Family Hope social insurance model and looking at new strategies, cost reduction, and system inefficiencies).*
    b. *Establishing a new Advisory Committee/Commission to advance the work to policy/legislation; and*
    c. *Building a critical stakeholder coalition.*

2. Stressed the need for home and community-based care to be equal, affordable, and high-quality, not overshadowing residential care.

3. Outlined a timetable for success: Council deliberation/adoption of the report, formation of a new Implementation PIG, meeting with the Governor for commitment/support, and conducting briefings (starting with Kupuna Caucus next week) to get legislation enacted for the Commission.

Action Item/Next Steps:

L. Nitz, presented two formal motions/proposals:

1. The Kupuna Advisory Council accept and adopt the LTC Financing PIG's report of findings, in whole, as submitted.
2. The establishment of a Kupuna Advisory Council LTC Financing Implementation Permitted Interaction Group (PIG) (3-7 volunteer members) with specific tasks (see Action Items below).

Public testimony – none.

Accept and Adopt Report	Kupuna Advisory Council (Vote)	Motion to be voted on: Accept and adopt the LTC Financing PIG's report of findings, in whole, as submitted.
Establish New PIG Taskforce	New LTC Implementation PIG	A motion was made and approved by the KAC members. With the LTC report

			approved by the current PIG and all deliverables completed, the KAC agreed to establish a new PIG with updated deliverables. The committee also discussed forming a Long-Term Care and Finance Advisory Work Group or Task Force by the end of 2025. This new PIG will be responsible for conducting ongoing briefings, drafting supporting legislation, and identifying sponsors and liaisons.	
	Conduct Ongoing Briefings	New LTC Implementation PIG	Recurring briefings for the Legislature, especially the Kupuna Caucus.	
	Draft Supporting Legislation	New LTC Implementation PIG	Draft legislation to establish and fund a Long-Term Care Financing Advisory Commission.	
	Identify Sponsors and Liaise	New LTC Implementation PIG	Work with key House/Senate subject matter committees/sponsors for introduction and enactment of legislation.	
	Present to Kupuna Caucus	Marilyn Seely	KAC approved that Marilyn Seely share the LTC Report at the Kupuna Caucus on behalf of the KAC.	
Announcements	None. Discussion regarding next meeting T. Visperas will send out a doodle poll for our next meeting			

Next Meeting/ Logistics	targeting Thursday, November 20, 2025. Doodle poll will ask if the majority can make 10AM-11AM; 11:30AM-12:30PM or 12:30-1:30PM.	
Adjournment	The meeting was adjourned at 1:29 p.m.	

September 2025

Final Report of Findings

Long-Term Care Financing Permitted Interaction Group

Kupuna Advisory Council
Melissa Ah Ho-Mauga, MBA
Ritabelle Fernandez, MD, JD, MPH
Cullen Hayashida, Ph.D
Lawrence Nitz, Ph.D
Melvin Sakurai, Ph.D
Marilyn Seeley, MPH
State Department of Health
State Health Planning & Development Agency

Final Report of Findings

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Foreword

More than 20 years ago an article in The Lancet, * a highly revered peer-reviewed medical journal founded in England in the 19th century, outlined the problem of Long-term as "essentially an economic problem." In the past we may have assumed we could save for our own care. This assumption shifted in the USA to believing incorrectly that long term care when needed would be paid for by Medicare. Given that the cost of nursing home and community based long term care can exceed $200,000/year in some cases in Hawaii and the fact that Medicare pays for very little long-term care, we ask who does pay for long term care and is it enough.

Medicaid pays for about 60% of long-term care in Hawaii and this does not cover costs adequately. A large portion of care is provided by friends and family without compensation or other assistance. We have cobbled together a fragile payment system that uses whatever source it can find including federal, state and local government funds, private charitable funding, and family resources that may strip a family of hard-earned savings, social security or caregiver earnings at times forcing caregivers to give up earnings to stay home and provide care needed. Even in the best of programs and services we can see that it is never enough either in terms of the service package itself per individual or the number of people who get access to scare services versus those who need it leaving an ever-growing deficit in the care of people with disabilities.

This response to caring for seniors and the disabled has long been a problem here and across the country. What has not happened is seriously delving into the issue and addressing it in all its aspects to finally come to terms with realistic costs and payment. With the impending crisis of reducing the already inadequate funding we do count on for care in the new proposals by the federal government the problem is greatly exacerbated to levels we can hardly imagine. The Lancet in 2003 concluded that in the little time left a "short window of opportunity, perhaps a decade or so, exists to address the challenges of long-term care before demand for it is soaring all over the world. Governments everywhere must take the initiative now to configure or restructure long-term care, first by examining their social and ethical values and public policies on care of the elderly. The subtitle of a WHO report on long-term care poses a compelling place to start: What does justice require? The question is on the table: now the imperative is to find an answer. "Twenty years down the road we still do not have the answers. *The Lancet, May 2003

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Executive Summary

Opportunity

The Long-Term Care Financing Permitted Interaction Group (LTC PIG), was established and chartered on March 11, 2025 by the State Health Planning Development Agency's Kūpuna Advisory Council (KAC) to investigate financing for long-term care for seniors residing in Hawai'i.

Hawai'i has been a leader in the U.S., a vanguard at the forefront of health care reform which began with the Prepaid Health Act that was enacted on June 12, 1974 to improve health care coverage by employer mandate.[1] In 2003 Hawai'i became the first state in the nation to enact legislation for a tax funded public insurance benefit program for long-term care financing which was unfortunately vetoed by Governor Linda Lingle.[2]

Health care reform is a three-legged stool that needs to address cost, access, and quality. This executive summary report highlights three key areas: (a) new sources of long-term care (LTC) funding, (b) reforming home- and community-based services (HCBS), and (c) cost containment strategies to improve care quality while managing expenditures.

Solution

A. LTC Funding

A proposed long-term care (LTC) benefit program should effectively partition LTC risk into two components: a front portion and a back portion. The program covers the front portion, beginning 30 days after the onset of services once the disability trigger is met. Importantly, the benefit period is intentionally limited so it does not fully replace the need for longer-term support. This division reinforces the role of individual planning in addressing long-term care needs. Complete public financing of LTC is generally considered infeasible across most of the United States.

[1] Haw. Rev. Stat. Ann. § 393-7 (Lexis).
[2] S.B. 1088, 22nd Reg. Sess. (Haw. 2003).

By covering the initial, front-end portion of LTC risk, the program leaves room for private long-term care insurance, family savings, and other personal resources to address the longer-term needs. Such a design provides meaningful private opportunities to protect family well-being and financial stability, while also delaying potential reliance on Medicaid-funded home and community-based services. Ultimately, this approach helps direct public assistance to families caring for frail members who need support most urgently.

A promising model for public long-term care financing is Washington State's *WA Cares Fund*. Established by the Long-Term Services and Supports Trust Act of 2019, WA Cares is a publicly funded insurance program designed to help all working Washingtonians access benefits for long-term care. Workers contribute to the program through a payroll tax of 0.58% of their earnings. To qualify for benefits, individuals generally must meet vesting requirements—typically 10 years of contributions—with recent adjustments creating alternative pathways for those nearing retirement. The program provides a lifetime benefit cap of approximately $36,500. According to a 2022 actuarial study by Milliman, the WA Cares Fund is projected to remain solvent through 2098, covering the full 75-year evaluation period under most scenarios at the current payroll tax rate.[3] This model demonstrates a sustainable approach to funding long-term services and supports through broad-based public contributions.

Driven by the rapid aging of the population, Japan introduced public long-term care insurance to reinforce healthcare services for the elderly in 2000. *Kaigo Hoken*—the country's long-term care insurance system—which operates as a public insurance program mandatory for all citizens aged 40 and older. It provides universal access to a wide range of services, including home-based care, rehabilitative services, and institutional care, with eligibility based on care needs rather than income.[4] Kaigo Hoken is financed through a balanced structure: approximately 50% public funding (national and local governments) and 50% from individual insurance premiums. This mixed financing model spreads the cost equitably across generations and offers stable, predictable funding. One of its core aims is to relieve the caregiving burden on families, while also ensuring sufficient compensation and workforce retention in the long-term care sector. The program places a strong emphasis on home- and community-based care to prevent premature institutionalization—an approach that deeply aligns with Hawai‘i's cultural

[3] Giese, C et al. (October 20, 2022). *2022 WA Cares Fund Actuarial Study*.
[4] Hasegawa, K., Tsukahara, T. & Nomiyama, T. Associations between long-term care-service use and service- or care-need level progression: a nationwide cohort study using the Japanese Long-Term Care Insurance Claims database. BMC Health Serv Res 23, 577 (2023).

values of keeping kūpuna connected to their families and communities. Kaigo Hoken offers a proven example of how a publicly supported LTC system can promote dignity, sustainability, and intergenerational equity.

B. Reforming Home- and Community-Based Services (HCBS)

There are numerous strategies proposed to reform HCBS, ranging from State Plan Amendments to expansion of Section 1115 demonstration waivers. However, there remains an urgent need to establish universal access to affordable, high-quality HCBS benefits. Achieving this goal requires a multi-faceted approach, including robust workforce development and training initiatives, adequate and sustained funding for the direct care workforce, expanded eligibility criteria for HCBS, and the enhancement of Medicare to include meaningful HCBS coverage.

Expanded and emergency respite services are essential to sustaining the well-being of family caregivers, who form the backbone of the long-term care system. Despite their critical contributions, caregivers often receive little recognition or support. Strengthening ethical and legal protections is necessary to uphold their rights and ensure they are treated with dignity and fairness. In addition, comprehensive financial relief measures are vital. These may include caregiver stipends or salaries, refundable tax credits, Social Security earning credits, expanded tax deductions, property tax relief or deferrals, and assistance with housing and transportation. Such targeted interventions not only acknowledge the economic and social value of unpaid caregiving but also help prevent caregiver burnout, reduce reliance on institutional care, and enable older adults and individuals with disabilities to age in place safely and with dignity.

In Hawai‘i, approximately one in four residents are covered by Medicaid. Medicaid funds both institutional nursing home care HCBS as part of its long-term support services. Efforts to divert kūpuna from institutional nursing homes to community-based settings—such as foster homes or returning to live with family—align closely with Hawai‘i’s cultural values and emphasis on ‘ohana care. A promising yet currently underutilized program is the ***Going Home Plus (GHP) Project***.[5] This initiative supports Medicaid recipients who have been living in hospitals or nursing facilities to transition safely and successfully back into the community. Participants who no longer require institutional care but need ongoing support can receive housing assistance and a tailored package of HCBS.[6] Working

[5] Nishita CM, Johnson J, Silverman M, Ozaki R, Koller L. Hawai'i's "Going Home Plus" project: a new option to support community living. Hawaii Med J. 2009 Aug;68(7):166-8.

[6] https://medquest.hawaii.gov/en/members-applicants/already-covered/going-home-plus/ghp-services.html

closely with a dedicated Health Coordinator, participants and their families develop a person-centered care plan that addresses their unique needs, helping to promote independence, improve quality of life, and reduce institutional care reliance.

C. Cost Containment

Cost containment programs for seniors are strategic approaches aimed at reducing overall health care and long-term care expenditures while maintaining—or even improving—quality of care and supporting independence. These programs focus on preventing costly hospitalizations, delaying or avoiding institutionalization, and improving coordination of care. Examples include case management, the Program of All-Inclusive Care for the Elderly (PACE), medication therapy management, telehealth and remote patient monitoring, as well as a range of home- and community-based services such as adult day care, adult day health, home health care, and hospice services. Together, these interventions promote aging in place, improve outcomes, and help manage rising public and private spending on long-term care.

Senior centers that promote healthy aging are a vital component of cost containment strategies in long-term care. A shining example is the ***Lanakila Multi-Purpose Senior Center***—Hawai'i's oldest and largest senior center. Built by the State in 1969 and operated by Catholic Charities Hawai'i since 1981, Lanakila serves approximately 2,000 kūpuna each year. Senior centers serve as community focal points where older adults can access essential services, participate in social activities, engage in lifelong learning, and receive health promotion and wellness support. In this context, healthy aging encompasses the physical, mental, and social well-being of older adults—empowering them to live longer, more active, independent, and fulfilling lives. Through preventive care, chronic disease management, social connection, and wellness programming, senior centers like Lanakila help delay institutional care, reduce health care utilization, and improve quality of life—making them both a compassionate and cost-effective solution.

The *Geriatric Resources for Assessment and Care of Elders (GRACE)* model, developed by the Indiana University, is a proven, evidence-based care coordination model designed to improve outcomes for frail older adults.[7] GRACE emphasizes proactive, person-centered care aimed at enhancing health and functional status, reducing emergency department visits and hospitalizations, and preventing

[7] Counsell SR, Callahan CM, Buttar AB et al. Geriatric Resources for Assessment and Care of Elders (GRACE): a new model of primary care for low-income seniors. *J Am Geriatr Soc*. 2006 Jul;54(7):1136-41.

premature nursing home placement. A distinctive feature of the GRACE model is its comprehensive in-home assessment conducted by a two-person team—typically a nurse practitioner and a social worker—who visit the patient together. This interdisciplinary approach allows for early identification of medical, functional, and psychosocial needs, leading to a tailored, coordinated care plan. Medicaid Managed Care Organizations have successfully adapted and piloted the GRACE model, demonstrating its scalability within existing health systems. In these implementations, care coordination teams—composed of registered nurses and social workers—conduct regular home visits, maintain monthly contact with members, and collaborate closely with primary care providers and specialists. The GRACE model serves as a strong example of how integrated, community-based care can improve outcomes and contain costs for high-risk senior populations.

Timeline

- 2025
    - Submission of LTC PIG report of findings KAC
    - KAC adoption of findings and concurrence to proceed
    - Formation and appointment of a KAC LTC Implementation PIG to drive legislative agenda
    - Collaborate with Legislative champions to build support for passage of legislation forming the autonomous Governor's LTC Financing Advisory Commission with separate general fund budget appropriation
- 2026
    - Legislature 2026—adoption of Commission formation and budget legislation
    - Staffing and procurement of Policy and Actuarial consultants to conduct feasibility assessments of the LTC financing package options
    - Commence formal assessment studies
    - Critical stakeholder engagement and constituency building
- 2027
    - Commission completes formal assessment of alternatives and options and reaches consensus about which financing options to implement and/or draft requisite implementation legislation

I. 3-Year LTC Financing Legislative Strategy & Timetable

Charter & Organization of the Final Report of Findings

The Long-Term Care Financing Permitted Interaction Group (LTC PIG), was established and chartered by the State Health Planning Development Agency's Kupuna Advisory Council (KAC) to "***investigate financing for long-term care for Kupuna***."

Our Final Report of Findings addresses that mandate in terms of three essentially interconnected domains: **(1)** a package of alternative financing options and mechanisms deemed worthy of further critical quantitative, actuarial, policy, and impact assessment, **(2)** a recommended mechanism to ensure the formal assessment of options over a 2–3-year period, and **(3)** critical strategic stakeholder coalition building to pave the way for legislative enactment.

1. A Package of Promising LTC Financing Options and Alternatives

Our investigation of LTC financing options and alternatives gathered information related to a complex of three highly interactive elements: **(1)** the creation of new sources of funding, **(2)** controlling and mitigating risks and cost containment, and **(3)** reforming and strengthening Hawai'i's home and community based LTC support system.

(A) New LTC Financing Money: These include options for generating new LTC financing money—not merely repurposing existing funds or shifting allocation priorities but generating new capital. Several critical briefings were conducted:

a. **Hawaii Family HOPE** (a mandatory income tax funded earned benefit program that was ultimately ***adopted by the Hawaii State Legislature on 5.1.2003*** and vetoed by Gov. Linda Lingle 7.8.2003).[8]

b. **WA Cares Fund** (a mandatory limited "front-end" payroll tax funded earned benefit LTC financing program enacted into law by Washington State in 2019).[9]

c. **Massachusetts Long-Term Services and Supports Feasibility Study** & **Reimagine Aging 2030: The Massachusetts Plan** (actuarial analysis of various LTSS financing options, including private and mandatory tax funded public insurance, effectiveness, and impacts).[10]

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[8] H. B. 31, 17th Leg., Reg. Sess. (Haw.1993); S. B. 1088 Sd2 HD2 CD1, 22nd Leg., Reg. Sess. (Haw. 2003).

[9] Chapter 50B.04 Revised Code of Washington, Long-Term Services and Supports Trust Program

[10] Milliman Inc. (2025), *Long-Term Services and Supports Feasibility Study.* Massachusetts Executive Office of Health and Human Services

d. Minnesota Own Your Future LTSS Funding and Services Initiative (a comprehensive initiative encompassing LTSS financing, Catastrophic Lite backend social insurance, enhanced/extended Medicare HCBS benefits, and Life State private insurance hybrid).[11]

e. California Department of Aging (CDA) Master Plan for Aging (MPA) (a person-centered, equity-focused, data-driven LTSS framework for advancing LTSS system changes related to Financing, Navigation, Access, and Workforce, briefing being scheduled).[12]

f. Diverting NH Patients Back to the Community (a plan to divert Med-QUEST nursing home patients to appropriate and cost-effective community-based care settings to generate Federal and State Medicaid savings that could be captured to expand the Hawai'i HCBS system).[13]

g. Milliman (consulting actuaries) LTC PIG Briefing: Basic Principles of Long-Term Care Financing (a briefing on financial and actuarial principles of public and private LTC financing alternatives by principles of the Milliman long-term care insurance consulting team headquartered in Milwaukee).[14]

(B) Risk & Cost Containment: Strategies to reduce the future risks and costs of needing and spending for LTSS which can encompass early intervention, prevention, healthy aging, and cross-platform coordinated care strategies This also included consideration of applying "single payer" leverage that would derive from a universal mandated "single-payer" financing plan to incorporating value-purchasing prospective capitated "global budget" payment structures like those now being tested for Medicare and Medicaid under Hawaii's CMS Achieving Healthcare Efficiency through Accountable Design (AHEAD) Model grant[15] as well as establishing strict outcome quality accountability for certified LTSS providers. The aim here is to reduce the financing burden on a new public insurance financing plan to keep it affordable, cost-effective, and solvent. Briefing and resource material included:

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[11] Minnesota Department of Human Services (2023), *The Own Your Future LTSS Funding and Services Initiative Actuarial Considerations Report.*

[12]California Department of Aging (ND), *Long-Term Services and Supports System Change in the Master Plan for Aging; Gap Analysis and Multi-Year Roadmap for Non-MediCAL Home and Community-Based Services. https://mpa.aging.ca.gov/*

[13] LTC PIG briefing (August 6, 2025).

[14] Milliman consulting actuaries (April 29, 2025), *LTC PIG Briefing: Basic Principles of LTC Financing.*
[15] Centers for Medicare & Medicaid Services, *Achieving Healthcare Efficiency through Accountable Design (AHEAD) Model. https://www.cms.gov/priorities/innovation/innovation-models/ahead.*

a. The Strategy of Fukuoka City Towards a Super-Aging Japan, The Fukuoka 100 Plan & Implications for Hawaii (a mandatory national tax funded program focused on community LTSS for active aging, wellness, and prevention).[16]

b. Solvency Design Features for Public Financing Programs (resource material concerned with financial-actuarial design principles to assure the long-range solvency of public financing programs).[17]

(C) Reforming the Hawai'i HCBS System: Strategies for building a far more resilient, fully integrated, and coordinated HCBS system with sufficient resources AND reach. Hawai'i's current HCBS system is woefully lacking and hampered by excessive siloing, fragmentation, limited and unstable reach, and missing or contradictory care standards with no uniform treatment service protocols and weak outcome accountability. Significant new funding to affect needed reforms is essential if we want to shift away from institutionalization in a way that is markedly better than what we have now. Resource material presented to the PIG include:

a. The False Mythology of Home & Community-Based Care As a Panacea for the LTC Financing Crisis (addressing the cost of essential Hawai'i HCBS system reforms).[18]

b. Vermont Blueprint for Health (a multi-payer blueprint plan encompassing Patient-Centered Medical Home, Community Health Teams, Opioid Hub, & Mental Health Integration).[19]

2. Governor's LTC Financing Advisory Commission

An accountable mechanism is needed to champion and assure completion of critical financial/actuarial analyses of the package of promising LTC financing options and alternatives to provide an objective basis for assessing the long-range feasibility, reliability, costs, and beneficial financial and social impacts of options and alternatives considered to support informed policymaking and legislative drafting—including the identification of additional options and alternatives.

The critical function can be accomplished by establishing an independent and autonomous Long-Term Care Financing Advisory Commission that would be attached to the Governor's Office for

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[16] The Strategy of Fukuoka City Towards a Super-Aging Japan, The Fukuoka 100 Plan & Implications for Hawaii (July 18, 2025).

[17] Research Information Services (September 4, 1989), *Memo to Dr. Jeanette C. Takamura, Director, Executive Office on Aging, LTC Insurance Product Design Features.*

[18] LTSS Primer Addendum 1 (August 2025), *The False Mythology of Home & Community-Based Care as a Panacea for the LTC Financing Crisis.*

[19] Vermont Blueprint for Health, Agency of Human Services (ND), *Blueprint for Health Overview & Funding;* and *Blueprint for Health 101* (slide deck).

administrative purposes only and would have an independent General Fund budget appropriation for support staffing and the authority to execute consulting actuarial and policy development/analysis competitive bid contracts.

There are at least two implementation paths for establishing the Commission. The Washington State Legislature established the Joint Legislative Executive Committee on Aging and Disability Issues through a budget proviso in the 2013-15 operating budget. The Massachusetts Long-Term Care Financing Advisory Committee was convened in 2009 at the request of Governor Deval Patrick (the committee was a joint effort of the Executive Office of Health and Human Services and the Executive Office of Elder Affairs). Ideally, Hawai'i's Commission can be a joint collaborative effort between Governor Green and the Legislature.

The Commission's agenda is LONG-RANGE and anticipates the need for objective technical feasibility forecasting and pricing work on the options identified options and alternatives, is sensitive to the current challenging fiscal environment (both in-State and coming externally from DC)—and sets a legislative action agenda target no earlier than 2027 (2.5 years from today during what is expected to be Governor Green's *legacy term*). This long timeline is needed to facilitate doing the technical actuarial and policy planning work, encourage legislative will, and execute an effective stakeholder coalition building effort to foster public engagement/investment and build general legislative support.

Appointed volunteer Commission members (ideally, government agency Commissioners will be discouraged from using substitute designees):

- Director of Health
- State Health Planning & Development Agency Administrator
- Director Executive Office on Aging
- Director of Human Services
- Med-QUEST Administrator
- Director of Taxation
- Insurance Commissioner (no designee or substation)
- Hawaii State Economist
- Executive Director University of Hawaii Economic Research Organization
- Director University of Hawaii Center on Aging
- State Director Hawaii Chapter American Association of Retired Persons
- President & CEO Healthcare Association of Hawaii
- Leadership for the Med-QUEST Managed Care Organizations (AlohaCare, HMSA, Kaiser Permanente, Ohana Health Plan, UnitedHealthCare Community Plan).

3. Critical Stakeholder Coalition Building: Ensuring SUCCESS!

The LTC PIG was also concerned about having a strategy to ensure success. Right now, the issue of paying for LTSS has hardly any visibility or presence—even though it touches so many people in Hawaii directly.

Issues of homelessness, affordable housing, cost of living, and native Hawaiian rights, not to mention the Lahaina recovery and huge uncertainties coming out of DC have the public spotlight.

In order to succeed, there is need to use the 2.5-year development calendar to mount an aggressive and effective stakeholder coalition building effort that will require spending and media to build awareness and visibility, counter uninformed knee-jerk opposition, enfranchise supporters, and convert skeptics and doubters so that the ground is prepared, and we are ready to act with force in 2027. We can look to both Washington and Massachusetts for successful critical stakeholder coalition building models to emulate:

(A) Building and Sustaining Effective Coalitions for Long-Term Care Policy Success (a briefing August 14, 2017, by the former Coalition Director of the WeCare for WA Care strategic stakeholder coalition building program encompassing key stakeholder mapping, constituency/audience specific messaging, legislative alliance building, threat mitigation, and paid media advocacy).[20]

(B) Sister state alliance-coalition building (LTC PIG members have already initiated and received positive responses and interest in building an alliance or coalition of like-minded states to collaborate in developing effective and reliable financing programs for LTSS—including Washington, California, Massachusetts, Minnesota, and Vermont).

[20] Gomez, Jessica (August 14, 2025), *Appendix: Coalition Building Toolkit.*

3-Year Timetable

- Rest of 2025
    - Submission of LTC PIG report of findings to KAC—a package of LTC Financing Options identified by the PIG as high-priority and a recommendation for the formation of an autonomous LTC Financing Advisory Commission attached to the Governor's office for administrative purposes with a separate general fund budget to conduct formal public policy and actuarial assessments of the high-priority options identified in the LTC PIG findings Package

    - KAC adoption of findings and concurrence to proceed

    - Formation and appointment of a KAC LTC Implementation PIG to drive legislative agenda (including the formation and funding of the Governor's Long-Term Care Financing Advisory Commission):

        - Meet with Governor Green before the end of October about establishing the Commission by Executive Order and securing funding

        - Conduct a series of briefings of the Legislative Kupuna Caucus

        - Draft Commission enactment and funding legislation

        - Find key House and Senate subject matter Committee sponsors for introduction of legislative enactment and funding bills

        - Continue on-going individual key House and Senate leadership liaising

        - Commence critical key stakeholder briefings

        - Initiate formal conversations with other potential sister state long-term care financing & Medicaid response teams to form a coalition of cooperating States

    - Collaborate with Legislative champions to build support for passage of legislation forming the autonomous Governor's LTC Financing Advisory Commission with separate general fund budget appropriation—target: Legislature 2026.

- 2026
    - Legislature 2026—adoption of Commission formation and budget legislation

- Staffing and procurement of Policy and Actuarial consultants to conduct feasibility assessments of the LTC financing package options

- Commence formal assessment studies

- Critical stakeholder engagement and constituency building

- 2027 and on (Governor Green's 2nd legacy term)
  - Commission completes formal assessment of alternatives and options and reaches consensus about which financing options to implement and/or draft requisite implementation legislation

  - Commission presents assessment findings to the Legislature (likely Legislature 2028)

  - Draft required financing option implementation legislation

  - Legislative adoption of LTC Financing legislation (Legislature 2028-29 at the earliest, Gov. Green's 2nd or 3rd legacy term year)

II. Long Term Support Services (LTSS): A Candid & Unvarnished Reference Primer

1. What are Long Term Support Services (LTSS)? What are the costs and who pays? What are the individual personal lifetime exposure risks of incurring financially catastrophic LTSS expenses? Inequities of the Medicaid "spend-down" community spouse impoverishment rule.

   LTSS encompass a broad range of Institutional and Home and Community-Based Services (HCBS) for persons (not necessarily elderly) with functional disabilities who need support because of age; physical, cognitive, developmental, or chronic health conditions; or other functional limitations that restrict their abilities to care for themselves. Two categories of daily living functionality include:

   - Basic Activities of Daily Living (BADLs or ADLs): These are the most fundamental, physical self-care tasks necessary for survival and basic personal hygiene, including:
     - Bathing/Showering: The ability to wash oneself, including getting in and out of the bath or shower, applying soap, rinsing, and drying.
     - Dressing: The ability to select appropriate clothing and put it on and take it off independently, including managing fasteners like buttons, zippers, and ties.
     - Eating/Feeding: The ability to bring food to the mouth and swallow it, which can include cutting food, using utensils, and managing liquids. This doesn't necessarily include meal preparation.
     - Toileting: The ability to get to and from the toilet, use it appropriately, and clean oneself afterward.
     - Continence: The ability to control bladder and bowel functions.
     - Transferring/Mobility: The ability to move from one position to another (e.g., getting in and out of bed or a chair) and to walk or move around independently, with or without assistive devices like a cane or walker.

   - Instrumental Activities of Daily Living (IADLs): These are more complex tasks that are not directly related to basic physical needs. IADLs often require more cognitive and organizational skills and include:
     - Meal Preparation: Planning meals, assembling ingredients, cooking, and serving food.

- Housekeeping/Home Management: Cleaning, tidying, organizing, doing laundry, and maintaining the living environment.
- Managing Medications: Obtaining medications, remembering to take them correctly, and managing refills.
- Managing Finances: Paying bills, managing a budget, banking, and handling money.
- Shopping: Planning a shopping list, getting to the store, making purchases, and carrying them home.
- Transportation: Driving, using public transport, or arranging other means of getting around.
- Communication Management: Using a telephone, mail, or other communication devices to stay in touch with others.

Institutional LTSS

- Acute Waitlisted ICF/SNF—*mainly acute Medicare and Medicaid patients who have recovered and are temporarily waiting for appropriate discharge placements* *(represents an inappropriate use of acute facility resources, contributes to throughput/resource utilization inefficiencies and uncompensated care for Medicare and other waitlisted patients)*
- Rural/CAH "swing beds"—*use of acute beds to provide SNF level care*
- Skilled Nursing Facility (SNF)
- Intermediate Care Facility (ICF)
- SNF/ICF facility—*prevailing facility type in Hawaii*
- Subacute facility

Home and Community-Based LTSS

(not exclusively for Kupuna)

• Adult Day Care • Adult Day Health • Assisted Living Services • Community Care Management Agency services • Counseling and training • Environmental access adaptation • Home delivered meals • Home maintenance • Moving assistance • Non-medical transportation • Personal assistance (chore & care) • Personal emergency response systems • Residential care home (ARCH/Extended ARCH) • Community Care Foster Family Home—*Medicaid living accommodation, typically 3 person limited; 2 Medicaid and 1 private pay patient who is often exploited to subsidize the inadequate Medicaid payment rates*	• Respite care • Skilled or private duty nursing • Specialized medical equipment & supplies • Career planning • Employment services • Nursing for intellectual/developmental disabilities I/DD • Additional residential support of I/DD • Assistive technology for I/DD • Community Learning Services

Table 1. LTSS Costs are Unsustainably Expensive for Most

	2024 LTSS Census, Occupancy, & Cost: Urban Honolulu or Hawaii (costs are higher for Outer Islands)									
LTC Setting & Support Services	**Number of Licensed Facilities**	**Number of Licensed Beds**	**Licensed Beds Not Available Mainly Due to Staffing[1]**	**Average Daily Census (ADC)**	**Average Daily Occupancy**	**Average Annual Facility Length of Stay, days (ALOS)**	**Type of Bed**	**Average Daily/Hourly Rate**	**Average Per-Person Monthly Cost[2]**	**Average Per-Person Annual Cost**
SNF/ICF[1]		4,132	450	3,168	76.7%	116.0	Private	$637	$19,375	$232,505
							Semi-Private	$582	$17,703	$212,430
							Ward	$573	$17,429	$209,145
SNF only[1]		101	33							
ICF/ICF[1]		127	27				Private	$586	$17,824	$213,890
							Semi-Private	$531	$16,151	$193,815
							Ward	$500	$15,208	$182,500
Community Access Hospital "swing" beds[2]	9	119								
ARCH/Expanded ARCH (primarily private pay)--E-ARCH Level 2, cost share/SSI in-eligible patient[3]	465	2,288						$122	$3,795	$45,542 *$54,000 -- $90,000*
Assisted Living Facility	17	2,593						$372	$11,315	$135,780
CCFFH-Community Care Foster Family Homes Medicaid rates (2 Medicaid, 1 private pay)--CCFFH Level 2, cost share/SSI in-eligible[3]	1,285	3,256						$122	$3,795	$45,542 *$36,000 -- $72,000*
Homemaker Services[4]								$25	$4,316	$51,786
Home Health Aide								$29	$5,125	$61,501

[1] State Health Planning & Development Agency, *Healthcare Utilization Report Hawaii 2023;* ALOS = Total Facility Inpatient Days/Annual Admissions--this is not a patient centered length of stay measure.

[2] Office of Healthcare Assurance, Hawaii Department of Health and QUEST, *Fee for Service Rates for Home and Community-Based Services (HCBS) Effective January 1, 2025 (MEMO NO. QI-2501A update to QI-2501).* ***These are Hawaii MedQUEST payment rates that are often questioned as to financial adequacy and anecdotally, result if significant cost shift to private-pay patients (especially for ARCH and CFFH care--*** *private-pay rates as a whole are*

[3] Inclusive of SSI + Hawaii Optional State Supplement (OSS) less Personal Needs Allowance ($1676/month) and Medicaid Service Payment per diem ($68.36/day; $2,119.16/month). **The estimated Private Pay rate range for E-ARCHs is $150-$250+/day, $4,500-$7,500/month; $3,000-$6,000/month for CCFFHs. The disparity between public and private pay rates and limited number of persons able to afford out of pocket private pay rates directly restricts access, creates staffing shortages, disincentivizes resource development/expansion, forces the use of unqualified staffing models, and creates significant efficiency and financial waste due to patient waitlisting in acute hospital beds (especially the Medicaid eligible).** *MedQuest Hawaii Medicaid MEMORANDUM MEMO NO. QI-2501A (Effective January 1, 2025)' Supplemental Security Income (SSI) in Hawaii - SSA Publication SSA Pub. No. 05-11108; Genworth 2024 Cost of Care Survey for Hawaii; Kupuna Care Pair--Community Care Foster Family Homes; House Concurrent Resolution HCR94 (2024)*

[4] *Home services assume* ***44 hours/week***

In 2023 the US Median annual cost for full-time homemaker services was $62,400, $68,640 for full-time health aide care, $116,8000 for private SNF placements, and $288,288 for round-the-clock home health aide services that replicate SNF care.[21]

[21] KFF, *10 Things About Long-Term Services and Supports (LTSS), July 8, 2024*

Table 1a. Hawaii Med-QUEST Fee-for-Service Rates

MedQUEST Home & Community Based Services Fee For Service Rates (eff. 1.1.2025)--not applicable to QUEST Integration Managed Care Organizations								
Community Care Foster Family Home (CCFFH) & Expanded Adult Residential Care								
	Patient Room & Board Cost Share				MedQUEST Service Per Diem			Combined R&B and Service TOTAL
1147 LOC	Monthly SSI	Monthly (PNA)	Monthly Patient Cost Share	Total Annual Patient Cost Share	Service Per Diem	MedQUEST Monthly Payment	MedQUEST Total Annual Payment	
SSI Patient--Oahu								
1	$1,751.00	-$75.00	$1,676.00	$20,112.00	$28.40	$880.40	**$10,564.80**	$30,676.80
2	$1,751.00	-$75.00	$1,676.00	$20,112.00	$68.36	$2,119.16	**$25,429.92**	$45,541.92
SSI Patient--Neighbor Island								
1	$1,751.00	-$75.00	$1,676.00	$20,112.00	$33.40	$1,035.40	**$12,424.80**	$32,536.80
2	$1,751.00	-$75.00	$1,676.00	$20,112.00	$73.76	$2,286.56	**$27,438.72**	$47,550.72
Spousal & non-Eligible SSI Cost-Share Patient--Oahu								
1		-$75.00	$418.00	$5,016.00	$65.50	$2,030.50	**$24,366.00**	$29,382.00
2		-$75.00	$418.00	$5,016.00	$105.45	$3,268.95	**$39,227.40**	$44,243.40
Spousal & non-Eligible SSI Cost-Share Patient--Neighbor Island								
1		-$75.00	$418.00	$5,016.00	$70.50	$2,185.50	**$26,226.00**	$31,242.00
2		-$75.00	$418.00	$5,016.00	$110.45	$3,423.95	**$41,087.40**	$46,103.40

In Home Support Services					
Type of Service	Payment	Service Rate	Extension	Extended Monthly Cost	Extended Annual Cost
Adult Day Health	per diem	$87.21	21 days	$1,831.41	$21,976.92
Adult Day Care	per diem	$63.06	21 days	$1,324.26	$15,891.12
Home Delivered Meals	per meal	$10.50	2 meal/31 days	$651.00	$7,812.00
Attendant Care	15 min.	$16.32	2 hrs./31 days	$4,047.36	$48,568.32
Homemaker Service	15 min.	$6.13	2 hrs./21 days	$1,029.84	$12,358.08
Personal Care	15 min.	$13.28	2 hrs./31 days	$3,293.44	$39,521.28
Home Health Aide/CNA	15 min.	$7.28	2 hrs./31 days	$1,805.44	$21,665.28
Emergency Response System	monthly	$54.06	monthly charge	$54.06	$648.72
Emergency Response Fee	monthly	$44.09	monthly charge	$44.09	$529.08
In Home RN Care	15 min.	$21.80	1 hr./21 days	$1,831.20	$21,974.40
In Home LPN Care	15 min.	$11.17	1 hr./21 days	$938.28	$11,259.36
Care Management	per diem	$14.60	31 days	$452.60	$5,431.20

Patient Driven Payment Model (PDPM) Fee-for-Service Attachment B Nursing Facility Rates[2]					
	Payment Unit	Avrg.	Extension	Extended Monthly Cost	Extended Annual Cost
Nursing Facility Rate	per diem	$548.37	31 days	$16,999.47	$203,993.64

[1] **Hawaii Department of Human Services, Med-QUEST Division**, (January 3, 2025), *Fee for Service Rates for Home and Community-Based Services (HCBS) Effective January 1, 2025.*

[2] **Hawaii Department of Human Services, Med-QUEST Division,** (January 26, 2025), *Medicaid Fee-for-Service Rates for All Nursing and Hospice Facilities Effective July 1, 2025.*

Table 2. Who Pays for LTSS—A Troubling Mix: The Vast Majority of Hawai'i's LTSS Bill for Long Term care is Paid by Uncompensated Caregivers

	Total Annual LTSS Payments by Payment Source: Hawaii							
	Medicare	Net Medicaid[2]		Private LTC Insurance[3]	Estimated[4] Out-of-Pocket Private Pay	Est. Value[5] of Unpaid Care for HCBSb	Older[6] Americans Act AAA	TOTAL
		Federal Share	Hawaii Share					
TOTAL LTSS	**$18,929,617**	**$313,027,760**	**$210,080,128**	**$118,686,480**	**$142,995,759**	**$2,325,600,000**	**$33,605,066**	**$3,162,924,810**
Payer Percentage Share of Total	**0.60%**	**9.90%**	**6.64%**	**3.75%**	**4.52%**	**73.53%**	**1.06%**	**100.00%**
TOTAL INSTITUTIONAL LTSS	$16,187,684[1]	$157,149,766	$105,466,822					$262,616,588
SNF								
ICF								
ARCH/Expanded ARCH								
Assisted Living Facility								
TOTAL NON-INSTITUTIONAL HCBS LTSS	$2,741,933[1]	$155,877,994	$104,613,306			**$2,325,600,000**	$16,802,533	$2,602,893,833
Home & Community Based Care (congregate like Adult Day Care)							$5,418,140	
Community Care Foster Family Homes (CCFFH)[2]								
Homemaker Services								
Home Health Aide								
At Home Assistance							$8,369,004	
Other (case management, legal, etc.)							$3,015,389	

[1] *CMS Medicare Geographic Variation by National , State & County (2023)*

[2] Rough estimate derived from: *FY2023 Medicaid Financial Management Report, Medicaid Budget & Expenditure System/State Children's Health Insurance Program Budget & Expenditure System (MBES/SBES) and AARP Medicaid LTSS Balance: Spending (2022)*

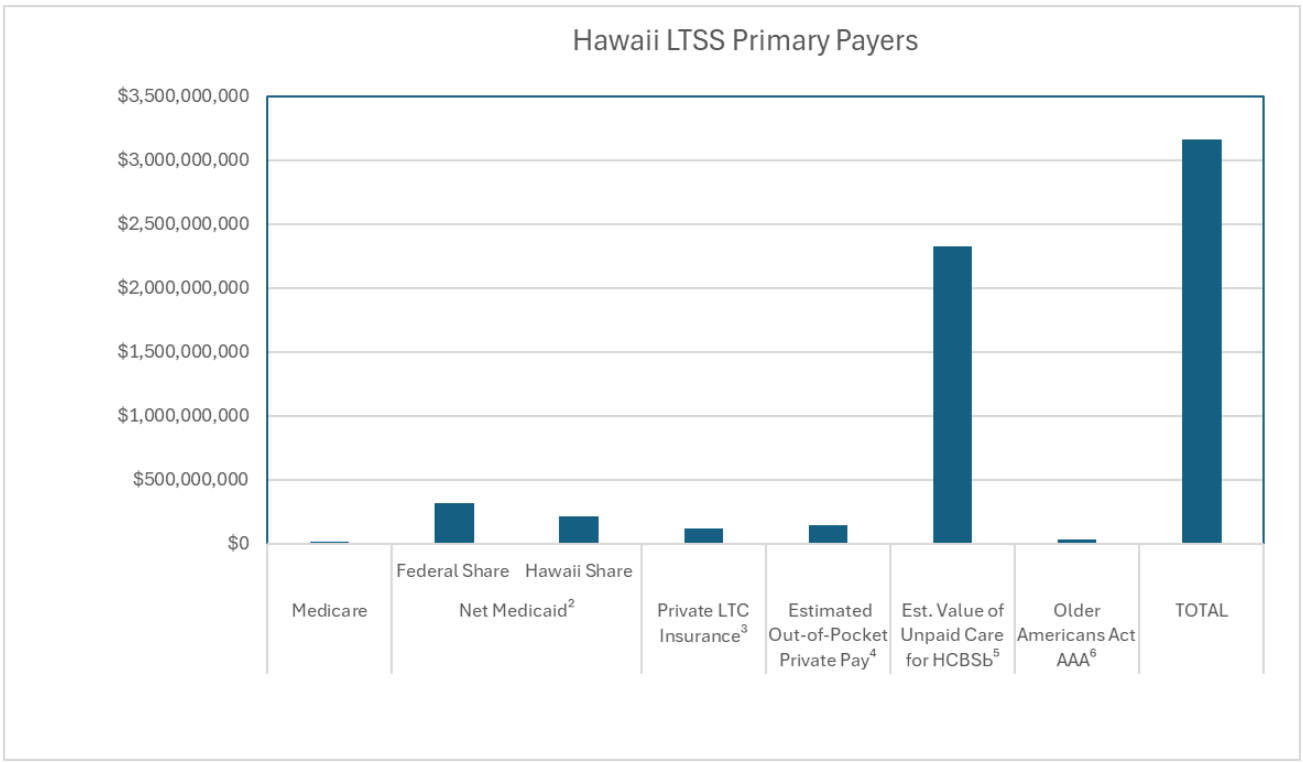
[3] National Association of Insurance Commissioners, *NAIC Long-Term Care Insurance Experience Reports for 2023, 2025.*

A proxy estimate of out-of-pocket LTSS spending is used because data are not available for Hawaii. Nationally, approximately 17% of total U.S. LTSS spending was in the form of private out-of-pocket expenditures--83% came for all other sources. We can estimate the total LTSS spend (including out-of-pocket payments) knowing that total LTSS payments were $694,329,015 (**not including** out of pocket payments) by solving the equation .83(x) = $694,329,015 (where 'x' is the total all inclusive LTSS spend **including** out-of-pocket payments), giving a total LTSS expenditure of $836,541,025 and a proxy out-of-pocket estimate of $142,995,759 (which is $836,544,025 - $694,329,051). KFF, *10 things about long-term services and support (LTSS), July 2024;* CMS, Office of the Actuary, *2022 National Health Expenditure Accounts.*

AARP, *Hawaii Ranks High for Long-Term Care Services, But More Support Needed for Family Caregivers (2023 Scorecard data)--estimates 154,000 unpaid family care givers providing 144 Million hours @ $16.15/hr. (25th percentile, CNA wage).*

Hawaii Executive Office on Aging, *Aging & Disabilities Database, WellSky, ACLOAAPS, Older Americans Act Performance System report FY2023 vs. 2024*

Medicaid is NOT the Primary Payer of LTSS in Hawaii



2. LTSS Expenses: Individual Personal Risk Exposures for Incurring Financially Catastrophic Lifetime LTSS Expenses

Table 3

LTSS Expense Exposure	Individual Risk of Incurring
Risk of incurring lifetime **out-of-pocket** LTSS expenses > $100,000[22]	14%
Risk of incurring lifetime LTSS costs > $250,000[22]	15%
Risk of incurring $120,900 of future LTSS expenses for Americans turning age 65 today (one-third paid out-of-pocket)[23]	Average population risk
Risk of being "frail" and at risk for persons age 85+[24]	25%
Risk of needing assistance with at least 2 activities of daily living after age 65[25]	>50%
Risk of needing any type of paid LTSS after age 65[25]	>50%
Rikh of using some Nursing Home Care after age 65[25]	>33%
Risk that the out-of-pocket cost for 12 months of SNF care will completely deplete the median Medicare beneficiary savings of $103,800[21]	100%
Medicaid "spend down" risk for persons needing LTSS[26]	70% - 80%
Median annual HCBS costs as a percentage of median income for households age 65+ (more than half the family income would be consumed annually for HCBS)[27]	63%
Median annual nursing home cost as a percentage of median income for household age 65+ (annual NH costs are more than double available income annually)[27]	227%

[22] AARP, *AARP TSS Scorecard, May 27, 2024*
[23] US Department of health and Human Services, *LTSS -risk-financing-2022.pdf*
[24]Medical School of South Carolina (MUSC), *Frailty: A New Predictor of Outcome as We Age, 2024*
[25] Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, *Economic Hardship and Medicaid Enrollment in Later Life: Assessing the Impact of Disability, Health, and Marital Status Shocks, 2021*
[26] Elder Care Resource Planning, *Projected 2024 Medicaid long term care financial eligibility criteria, 2024*
[27] Genworth, *Long-Term Care Costs Increase in Hawaii, Exceeding National Costs (March 2025).*

Table 3a. More Than 50% of Hawai'i Families Earning Between $25,000 - $125,000 Cannot Afford Long Term Support Services Without Becoming Impoverished to Qualify for Medicaid

	Sources of LTSS Coverage for Hawaii Families by Annual Income[1]					
Annual Family Income	Percent of Population	MedQUEST	Alternative Care	Older American's Act	Ot-of-Pocker	Private LTC Insurance
<$10,000	2.80%	X	not affordable	n/a	not affordable	not affordable
$10,000-$24,999	6.60%	X	marginally affordable	temporary grant	not affordable	not affordable
$25,000-$49,999	16.10%	n/a[2]	marginally affordable	temporary grant	not affordable	not affordable
$50,000-$74,999	14.10%	n/a[2]	marginally affordable	temporary grant	not affordable	not affordable
$75,000-$99,999	10.30%	n/a[2]	n/a	n/a	not affordable	not affordable
$100,000-$124,000	9.90%	n/a[2]	n/a	n/a	marginally affordable	not affordable
$125,000-$149,999	7.60%	n/a[2]	n/a	n/a	X	X
>$150,000	30.40%	n/a[2]	n/a	n/a	X	X

[1]**U.S. Cencus Bureau** (2023) Table ID: B19001. *American Sommunity Survey (ACS), Household Inome in the Past 12 Months (in 202 Inflation-Adjusted Dollars)*

[2]Medicaid benefits are income qualified and "spend down" is required for incomes above maximum allowable limits.

3. The Growing Need for LTSS Resources And the Financing Driven Deficit

There is a rapidly escalating unmet need for LTSS resources driven by a broken LTSS financing system. Exacerbated by the relatively high acuity of Hawaii's institutionalized patients.

Table 4. LTSS Resource Deficits

Indicator	Measure
Hawaii population age 65+ (2023)	282,567, projected to double by 2060 with the population age 85+ projected to increase by 155% by 2035[28]
Percentage of Hawaii population age 65-74 with at least 1 disability	21.1%[29]
Percentage of Hawaii population 85+ with at least 1 disability	70.9%[29]
Percent of surviving population age 65 projected to have multiple severe LTSS needs nationally	70.0%[28]
Projected Hawaii statewide nursing home bed shortage[30]	8,458 beds
Number of Med-Quest beneficiaries in nursing homes	3,800
Average Hawaii Nursing Home staff turnover[28] National average 53.9%; best state Hawaii	39.3%
Projected shortage of Hawaii HCBS	Still TBD, but expected to be substantial with 11,300 Medicaid beneficiaries using some form of HCBS and 8,400 older adults receiving Older Americans Act services[31]
Annual Hawaii Home care job openings[39]	1,840

[28] AARP, *Hawaii \ Long-Term Services and Supports State Scorecard (Demographic section);* Medicaid, *Long-Term Services and Supports Rebalancing Toolkit – Medicaid (Demographic Trends section)*
[29] Hawaii DBEDT, *The Elderly Population in Hawaii: Current Living Circumstances and Housing Options, December 2021.*
[30] Hawaii State Department of Health, *2020 SHPDA data*
[31] CMS, *Trends in Users and Expenditures for Hoe and Community-Based Services as a Share of Total Medicaid LTSS Users and Expenditures, 2022;* Executive Office on Aging, *Annual Report for -SFY 2020*

Indicator	Measure
Number of Hawaii adults age 18+ providing unpaid caregiving[32]	154,000
Likelihood of being an unpaid caregiver in Hawaii[32]	13.6% 1 in 7 adults age 18+ are unpaid caregivers
Hours of unpaid caregiving annually[32]	144,000,000 One hundred forty four million hours
Estimated annual value of unpaid (family) Care in Hawaii[33]	**$2,325,600,000** $2.326 Billion Dollars
Hawaii Assisted Living/Residential Care Supply/1,000 age 75+[28] National 55/1,000; best state 138/1,000	40/1,000 pop. age 75+
Hawaii Adult Day Services Supply/10,000 age 65+[28] National 54/1,000; best state 154/1,000	100/10,000 pop. age 65+
Hawaii Home Health Aide Supply/100 age 18+ with an ADL disability[28] National 24.8/100; best state 55.7/100	13.5/100 pop. age 18+ w/ADL Disability
Number of Hawaii people using self-directed HCBS/1,000 population with a disability[28] National 35.8/1,000; highest state 168/1,000	23.8%
Percentage of Hawaii NH Residents with Low Care Needs (Virtually all of Hawaii's institutionalized resident population have generally elevated care needs; very few marginally eligible)[28,34]	3.4%

[32] AARP, *Valuing the Invaluable: 2023 Update Strengthening Supports for Family Caregivers*; *Hawai'i Ranks High for long-Term Care Services, But More Support Needed for Family Caregivers (2023 Scorecard data);* ILWU Local 142, *The high costs of long-term care is everyone's business.*

[33] Based on the prevailing 25th percentile CNA wage of $16.15/hour for 144 million hours

[34] The percentage of nursing home residents who met the criteria of having low care needs. MDS assessments were used to establish the population of residents in all nursing facilities on the 1st Thursday in April. This measure was calculated from the most recent MDS assessment as of April 2021. Low care status is met if a resident does not require physical assistance in any of the four late-loss ADLs (bed mobility, transferring, using the toilet, and eating) and is not classified in either the "Special Rehab" or "Clinically Complex" Resource Utilization Group (RUG-IV). *Low care status may apply to a resident who is also classified in either of the lowest 2 of the 44 RUG-IV groups.

*On October 1, 2019, CMS replaced RUG-IV with a new case mix methodology, the Patient Driven Payment Model (PDPM), and stopped supporting precalculated RUG-IV values via the MDS. To continue utilizing the low care algorithm, RUG-IV values for a given MDS assessment were instead calculated using the last version of the public SAS classification code available from CMS.

Data are presented for all residents and for each race/ethnicity group with sufficient sample size to report. Residents without any race/ethnicity category selected are included in all residents but not in any subgroup.

Analysis of 2021 MDS 3.0 state-level care data provided by the Changing Long-Term Care in America Project at Brown University in February-April 2023.

Indicator	Measure
National average 8.8%; lowest state Hawaii	
Percentage of Hawaii long-stay NH Patients hospitalized within 6-months[28] National average 17.8%; best state 11.8%	13.4%
Percentage of Hawaii high-risk NH patients w/pressure sores[28] National average 11.8%; best state 7.1%	7.2%
Percentage of Hawaii home health patients with hospital admission[28] National average 14.1%; best state 12.1%	13.3%
Percentage of Hawaii people with an ADL disability below 250% of poverty receiving Med-QUEST or other government assistance [28] National percentage 59.1%; highest state 76.8%	58.2%
Median annual Hawaii nursing home cost (private room) as a percentage of median household income for persons age 65+[28] Hawaii median household income for persons age 65+ $74,606; national 213%	213%
Median annual Hawaii home care cost (30 hrs./week) as a percentage of median household income for persons age 65+[28] Hawaii median household income for persons age 65+ $74,606; national 83%	63%

Brown University (2023). Changing Long Term Care in America Project at Brown University funded in part by the National Institute on Aging (1P01AG027296). Providence, RI: Brown University School of Public Health, http://ltcfocus.org/.

4. Hawaii LTSS Workforce Crisis

Until we directly confront and fix the LTSS financing deficit, prospects for having a sufficient, qualified, competent and capable LTSS workforce are dim. Inadequate and unreliable financing not only inhibits investing in infrastructure development and service innovation/expansion but also the ability to offer competitive wages and career paths which in turn negatively affects workforce recruitment and retention.

The reality is that a fully functional and reliable LTSS system **cannot be built on the labor of an under-compensated workforce and volunteers.**

The issue is especially pressing for the home and community-based support system.

A two-part Milliman HCBS rate study for Med-QUEST reported the following workforce wage level related stakeholder feedback themes[35]:

- Significant pressure on HCBS workforce wages due to:
  - Competition from other programs and the private sector
  - Employee expectations about appropriate compensation for arduous and intense work
- Workforce retention difficulties at all staff levels due to:
  - The intensity of community-based care work
  - Limited recruiting candidate pipeline with schools
  - Ability to obtain higher pay with other competing employers offering less demanding work
- Eroded workforce experience and competency due to the loss of experienced staff
- Negative fallout for minimum wage increases such that:
  - HCBS providers must compete with food/service industry employers
  - Especially challenging for recruiting and retaining Certified Nurse Aides (CNA) who carry the bulk of direct care workloads in community settings.

The Milliman study looked at the prevailing wages for different HCBS employee functions utilizing Bureau of Labor Statistics (BLS) wage data for Hawaii.[36] The result, trended forward to 2024 @ 3.12%/annum are reported in Figure 13 extracted verbatim from the report below.

Hawaii HCBS Workforce Wages

[35] Milliman, Inc. *Home and Community-Based Services (HCBS) Rate Study Report—Hawaii Medicaid, December 30, 2022;* and *Phase II HCBS Rate Study Report—Hawaii Medicaid, January 10, 2024.*
[36] Bureau of Labor Statistics, *May 2022 State Occupational Employment and Wage Estimates: Hawaii (April 2023).*

Figure 13 below summarizes the trended wage assumptions underlying the rate model. The proposed model wages were informed by the BLS wage data, the provider survey results, stakeholder feedback, and input from MQD. A summary of the wage assumptions included in each rate scenario is provided in Appendix C.

FIGURE 13: DIRECT CARE WORKER AND SUPERVISOR STAFF WAGE ASSUMPTIONS

DIRECT CARE WORKER GROUPINGS BLS OCCUPATION CODES	WAGE WEIGHTING	JULY 2024 – TRENDED BLS WAGES (3.12% ANNUAL TREND RATE) 25TH PERCENTILE	50TH PERCENTILE	75TH PERCENTILE
Activity Assistant (Adult Day Aide)		**$16.15**	**$18.44**	**$21.02**
Home Health and Personal Care Aides	75%	$14.50	$16.48	$18.50
Maids and Housekeeping Cleaners	25%	$21.11	$24.30	$28.57
Supervisor		**$16.15**	**$18.44**	**$21.02**
Home Health and Personal Care Aides	75%	$14.50	$16.48	$18.50
Maids and Housekeeping Cleaners	25%	$21.11	$24.30	$28.57
Case Manager		**$44.87**	**$56.10**	**$63.17**
Healthcare Social Workers	25%	$29.33	$39.25	$42.88
Registered Nurses	75%	$50.05	$61.72	$69.93
Nurse Aide		**$17.45**	**$19.15**	**$23.70**
Nursing Assistants	100%	$17.45	$19.15	$23.70
Registered Nurse		**$50.05**	**$61.72**	**$69.93**
Registered Nurses	100%	$50.05	$61.72	$69.93

Focusing on Certified Nurse Aides (CNA) who form the bulk of the hands-on direct care HCBS workforce, we can see that the hourly Hawaii CNA wage even at the 75th Percentile level was just $23.70 (i.e., 75% of CNAs in Hawaii made less than $23.70/hour). To put that into context:

- $33.74/hour: Overall average hourly wage in Honolulu[37]
- $30.02/hour: Minimum living wage to meet basic needs in Honolulu for a single adult with no children[38]
- Other Entry-Level/Lower-Skilled Jobs[37]
  - $20.89/hour: Food preparation and serving related occupations
  - $21.78/hour: Building and grounds cleaning and maintenance
  - $20.59/hour: Personal care services
  - $24.81/hour: Office and administrative support

Most CNAs do not make a minimum living wage working as CNAs. It is also evident that CNAs can earn comparable or better pay in less demanding employment with career-paths than they can as CNAs.

[37] Bureau of Labor Statistics, *Occupational Employment and Wages in Urban Honolulu, May 2024*

[38] Massachusetts Institute of Technology, *Living Wage Calculator—Honolulu County, Hawaii*

Discouraging metrics[39]: Not surprisingly, the nursing home staff turnover rate is 39%. The professional paid home care workforce in Hawaii is currently about 9,020 (2022) with a projected need of 13,620 by 2028. High turnover rates mean there are approximately 1,840 home care job openings annually in a Hawaii job market with a 2.8% Unemployment rate.[40] Employee turnover rates more than 20-25% are generally considered "High" and pose significant operational issues. The high nursing home staff turnover rate is among the highest sector rate in Hawaii.[41]

It's worth repeating that we cannot build a fully functional LTSS system on the labor of an under-compensated workforce and until we confront and fix the broken and inadequate existing system of paying for LTSS, it is not likely we can remedy the workforce deficit.

LTSS and Acute Care System Collateral Damage

The severe LTSS workforce shortage is causing systemic damage to Hawaii's healthcare system as a whole by severely affecting access to appropriate needed care:

1. Taking already limited nursing home beds out of service due to staff shortages: The SHPDA Health care Utilization Report found that in 2023 510 of the statewide total of 4,360 SNF/ICF beds were not in service due mainly to "no available staff" (principally CNAs).[42] This represents 12% of available beds being out of service because they could not be staffed—an enormous and inefficient waste of precious LTSS resources we cannot afford squander.

2. LTSS patients backed up in acute care hospital beds (waitlisting): The same SHPDA report found that of the 1,729 licensed acute hospital beds statewide, 157 (12.8%) were occupied by LTSS eligible patients who could not be discharged because those patients were waiting for appropriate LTSS placements:

Discharge Placement Needed	Number Waitlisted
SNF, ICF, SNF/ICF	157
Care home	22
Home health	7
Other type of facility/care	5

[39] Federal Reserve Bank of San Francisco, *Snapshot: Home Care I Hawaii (2022);* NCBI, *Hawai'i's Nursing Workforce: Keeping Pace with Healthcare - PMC*
[40] Hawaii Department of Business Economic Development & Tourism; U.S. Bureau of Labor Statistics.
[41] Hawaii Employers Council, *2023 Employee Turnover & Sick Time Statistics Survey, May 2023; Key Takeaways of the 2025 Employee Turnover & Sick Time Statistics Survey, May 2025.*
[42] Hawaii State Health Planning and Development Agency, Department of Health, *SHPDA Healthcare Utilization Report, Hawaii 2023.*

This level of waitlisting is causing a substantial erosion of acute care access, wasteful inefficient utilization of scarce resources, potential compromise of healthcare outcomes, and tens of millions of dollars in annual revenue losses that increase the cost of care for everyone.[43]

3. Transition from institutional to HCBS care backed up as well: Not surprisingly, SHPDA found evidence that institutionalized LTC patients who were eligible for community-based HCBS care were also experiencing access issues; more than half of the 53 waitlisted nursing home patients were waiting for HCBS placements. The relatively small number of waitlisted institutional patients is likely a reflection of the generally high acuity level of nursing home patients in Hawaii.

[43]Research Information Services*, Public-Private Collaborative Partnership Solution for Post-Acute Care Waitlisted Patients in Hawaii Hospitals: Re-Imagining the Public Healthcare Role for Hawaii Healthcare Systems Corporation, Oahu Region Facilities*, for Hawaii Healthcare Systems Corporation, Oahu Region

5. The Hidden Plight of Hawai'i's Unpaid Community Caregivers

The vast majority of Hawaii's LTSS bill is borne by unpaid community caregivers who shoulder an estimated 74.1% of the total (see Table 2.). By comparison, Medicaid, often portrayed as the primary payer of LTSS, pays for only an estimated 16.7% of Hawaii's total estimated LTSS bill.

While the estimated dollar value of direct care provided by unpaid Hawaii community caregivers (which does not include volunteer services) is daunting, it is not fully reflective of the indirect collateral toll and hardships endured—which are often harsh and physically, mentally, and financially ruinous.

Our current LTSS financing and services system has largely failed, and some would say abandoned, our unpaid community caregivers. Token caregiver supports like tax credits and sporadic respite, while better than nothing, can hardly compensate for the often-devastating consequences and effects of making up for the shortcomings of a paid LTSS services system that is expensive, underfunded, and has insufficient resources.

National research findings can give us a picture of the plight suffered by unpaid Hawaii community caregivers (there is no reason to believe circumstances for unpaid Hawaii community caregivers would be more benign).[44]

A Toll on Caregiver Well-Being: Creating a New Cohort Needing Care

- Many caregivers neglect their own health; placing themselves at risk of becoming a new cohort needing care: 23% (about 1 in 4) of caregivers' report having difficulty caring for their own health because of caregiving. This is not surprising given the care burden they bear, and the physical and emotional strains suffered because of caregiving. For caregivers who reported difficulties caring for themselves:
    - 48.4, average age of the caregiver
    - 66.2, average age of the care recipient
    - 57% were providing "high intensity" care involving an average of 2.1 ADL and 5.1 IADL deficiencies
    - 32.9 hours of weekly caregiving
    - 55% experienced feeling lonely
    - 38% reported experiencing high physical strain
    - 70% experienced high emotional stress
    - 36% experienced high financial stress
    - 72% indicated they had no choice about taking on care

- Many caregivers experience emotional stress: 36% (nearly 4 in 10) of caregivers regard their caregiving circumstance as being highly stressful.

- Many caregivers experience feelings of being alone and isolated: 21% (1 in 5) caregivers feel alone and isolated.

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[44] AARP, National Alliance for Caregiving, *Caregiving in the U.S,* ; CDC/NCHS, *Summary Health Statistics: National Health Interview Survey, 2018*; BlueCross BlueShield Health of America, *The Economic Consequences of Millennial Health, November 2019,*

These are profoundly serious risks for unpaid community caregivers that could very well result in a new cohort of persons who become in need of care services because of their caregiving—amplifying the financial and demand burden for an already overburdened and underfunded LTSS system.

Direct Financial Adversities Suffered by Unpaid Caregivers: Seriously Compromising Financial Planning for Their Own Needs

- The direct financial strain resulting from caregiving is severely affecting the financial planning for future needs: 18% (almost 1 in 5) of all caregivers report significant short-term and long-term strain because of their caregiving. Financial stress is even higher for prime working-age adults 18-49, 34% of whom report suffering financial strains.

  The financial strains and compromises suffered have serious near- and long-term consequences:
  - 28% of caregivers stopped saving
  - 23% of caregivers had to take on more debt
  - 22% of caregivers had to completely deplete personal savings
  - 19% of caregivers had unpaid or late-paid bills
  - 15% of caregivers were forced to borrow from family and friends

Careers Ruined

- 61% of unpaid community caregivers are employed and there are grave consequences for their caregiving
  - 60% work full time, 15% work between 30-39 hours per week.
  - 35.7 hours per week: average for employed caregivers
  - The ratio of work to caregiving hours is punishing and not sustainable:
    - Caregivers of their parents worked 36.9 hours per week on average while providing 20.8 hours of care.
    - Caregiving spouses worked 35.7 hours per week on average and provided 36 hours of care.

- The coping behavior of employed caregivers to accommodate their caregiving can be ruinous for their careers, compromise prospects for advancement, and limit pay increases—making financial consequences even worse
  - 53% reported going in late, leaving early, and taking time off
  - 15% shifted to part-time employment or reducing work hours
  - 14% had to take leaves of absence
  - 8% received performance or attendance warnings
  - 7% turned down promotions
  - 6% quit working entirely

- 5% retired early
- 4% loss job benefits

The harsh and severe physical, mental, and financial consequences suffered by Hawaii's unpaid community caregivers are especially insidious because they can ruin families, undermine preparing, and have lingering effects for "life after caregiving" (such as bankruptcy, ruined careers and credit ratings, and the onset of chronic health conditions as a result of caregiving). The irony is that because of financing and service system failures, acts of kindness by Hawaii's unpaid caregivers is contributing to creating the next new cohort of high-need patients who must deal with scarce care resources—in a vicious cycle.

6. Medicare LTSS Coverage in Hawaii[45]

Medicare generally *does not* cover long-term custodial care, i.e., non-medical help with daily activities like dressing, bathing, and eating. Medicare's coverage of long-term care is limited to specific, short-term skilled nursing care or home health care for certain medical conditions.

Limited Medicare Covered LTSS-related services:

- Skilled Nursing Facility (SNF) Care: Medicare covers up to 100 days in a skilled nursing facility for enrollees who meet medical and level of care criteria, but only if they require *skilled* nursing or therapy services, not just custodial care.

  ### Qualifying rules for Medicare SNF coverage:

  - Qualifying Inpatient Hospital Stay: A medically necessary inpatient hospital stays of at least 3 consecutive days (starting the day of admission, but not including the day of discharge).
    Time spent in the emergency department or under observation status does *not* count towards the 3-day inpatient stay requirement.
  - Waiver Exception: For patients, whose doctors participate in certain Medicare initiatives, such as Accountable Care Organizations (ACOs), may have "Skilled Nursing Facility 3-Day Rule Waivers."
  - Admission to SNF Within 30 Days: Admission to a Medicare-certified SNF, generally within 30 days of discharge.
  - Daily Skilled Care Requirement: Doctor certified need for daily skilled nursing care or skilled therapy services (like physical therapy, occupational therapy, or speech-language pathology) provided, or under the supervision of, skilled nursing or therapy staff.
    - Examples of Skilled Care: Intravenous injections, wound care, physical therapy to recover from a stroke, rehabilitation after major surgery.
    - Skilled Care does not include help exclusively with activities of daily living (ADLs) like bathing, dressing, eating, or using the bathroom, if ADL assistance is the *only* care needed—it's considered custodial care.

[45]Medicare.gov: Long Term Care Coveragehttps://www.medicare.gov/coverage/long-term-care -

- **Related Condition:** The skilled nursing care services received must be for a condition that was treated during the qualifying inpatient hospital stay, or a new condition that started while receiving SNF care for the ongoing condition.
- **Medicare-Certified SNF:** The facility must be a Medicare-certified skilled nursing facility.

Benefit Period: The SNF benefit period begins the day of admission as an inpatient in an SNF and ends when inpatient SNF care ends or up to 100 days of skilled care in a SNF.

Days Covered:

- Days 1-20: Medicare pays 100% (after the Part A deductible is met, if applicable).
- Days 21-100: the daily copayment ($209.50 per day in 2025).
- Days 101 and beyond: no coverage.

- **Home Health Services:** Medicare may cover skilled nursing care, physical therapy, occupational therapy, and speech-language pathology services provided at home if the individual is homebound and requires intermittent skilled care.

  Qualifying Rules for Medicare Home Health Care:

  - **Physician Order and Plan of Care:** A doctor must order home health care and sign a plan of care for services based on a face-to-face assessment.
  - **Need for Skilled Care:** the need for skilled nursing, physical therapy, speech-language pathology or occupational therapy services must be intermittent (not continuous).
  - **Intermittent Care:** It generally means less than 8 hours a day and 28 hours a week (though more hours may be approved for short periods if medically necessary).
  - **Occupational Therapy:** Cannot *initiate* coverage if no other skilled services are needed--
  - **Homebound Status:** Patient must be "homebound," meaning:

    * Leaving the home takes considerable and taxing effort.
    * The condition restricts the ability to leave home without help (e.g., requiring the use of a cane, wheelchair, or assistance from another person).
      Being homebound doesn't mean not being to ever leave. Patients can still leave for medical appointments, religious services, or brief, infrequent absences for non-medical reasons.
  - **Medicare-Certified Home Health Agency:** The care must be provided by a Medicare-certified home health agency.
  - **Medicare Home Health Care Doesn't Cover:** 24-hour care at home, home meal delivery, homemaker services (like shopping and cleaning) unrelated to a care plan, or custodial care (help with ADLs) if that's the *only* care needed.

- **Hospice Care:** For individuals with a terminal illness, Medicare covers hospice care, which can include some supportive services at home or in a facility.

- Qualifying Rules for Medicare Hospice Care:

  - **Medicare Part A Eligibility:** Must be eligible for Medicare Part A (Hospital Insurance).

- Terminal Illness Certification: Certification by hospice doctor and patient physician that patient is terminally ill with a life expectancy of 6 months or less.
- Acceptance of Palliative Care: Mandatory acceptance of comfort care (palliative care)—Medicare will still cover care for health problems unrelated to the terminal illness.
- Hospice Election Statement: A signed statement choosing hospice care over other Medicare-covered care.
- Medicare-Approved Hospice Provider: Medicare-approved hospice provider.

- Program of All-inclusive Care for the Elderly (PACE): PACE is a Medicare and Medicaid program that helps people meet their health care needs in the community instead of going to a nursing home. It provides comprehensive medical and social services, including some LTSS, to eligible individuals. Eligibility typically requires being 55 or older, living in a PACE service area, being state certified as needing nursing home level care, and being able to live safely in the community with PACE services. Hawaii no longer has an active PACE program.

7. Medicaid (Med-QUEST) LTSS Coverage[46]

Hawaii's Medicaid program, known as QUEST Integration (QUEST), is the primary government payer for comprehensive long-term services and supports for eligible Hawaii residents (nearly two-thirds of total Hawaii LTSS costs are borne by unpaid family caregivers). Med-QUEST is a managed care program that provides medical, behavioral health, and long-term services and supports to individuals of all ages, including seniors and people with disabilities.

Eligibility: Medicaid LTSS are needs-based programs with strict financial (income and asset) and medical eligibility requirements.

Managed Care Organizations (MCOs): In Hawaii, most Medicaid services, including LTSS, are delivered through Managed Care Organizations (MCOs). These include Aloha Care, HMSA, Kaiser Permanente, 'Ohana Health Plan, and UnitedHealthcare Community Plan. Individuals enrolled in QUEST Integration choose a health plan to receive their benefits. As a result, granular expenditure data for the services and care provided by MCOs is only available via an arduous and time consuming "encounter record" de-coding process that renders a substantial portion of total Medicaid spending in Hawaii functionally cloaked (we

[46] Hawaii Medicaid (Med-QUEST) Long Term Care Programs, Benefits & Eligibility Requirements: https://www.medicaidlongtermcare.org/eligibility/hawaii/

know that in 2023 total MCO spending for all covered Med-QUEST services (not just LTSS) was approximately $2.423 Billion but do now know precisely on what services and for what care).

Dual-Eligible Individuals: For individuals who have both Medicare and Medicaid (dual-eligible), Medicare covers primary health services, while Medicaid fills in gaps, especially for long-term care needs not covered by Medicare. Dual Special Needs Plans (D-SNPs) are available for these individuals to help coordinate their benefits.

LTSS under Hawaii's QUEST Integration program are broadly divided into two categories: Home and Community-Based Services (HCBS) and Institutional Services.

Home and Community-Based Services (HCBS) covered by Hawaii Med-QUEST include:

- Adult Day Care: Regular supportive care for disabled adults, including observation, supervision, and therapeutic, social, educational, and recreational activities.
- Adult Day Health: Organized day programs providing therapeutic, social, and health services for adults with physical or mental impairments to help them remain in the community.
- Assisted Living Services: Personal and supportive care services provided to members residing in an assisted living facility.
- Community Care Management Agency (CCMA) Services: Continuous and ongoing nurse delegation to caregivers, assessments, service plan development, and communication with physicians for individuals in various community settings.
- Counseling and Training: Care training for individuals, families, and caregivers on disease management.
- Environmental Accessibility Adaptations: Physical home adaptations to ensure health, welfare, and safety, or to enable independent functioning (e.g., ramps, grab bars, bathroom modifications).
- Home Delivered Meals: Nutritionally sound meals delivered to members who cannot prepare them and would otherwise be institutionalized.
- Home Maintenance: Services to maintain a safe, clean, and sanitary environment, including heavy duty cleaning and minor repairs.
- Moving Assistance: Help with moving expenses for individuals transitioning from a Medicaid-approved facility into their own home or a community setting (through the Money Follows the Person (MFP) program).
- Non-Medical Transportation: Transportation for non-medical needs.
- Personal Assistance Services (Level I and Level II):

    - **Level I (Chore Services):** Routine housecleaning, care of clothing, marketing, shopping, light yard work.
    - **Level II (Hands-on Care):** Assistance with Activities of Daily Living (ADLs) such as mobility, bathing, dressing, eating, and toileting. This can also include companion and homemaker services.
- **Personal Emergency Response Systems (PERS):** Systems that allow individuals to signal for help in an emergency.
- **Residential Care (including E-ARCH and CCFFH):** Services provided in Expanded Adult Residential Care Homes (E-ARCHs) and Community Care Foster Family Homes (CCFFHs).
- **Respite Care:** Temporary relief for primary caregivers.
- **Skilled (or Private Duty) Nursing:** Skilled nursing care provided in the home.
- **Specialized Medical Equipment and Supplies:** Equipment and supplies necessary for the individual's care.
- **Specialized Case Management:** Case management services for complex needs.

Institutional Services covered by Hawaii Med-QUEST include:

- **Nursing Facility (NF), Skilled Nursing Facility (SNF), or Intermediate Care Facility (ICF) Services:** Coverage for long-term care in a nursing home for individuals who meet Nursing Facility Level of Care requirements. This includes room and board, personal care, skilled nursing, physician visits, prescription medication, medication management, and social activities.
- **Subacute facility services.**
- **Acute Waitlisted ICF/SNF:** Services for individuals awaiting placement in an ICF or SNF.

Functional and Medical Need Qualifications for Med-Quest Nursing Home Coverage To qualify for Med-QUEST nursing home coverage, an individual must be assessed requiring a **Nursing Facility Level of Care (NFLOC)**. This means they need continuous supervision and personal care services typically provided in a nursing home.[47]

- **Assessment Tool:** The primary tool for this assessment is the **DHS Form 1147: Level of Care (LOC) and At-Risk Evaluation**. This clinical assessment form is completed

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[47] **DHS Form 1147: Level of Care (LOC) and At Risk Evaluation:** STATE (As of July 2025, this is a recent version); INSTRUCTIONS DHS FORM 1147

by a qualified healthcare professional (Registered Nurse, Physician, or Primary Care Provider) and scored to make a determination of qualification for nursing home coverage

- Key Factors Assessed by DHS 1147:
    - Activities of Daily Living (ADLs): The individual's ability to perform essential self-care tasks such as bathing, dressing, eating, transferring, toileting, and continence. Significant impairment in a certain number of ADLs is generally required.
    - Instrumental Activities of Daily Living (IADLs): While not as heavily weighted as ADLs for NFLOC determination, this assessment gauges the ability to live independently (e.g., medication management, meal preparation, shopping, managing finances).
    - Medical Conditions and Treatments: The presence of chronic illnesses, cognitive impairments (like dementia), behavioral issues (e.g., wandering, aggression), and the need for ongoing medical treatments (e.g., tube feeding, catheter care, wound care) that necessitate skilled nursing or significant personal assistance.
    - Cognitive Status: Evaluation of memory, orientation, and decision-making abilities.
- Physician Certification: A physician must certify that the individual requires the NFLOC.
- Duration of Need: The need for long-term care services must be for at least 30 consecutive days.

Med-QUEST Section 1115 HCBS Demonstration Waiver

Med Quest's 1115 HCBS Waiver (part of the broader QUEST Integration waiver) allows Aged, Blind, or Disables (ABD) individuals qualified for NFLOC to remain in their homes or other community setting to receive BCBS instead of being institutionalized in nursing homes.[48] Hawaii's HCBS Waiver entails:

- Managed Care Model: Services are delivered through managed care organizations (MCOs), which coordinate all a beneficiary's Medicaid benefits, including medical care, behavioral health services, and long-term services and supports.
- Nursing Facility Level of Care (NFLOC) qualification: Individuals must typically be assessed as requiring a Nursing Facility Level of Care (NFLOC) or be at risk of requiring it. This assessment determines if the individual's needs are such that they would otherwise require institutionalization in a nursing home.

[48] Centers for Medicare & Medicaid Services. (2025, January 8). *Hawaii QUEST Integration 2025 Extension Approval Letter*.

- No Enrollment Cap: There is no enrollment cap under Hawaii's Waiver program; all eligible senior meeting stipulated financial and medical criteria can enroll.
- Services Provided: The HCBS waiver covers a wide range of services designed to support individuals qualified for institutional nursing care or at risk of needing such care in community settings. These can include:
    - Adult Day Care / Adult Day Health
    - Assisted Living Services
    - Community Care Foster Family Homes (CCFFH)
    - Adult Residential Care Homes (ARCHs).
    - Personal Assistance Services (in-home care)
    - Home-delivered meals
    - Environmental accessibility adaptations (home modifications)
    - Personal Emergency Response Systems (PERS)
    - Skilled nursing (private duty nursing)
    - Counseling and training
    - Non-medical transportation
    - Respite care

Eligibility Criteria for Waiver coverage (2025):

- Age/Disability: Individuals must be 65 years of age or older, legally blind, or have a disability.
- Residency: Must be a resident of Hawaii.
- Citizenship: Must be a U.S. citizen or legal alien.
- Financial Limits: For HCBS, as of 2025:
    - Income Limit: The monthly income limit for a single applicant is typically around 100% of Hawaii's Federal Poverty Level (FPL), which is approximately $1,500 per month (as of February 2025, though these amounts can adjust annually). For married couples, different rules apply regarding spousal income allowances to prevent "spousal impoverishment."
    - Asset Limit: The asset limit for a single applicant is generally $2,000. For married couples where one spouse is applying, the non-applicant spouse may be able to retain a significant amount of assets as a Community Spouse Resource Allowance (CSRA), which was up to $157,920 in 2025.
    - Medically Needy Pathway "Spend Down": Individuals whose income exceeds the standard limits but have high medical expenses can "spend down" their income to qualify.
- Functional (Medical) Need: Need for Nursing Facility Level of Care (NFLOC) certified by a physician.

MedQuest Means Test and Spend Down Rules

Hawaii's Medicaid program, Med-QUEST, has specific rules regarding income and asset limits ("means test"), as well as a "spend down" provision for those who exceed these limits. There are different eligibility criteria specific benefit programs (e.g., for children,

pregnant women, adults, or aged, blind, and disabled individuals) and whether long-term care is involved.

Hawaii Med-QUEST Means Test (Income and Asset Limits)[49]

Med-QUEST eligibility is generally determined by a claimants Modified Adjusted Gross Income (MAGI). However, for "MAGI-excepted" groups, such as those who are aged, blind, or disabled (ABD) and seeking long-term care, both income and assets are considered.

- General Income Limits (2025):
  - **Adults (19-64, non-disabled/non-Medicare/non-SSI):** Up to 138% of the Federal Poverty Level (FPL). For a single person, this was around $2,069 per month in January 2025.
  - **Children (0-18):** Up to 313% of the FPL (for CHIP).
  - **Pregnant Women:** Up to 196% of the FPL.
  - **Parents/Caretaker Relatives:** Up to 105% of the FPL.

- **Income and Asset Limits for Aged, Blind, and Disabled (ABD) / Long-Term Care (2025):**
  These categories are "MAGI-excepted" and have asset limits in addition to income limits.

- **Income Limit (ABD / Long-Term Care):**
  - For many ABD programs, the income limit is 100% of the FPL ($1,500 per month for a single applicant as of February 2025).
  - For Nursing Home Medicaid and Home and Community-Based Services (HCBS), there is often *no hard income limit* for the applicant, but nearly all income must be contributed towards care costs, with a small Personal Needs Allowance (PNA) retained (e.g., $50-$70 per month).
  - **Spousal Impoverishment Rules:** When one spouse applies for long-term care Medicaid and the other does not (the "community spouse"), the non-applicant spouse may be entitled to a **Minimum Monthly Maintenance Needs Allowance (MMMNA)** of $3,948 per month (2025). Income can be transferred from the applicant spouse to the non-applicant spouse to bring their income up to this level.

- **Asset Limit** (additional limit for ABD Long-Term Care claims):
  - **Single Applicant:** $2,000
  - **Married Couple (both applying):** $3,000
  - **Married Couple (one spouse applying):**
    - Applicant spouse: $2,000
    - Non-applicant (community) spouse: Up to $157,920 as a **Community Spouse Resource Allowance (CSRA)**.

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[49] **Hawaii Medicaid QUEST Integration (QI) Program - MedicaidPlanningAssistance.org:** https://www.medicaidplanningassistance.org/hawaii-quest-integration-program/
Hawaii Medicaid / Med-QUEST Eligibility for Long-Term Care - MedicaidPlanningAssistance.org: https://www.medicaidplanningassistance.org/medicaid-eligibility-hawaii/
2025 MAGI MAX INCOME LIMIT (Effective: 01/01/2025) - Hawaii Med-QUEST Division: https://medquest.hawaii.gov/content/dam/formsanddocuments/resources/magi-and-magi-excepted-income-standard-charts/Increase%20in%20FPL%20for%202025%20and%20COLA%20Mass%20Change.pdf
Hawaii's Med-QUEST: Eligibility and Benefits - Paying for Senior Care: https://www.payingforseniorcare.com/hawaii/medicaid-waivers/quest-expanded-access

Countable vs. Non-Countable Assets:

- Countable assets generally include cash, bank accounts, stocks, bonds, and real property (other than the home).
- Exempt assets typically include the primary home (with equity interest limits, e.g., less than $1,071,000 in 2024), one motor vehicle, household furnishings, and personal belongings. Reality check: being able to afford maintaining the exempt home with the modest MMNA is open to question and likely to force displacement (i.e., forced sale of the home) at some point (see the Medicaid Spend Down Rule below).

- Look-Back Period: For long-term care services Med-Quest has a 60-month (5-year) "look-back period." This means Med-QUEST reviews financial transactions (gifts or asset transfers for less than fair market value) made within 60 months prior to the Medicaid application date. Violating this rule can result in a penalty period of Medicaid ineligibility.

- Annual Changes: Income and asset limits, especially those tied to the Federal Poverty Level, are subject to annual adjustments, typically in January or February.

Hawaii Med-QUEST Spend Down Rule

Hawaii has a "Medically Needy Spenddown Program" for individuals whose income is above the Medicaid limit but who have high medical expenses. This allows them to "spend down" their excess income on medical costs until their remaining income falls below the medically needy income level.

Persons with income exceeding the Med-QUEST income limit can still qualify for benefits by incurring medical expenses (medications, paid medical bills, unpaid medical bills from the prior 3 months, nursing home care, health-related home renovations, transportation to medical appointments) that reduce their "countable" income to the Medically Needy Income Level (MNIL).[50]

- Medically Needy Income Level (MNIL): Is the income remaining after paying for medical expenses, i.e., "spending down" income. In 2025 the MNIL for a single applicant is $469 per month; for a married couple with both applying, $632 per month.
- Aged, Blind, and Disabled Exception: For aged, blind, and disabled individuals, there is typically no gross income limit for the spend-down, but the amount of income exceeding the MNIL must be used for medical expenses.

Inequities of the Medicaid Spend Down Rule

There is significant debate about the perceived inequity of the Medicaid Spend Down Rule, especially for low-income and middle-class individuals needing long-term care. Since Medicaid is a means-tested entitlement and not an earned benefit program, it is necessary to have provisions that control

[50] Med-QUEST, *Benefits* Checkup: https://benefitscheckup.org/program/medicaid_hi_medicaid
Hawaii QUEST Integration Section 1115(a) Demonstration (CMS Waiver Authorities) - Hawaii Med-QUEST Division: https://medquest.hawaii.gov/content/dam/formsanddocuments/med-quest/section-1115-demonstration-renewal-for-2024/Hawaii%201115%20Extension%20WA%20EA%20STCs%202025%20Final.pdf
Med-QUEST Medical Assistance - Hawaii.gov (DHRD FAQs): https://dhrd.hawaii.gov/wp-content/uploads/2015/09/Med-QUEST-Questions-and-Answers-Rev-201508-FINAL.pdf

becoming eligible for benefits. A complex, confusing, onerous, and perhaps necessarily inequitable set of rules has emerged to serve that purpose.

Essentially, the spend down works like an insurance deductible. If a person's income or assets are above the Medicaid threshold, the person must "spend down" the excess amount on medical expenses or other allowable expenditures until resources fall within the eligibility limits before Medicaid begins to cover eligible medical/LTSS costs. This often results in devastating, and many would say inequitable financial hardship for persons and families of modest means.

Sources of Inequity in the Spend Down Rule:

- Imposing a Financial Burden on Vulnerable Individuals: The core of the inequity lies in requiring individuals, often already struggling financially, to deplete their remaining savings and assets to qualify for essential long-term care. This can wipe out a lifetime of modest savings, leaving little or nothing for a healthy spouse, other family members, or for expenses not covered by Medicaid.
- "Impoverishment" for the Healthy Spouse (Community Spouse): While there are spousal protections (Community Spouse Resource Allowance - CSRA), these are often insufficient to prevent financial hardship for the healthy spouse. The CSRA allows the non-applicant spouse to keep a certain amount of assets, but this amount may not be enough to maintain their quality of life, especially if they relied on the couple's shared assets.
- The "Look-Back" Period and Penalties: Medicaid has a "look-back" period (typically five years) during which it reviews asset transfers. If an individual has gifted assets or sold them for less than fair market value within this period, they can face a penalty period of Medicaid ineligibility. This is designed to prevent people from divesting assets simply to qualify for Medicaid, but it can inadvertently penalize individuals who made legitimate gifts or financial arrangements years before needing care, or who were simply trying to help family members.
- Complexity and Lack of Understanding: The rules surrounding Medicaid eligibility, including spend down, are incredibly complex. Many individuals and families are unaware of these intricate regulations until they are in a crisis, making it difficult to plan effectively. This often leads to poor decisions or missed opportunities to protect assets legally.
- Forced Spending on Unnecessary Items (sometimes): While there are legitimate ways to "spend down" (e.g., paying off debts, making home modifications for accessibility, pre-paying funeral expenses, purchasing exempt assets), the pressure to quickly reduce assets can sometimes lead to spending on items or services that aren't the highest priority for the individual, simply to meet the rules.
- Disproportionate Impact on Low- and Middle-Income Families: Wealthier individuals often have access to sophisticated estate planning and elder law attorneys who can help them strategically plan to protect assets years in advance. Low- and middle-income families, who are less likely to have these resources, are more directly impacted by the spend down, as their limited assets are more easily depleted.

Allowable Spend Down Strategies—largely for those with means (further amplifying the inequity)

“Spending down" doesn't necessarily mean throwing money away (although, as the foregoing indicates, wasting can happen). There are legally permissible ways to reduce countable assets (largely for those with means), which may include:

- Paying off existing debts: Mortgages, credit card debt, car loans, etc.
- Making home modifications: Installing ramps, grab bars, or other accessibility improvements to a primary residence (which is often an exempt asset).
- Prepaying funeral and burial expenses: Setting up irrevocable funeral trusts.
- Purchasing exempt assets: Such as a primary residence (within limits), a single vehicle, or essential household goods and personal effects.
- Paying for medical expenses not covered by insurance: Including overdue medical bills, dentures, hearing aids, etc.
- Creating a "Caregiver Child Exemption" or "Sibling Exemption": In certain circumstances, transferring a home to a child who has provided care or a sibling who co-owned the home may be exempt.
- Medicaid Compliant Annuities or Qualified Income Trusts (Miller Trusts): These are complex financial tools, often used in conjunction with an elder law attorney, to convert countable assets or excess income into a stream of income for a spouse or to "spend down" income to qualify.

The “exempt home” fallacy

1. The "Exempt" Home - A Conditional Exemption:
    - General Rule: A primary residence is generally considered an "exempt asset" for Medicaid eligibility purposes when one spouse (the "community spouse") continues to live in it. This means the home's value doesn't count against the asset limit for the institutionalized spouse to qualify for Medicaid. This protection is a crucial element of spousal impoverishment provisions, aiming to allow the community spouse to maintain their independent living.
    - Home Equity Limit: However, there is a state-specific home equity limit of $1,097,000 for Hawaii (2025). If the home's equity *exceeds* this threshold, the equity above the limit may be considered a countable asset, potentially preventing Medicaid eligibility until that excess is spent down.
    - "Intent to Return" (for single applicants): For a single individual applying for Medicaid, the home is exempt if they have an "intent to return" to it, even if that intent is not realistically possible. This is less relevant for a married couple where one spouse still lives in the home.
2. The Dilemma of Selling the "Exempt" Home:
   Even if the home is exempt for eligibility determinations, a community spouse might *still* be pressured or compelled to sell it for various reasons, leading to severe complications:
    - Maintenance Costs: While the home itself is exempt, the community spouse still needs income to maintain it. Property taxes, utilities, insurance, and repairs can quickly become unaffordable, especially if the community spouse's own income is low and the institutionalized spouse's income is largely diverted to the nursing home (minus the Minimum Monthly Maintenance Needs Allowance - MMMNA). The MMMNA is designed to provide for the community spouse, but it may not always be sufficient to cover high housing costs in expensive Hawaii
    - Lack of Liquid Assets: Even with the Community Spouse Resource Allowance (CSRA), the healthy spouse might not have enough liquid assets to cover ongoing living expenses,

including unexpected home repairs or medical costs not covered by their own insurance. The CSRA is a one-time allowance of countable assets; it doesn't guarantee ongoing income for home maintenance.

- **Estate Recovery Concerns (Post-Mortem):** While the home is protected *during the lifetime* of the community spouse, Medicaid law requires attempting to recover Medicaid costs from the estate of the deceased recipient. If the community spouse dies before the institutionalized spouse, or if they sell the home and don't re-invest the proceeds into another exempt asset, the state could place a lien on the home or seek recovery from its sale proceeds after both spouses have passed away. This future risk can pressure families to sell sooner.

The "Post-Spend Down" Trap:

- **Proceeds become Countable Assets:** If the exempt home is sold, the cash proceeds immediately become a *countable asset*. This can instantly throw the institutionalized spouse out of Medicaid eligibility.
- **New Spend Down:** The couple then faces a *new* spend-down requirement for these home sale proceeds. This means they must spend down potentially hundreds of thousands of dollars before Medicaid resumes coverage for the institutionalized spouse. This can result in a lengthy period where the family must privately pay for expensive long-term care, draining the very funds intended to house the community spouse.
- **Disruption of Payments for Institutionalized Spouse:** During this new spend-down period, payments to the nursing home from Medicaid cease, and the family is suddenly responsible for the full, often exorbitant, cost. This creates immense financial and emotional distress.
- **Homelessness Risk for Community Spouse:** After selling the home and spending down the proceeds on the institutionalized spouse's care, the community spouse may be left with insufficient funds to secure new, safe, and affordable housing. This can become a direct pathway to potential homelessness or reliance on other family members.

Factors that Exacerbate the Problem:

- **Lack of Planning/Education:** Many families are unaware of these complex rules until a crisis hits. They may make impulsive decisions, like selling a home, without understanding the profound negative impact on Medicaid eligibility and the community spouse's future.
- **Market Conditions:** Selling a home quickly under pressure may mean selling it below market value, further reducing the funds available to the family.
- **Emotional Burden:** The decision to sell a family home is often emotionally charged, especially for an elderly spouse who may have lived there for decades. Forcing this sale due to bureaucratic rules adds immense psychological stress to an already demanding situation.

Example Scenario (Hypothetical, simplified):

Imagine a couple in Hawaii. The husband needs nursing home care, and the wife remains in their home, which has an equity of $800,000 (well within Hawaii's $1,097,000 exemption). Their other countable assets are $50,000. Under Hawaii's 2025 CSRA, the wife can keep up to $157,920 of the couple's assets. Let's say their $50,000 is transferred to her, so she's within the CSRA. The husband qualifies for Medicaid nursing home coverage, and the wife lives in the exempt home.

However, the wife's only income is Social Security, and it's barely enough to cover utilities and groceries, let alone property taxes or a new roof. After a few years, a major repair is needed, or

the property taxes increase significantly. She cannot afford it. She decides, with a heavy heart, to sell the home for $800,000.

Now, she has $800,000 in cash. Even if she tries to use some for her own living expenses, the vast majority is countable. The husband immediately becomes ineligible for Medicaid. The family must now privately pay for the nursing home, at potentially $20,000+ per month, using the home sale proceeds. This $800,000 could be depleted in a little more than 3 years, leaving the wife with no home and potentially very little money to find new housing. She could face a severe housing crisis or homelessness.

While the "exempt home" provision is a vital protection, the practicalities of maintaining that home, coupled with the consequences of its sale, can still lead to the impoverishment and even homelessness of the community spouse. This highlights the ongoing need for comprehensive long-term care solutions that genuinely protect the dignity and financial stability of both spouses in facing the immense costs of long-term care. Unfortunately, successfully navigating the complex and confusing rules of our current LTSS financing structure to mitigate and avoid unintended consequences require the services of an elder law attorney—something that is not affordable to most

8. Private Long-Term Care Insurance

According to the National Association of Insurance Commissioners (NAIC) 71,224 lives in Hawaii were covered by stand-alone LTC insurance in 2023 with incurred claims of $113 million.[51] Incurred claims include the amounts paid for claims opened during the year as well as the estimated future amounts for those claims that have not yet been paid (because payments can extend beyond the year). Hence, the amount of paid claims can be higher or lower than reported depending on actual experience.

2023 LONG-TERM CARE INSURANCE EXPERIENCE REPORTING FORM 5
STAND - ALONE LTC MARKET SHARE - TOP TEN COMPANIES
BY ACTUAL EARNED PREMIUMS

HAWAII

Rank	Company Code	Group Code	Company Name	State of Domicile	NBR of New Lives Insured	NBR of Lives In Force Year End	Earned Premiums	Incurred Claims	Market Share Percentage	Cummulative Market Share
1	62235	565	Unum Life Ins Co Of Amer	ME	2,361	36,020	25,181	23,217	24.74	24.74
2	70025	4011	Genworth Life Ins Co	DE	1	6,396	14,816	16,199	14.56	39.30
3	65838	904	John Hancock Life Ins Co USA	MI	0	6,934	13,227	16,736	13.00	52.30
4	65978	241	Metropolitan Life Ins Co	NY	0	2,629	5,356	5,550	5.26	57.56
5	69000	860	Northwestern Long Term Care Ins Co	WI	27	1,151	4,120	1,091	4.05	61.61
6	86231	468	Transamerica Life Ins Co	IA	0	1,722	3,943	4,004	3.87	65.49
7	66915	826	New York Life Ins Co	NY	52	1,716	3,925	4,472	3.86	69.34
8	71412	261	Mutual Of Omaha Ins Co	NE	47	1,466	3,784	782	3.72	73.06
9	20443	218	Continental Cas Co	IL	0	1,996	3,080	9,393	3.03	76.09
10	65005	4	RiverSource Life Ins Co	MN	0	1,006	2,731	7,885	2.68	78.77
			** STATE TOTAL**		2,543	71,224	101,764	113,058	100.00	100.00

Extended Benefit policies are riders attached to life insurance or annuities that allow LTC benefits to be paid from the death or annuity benefit and provide extended coverage beyond the benefit limits in the event of continued need for LTC services. 1,927 lives were covered by such policies in Hawaii with incurred claims of $526 million in 2023.

[51] National Association of Insurance Commissioners, *NAIC Long-Term Care Insurance Experience Reports for 2023, 2025.*

2023 LONG-TERM CARE INSURANCE EXPERIENCE REPORTING FORM 5
EXTENDED BENEFITS POLICIES - MARKET SHARE - TOP TEN COMPANIES
BY ACTUAL EARNED PREMIUMS

HAWAII

Rank	Company Code	Group Code	Company Name	State of Domicile	NBR of New Lives Insured	NBR of Lives In Force Year End	Earned Premiums	Incurred Claims	Market Share Percentage	Cummulative Market Share
1	65676	20	Lincoln Natl Life Ins Co	IN	72	1,442	3,974,687	333,009	79.23	79.23
2	91596	826	New York Life Ins & Ann Corp	DE	12	12	910,699	2,881	18.15	97.38
3	67652	20	First Penn Pacific Life Ins Co	IN	0	167	130,410	191,094	2.60	99.98
4	67091	860	Northwestern Mut Life Ins Co	WI	11	11	473	0	0.01	99.99
5	65838	904	John Hancock Life Ins Co USA	MI	0	146	343	0	0.01	100.00
6	87726	4932	Brighthouse Life Ins Co	DE	13	24	40	0	0.00	100.00
7	65005	4	RiverSource Life Ins Co	MN	0	11	18	0	0.00	100.00
7	65935	435	Massachusetts Mut Life Ins Co	MA	3	60	18	0	0.00	100.00
9	70025	4011	Genworth Life Ins Co	DE	0	54	0	0	0.00	100.00
			** STATE TOTAL**		111	1,927	5,016,688	526,984	100.00	100.00

Accelerated benefit only policies are riders like Extended Benefit policies except that LTC draws are capped by the underlying death or annuity maximum amounts (i.e., additional extended benefits are not provided when the need for LTC services exceed the death or annuity policy value).

2023 LONG-TERM CARE INSURANCE EXPERIENCE REPORTING FORM 5
ACCELERATION ONLY - MARKET SHARE - TOP TEN COMPANIES
BY ACTUAL EARNED PREMIUMS

HAWAII

Rank	Company Code	Group Code	Company Name	State of Domicile	NBR of New Lives Insured	NBR of Lives In Force Year End	Earned Premiums	Incurred Claims	Market Share Percentage	Cummulative Market Share
1	65676	20	Lincoln Natl Life Ins Co	IN	0	41	91,288	25,284	71.22	71.22
2	91596	826	New York Life Ins & Ann Corp	DE	1	1	30,843	11,472	24.06	95.28
3	67652	20	First Penn Pacific Life Ins Co	IN	0	14	3,994	2,871	3.12	98.40
4	65838	904	John Hancock Life Ins Co USA	MI	68	3,286	1,308	290	1.02	99.42
5	65005	4	RiverSource Life Ins Co	MN	81	1,014	455	215	0.35	99.77
6	67091	860	Northwestern Mut Life Ins Co	WI	179	704	209	16	0.16	99.94
7	65935	435	Massachusetts Mut Life Ins Co	MA	34	327	41	0	0.03	99.97
8	86231	468	Transamerica Life Ins Co	IA	400	3,778	27	0	0.02	99.99
	87726	4932	Bri							

It's estimated that there are approximately 102 private long-term care insurance policies in force per 1,000 people age 40+ in Hawaii (a 10.2% penetration rate despite the decades long availability of these products).[28]

Issues and Challenges[52]

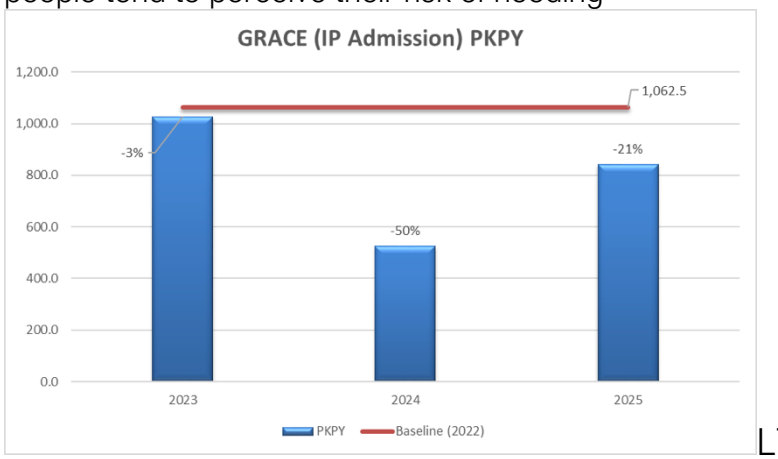
[52] **KFF Health News:** "Why Long-Term Care Insurance Falls Short for So Many" (November 21, 2023). https://kffhealthnews.org/news/article/dying-broke-why-long-term-care-insurance-falls-short/
Smart Asset: *Long-Term Care Insurance Pros and Con*" (January 30, 2025); JRC Insurance Group, *Pros and Cons of Life Insurance with a Long Term Care Rider*; American Academy of Actuaries, *Issue Brief - Long-Term Care Insurance Products*

- Underwriting and Eligibility Limitations: Private long-term care insurance is not available to everyone. Insurers underwrite or pre-evaluate the risk posed by individual applicants before accepting applications to limit their exposure to claims that could occur soon after joining with little premiums collected to help pay for the benefit claims, including factors (like chronic disease) that increase or elevate the likelihood of claiming benefits in the future. This is an essential and necessary means of assuring solvency and having sufficient funds to take care of claim benefit obligations (and what is supposed to be reasonable profits).

    - Strict Health Requirements eliminate many: To qualify for long-term care insurance, applicants typically undergo detailed health screenings and evaluations. Those with pre-existing conditions (e.g., Alzheimer's, dementia, MS, Parkinson's, stroke) or even common conditions like arthritis or diabetes may be denied coverage or face much higher premiums—in order to control and mitigate financial claim payment risks for the insurer.

      Industry estimates suggest 15-20% of applicants are denied. Unlike public insurance programs, private long-term care insurance is not "take all comers."

    - Age as a Factor: Younger and healthier applicants are more likely to be accepted and at a lower premium. Older applicants face higher denial rates and significantly higher costs. Young people tend to perceive their risk of needing



LTSS as being low and there is less incentive to apply when acceptance is more assured and premiums more affordable.

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and Addressing the 'Use It or Lose It' Concern (February 2020); U.S. Department of Health and Human Services (ASPE), *Long-Term Care Insurance Research Brief" (February 9, 2013)*; KFF (Kaiser Family Foundation), *The Challenge of Private Long-Term Care Insurance (Undated, but report from 2013)*;
LTCI Partners, The Challenges and Future of Traditional Long-Term Care Insurance" (February 4, 2024); Milliman, "Could legacy long-term care (LTC) blocks be the next wave of M&A deals?" (September 2023);
Long-term care first principles modeling: Lapse assumptions (November 2016); Anatomy of a long-term care rate increase (January 2021); American Academy of Actuaries (AAA), *Long-Term Care Insurance: Considerations for Treatment of Past Losses in Rate Increase Requests; Long-Term Care Insurance Mortality and Lapse Study (November 2021);* Society of Actuaries (SOA), *Lapses in Long-Term Care Insurance (Schwartz Center for Economic Policy Analysis, discusses cognitive impairment and lapse rates, relevant for anti-selection implications); Effect Of Lapse Rates On Profitability Reinsurance View*; ASPE (Assistant Secretary for Planning and Evaluation, HHS), *Understanding the Factors behind Carriers' Decision to Leave the Long-Term Care Insurance Market.*

Underwriting denials and costs increase as the perceived risk of needing help increases with age.

- Expensive and Unpredictable Premiums: It's generally acknowledged that LTC insurance premiums are expensive and a major deterrent for consumer enrollment—especially for older persons with higher perceived and actual risks of needing care. In addition, stand-alone LTC insurance policies have historically been notorious for double-digit premium increases of 20% to 130% or more. While modern actuarial practices based on more conservative pricing/reserve assumptions have helped quell the issue of dramatic unpredictable future hikes a bit—still, annual compound increases of 3%-5% are observed and expected.

  The Issue of High and Unpredictable Costs

  The high and unpredictable cost of LTC insurance is not a simple pricing issue in the conventional sense. Rather, this complex affordability issue has actuarial, behavioral and even marketing origins that are endemic to the product.

  - Faulty and inaccurate Lapse Rate Assumptions—origins of the problem

    LTC insurance is fundamentally a **"lapse supported"** product where financial stability and solvency is predicated on the assumption that a significant percentage of policyholders will pay premiums and quit before collecting any benefits—leaving behind money they paid in to help cover benefit claim losses for the remaining policyholders. This helps reduced the amount of premium income needing to be collected—IF enough policyholders quit before claiming benefits.

    Due in part to the lack of actual experience as well as marketing concerns about the affordability of a new emerging product line, insurers initially priced legacy LTC insurance policies at lower rates based on the assumption of much higher annual lapse rates similar to life or disability insurance; 3% - 5% (which is substantial over decades).

    Significant financial problems arise when not enough people quit their policies before collecting benefits because this results in far more claim payment obligations remaining for the insurer than were initially priced for than available premium revenue (and reserves) are able to cover. As a result, insurers sought and obtained premium rate increases from state insurance regulators to meet their obligations. This is insidious because LTC insurance, by design, protects against "long-tailed risks" of needing care—i.e., for most policyholders (accepted after underwriting) the risk of needing care is many years, even decades, in the future at the time they enrolled. Because of the long-tailed risk being covered, the onset of the need for more premiums generally happened just as many policyholders aged to a point where they had elevated risks of needing care and fixed retirement incomes that made major premium increases unaffordable; causing many to quit or lapse their policies at the very time when their need for protection was highest.

    The tragedy of **"Forced Lapse"** is exacerbated when insurers use premium rate increases to assertively "trim" the insurance book of policyholders (generally older) to reduce and off load benefit claim liabilities and preserve profit margins.

    The Vicious Cycle: Lapses and Anti-Selection

As it gradually became apparent that the actual lapse rates for LTC insurance were much lower (often 1% or less, sometimes even approaching zero for older blocks of business where older policyholders with emerging health concerns persisted in keep their policies in-force) the most viable option for insurers was to seek and impose premium rate increases.[53]

Dynamics of the vicious cycle—undesirable and arguably unintended consequences:

- Initial Low Lapse assumptions: Insurers price assuming high lapses.
- Actual Low Lapses: Policyholders hold on, leading to under-reserving and financial strain for the insurer.
- Rate Hikes: Insurers are forced to raise premiums significantly to restore solvency.
- "Shock Lapses" and Anti-Selection: Large rate hikes can trigger a wave of new lapses (often called "shock lapses"). However, the *type* of policyholder who lapses now becomes critical.
- Financial Lapses: Some policyholders simply cannot afford the increased premiums, regardless of their health status.
- Adverse Selection / Anti-Selection: Healthier policyholders, who perceive their risk of needing care as lower, might be more likely to lapse their policies after a rate hike. *This leaves a less healthy, higher-risk pool of policyholders remaining. This "adverse selection" can further worsen the risk profile of the remaining in-force block, potentially leading to future pressure for further rate increases*.

- Under estimation of morbidity (incidence and duration of claims)
  - More policy holders than expected lived to claim benefits
  - Medical advances contributed to prolonging the duration of care
  - The severity of expensive (institutional) care need was higher than expected

- Poor investment returns
  - Overly optimistic expectations for stable and lucrative investment return rates did not materialize and the prolonged period of low interests rates following the 2008 financial crisis meant that returns on collected premiums could not support anticipated claim liabilities. The accuracy of long range earnings forecasts are crucial for maintaining the solvency of long-tailed products like LTC insurance since the compounded earnings collected on early premiums materially affects having sufficient funds to pay claims that will occur decades in the future.

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[53] The vast majority of LTC insurance policies are guaranteed renewable as opposed to non-cancellable. The distinction is extremely important and a source of misleading confusion for many policyholders. Guaranteed renewable policies simply mean that the insurer cannot cancel the policy as long as premiums are paid—these policies do not guarantee flat unchanging premiums. Accordingly, this limits what insurers can do as claim liabilities increase. On the positive side, they cannot egregiously collect a lot of up front premiums when claims are low and then cancel the entire book of business when claims mount. BUT, insurers are not contractually or statutorily prohibited from filing for aggressive (actuarially justified) premium hikes from regulators as the book turns sour— often forcing some policyholders to quit and lapse their policies as premiums become unaffordable on fixed incomes and be left with no protection after years of paying premiums (The terms and premiums cannot be changed with non-cancellable insurance contracts.)

- Faulty mortality assumptions
  - More policyholders survived to advanced ages than predicted. Combined with the high persistence of older policyholders (who didn't quit their policies) meant that there were more policyholders of advanced age with higher risks of claiming benefits than expected.

Correcting underpricing mistakes of the past: Even more expensive

There are no escaping high costs. Reflecting hard lessons learned, modern LTC insurance products based on more informed and advanced actuarial modelling are priced much more conservatively, with lapse rate assumptions of 1% or even lower, more robust morbidity experience data (claim incidence) , conservative interest earning assumptions, and greater "buffer" margins to absorb unexpected deviations.

This necessarily makes them significantly more expensive upfront but theoretically more stable in the long run. The industry has had to re-evaluate its understanding of policyholder behavior, recognizing that LTC insurance is not a "disposable" product like auto insurance, but a highly valued and sticky form of protection for individuals concerned about catastrophic long-term care costs.

In addition, the relatively tiny pool of covered lives, even today, means a much higher risk of actuarial price forecasting error. There are simply fewer actual experience data points on which to build highly accurate and robust forecasting/predictive models. This is a critical vulnerability given the long-tail nature of LTC insurance where the incidence and cost of benefit liabilities are decades in the future.

III. Long-Term Services and Supports for Hawaii: Can it be Insured?

In 2003 Hawaii became what is likely the first state in the nation to enact legislation for a tax funded public insurance benefit program for long-term care financing with the passage of S.B. 1088, SD HD2 CD1 (22nd Legislature Regular Session, 2003)—which was subsequently vetoed by Governor Linda Lingle. That left the door open for the state of Washington to become the first state in the nation to establish a mandatory payroll tax financed public LTC insurance plan: WA Cares (Chapter 50B.04, Revised Code of Washington) now scheduled to begin benefit payments in January 2026.

1 The problems of seeing long-term needs

The picture of long-term care (LTC), also referred to as long-term services and supports (LTSS) in this report, is in many ways a collage. Pieces come from all possible viewpoints and sometimes overlap or even obscure each other. To begin the process of setting policy to address the problems—family outcomes—services—workforce—financing—access, it is necessary to look at some of the pieces:

- Baby boomers and other generations can be strapped between the costs of everyday life and the costs of long-term care for their parents and planning for themselves;[1]
- Women at risk of becoming poor and of having no one to care for them in their own old age;[2]
- Elders seeing their life savings threatened;
- Employers who will lose revenue as employee productivity drops from stress and taking time off to juggle long-term care costs and responsibilities.
- Employed caregivers often have to reduce hours or take early retirement, thus jeopardizing their own financial stability[3].

The financing options available to the community are also at best little cuttings from what might be a more comprehensive picture:

- Draining elder citizens' cash to cover long-term services and supports for their disabilities and limitations;
- Liquidation of non-housing assets to pay nursing home costs[4];
- Conversion of housing assets to pay care costs, via sale or reverse mortgages;
- Coverage with private long-term care insurance;
- "Spending Down" to the income and asset levels required for Medicaid to pay for long-term care costs.

[1] Boomers faced the loss of 22.4% of their net worth between 2007 and 2010. Lori A. Trawinski, Assets and Debt across Generations: The Middle-Class Balance Sheet, 1989-2010. AARP Policy Institute, Middle Class Security Project, January 2013, p. 10.
[2] It is well known that never-married, never-partnered people have fewer potential caregivers.
[3] An additional complication affects women who withdraw from the labor force to become

caregivers—their own income and future retirement benefits may be diminished.

[4] There may not be much ground for optimism about covering LTSS costs from household assets. Census Bureau analyses of the Survey of Income and Program Participation find that by groupings of monthly household income in quintiles, the first through fourth quintiles hold average non-housing assets in the amounts of (1) $1,397; (2) $6,340; (3) $15,324, and (4) $45,331. Thus, the lowest 80% of the population by monthly income does not hold over $45,331 in assets, on average. U.S. Census Bureau, Survey of Income and Program Participation, 208 Panel Wave 10. Interned Release Date 3/21/2013. Updated 5/13/2013.

The problems of seeing long-term care needs are that it requires forethought and expertise that people may not have. To foresee potential long-term care needs requires knowledge and understanding of aging and frailty that may only come from experience (either personally or secondarily through the lives of family and friends). Planning for long-term care requires financial expertise (to ensure care resources) and policy expertise (federal, state, community, and private care provisions can interact with each other or deal with completely different domains and navigating all these programs can be time and resource-consuming).

What is clear is that any public policy to help families adjust to providing care, to accommodate care needs to workplace requirements, and to plan rational family financial commitments must attempt to knit together the snippets of the collage of care and financing. The Executive Office on Aging (EOA) has identified strategies to address the overlapping needs. These strategies help to identify actions that can be taken and new perceptions that may be created:

- Empower older people, their families, and other consumers to make informed decisions about, and to be able to easily access existing health and long-term supports and service options.
- Enable seniors to remain in their own homes with a high quality of life for as long as possible through the provision of home and community-based services, including support for family caregivers.
- Empower older people to stay active and healthy, among other ways, including Older Americans Act services and the new prevention benefits under Medicare; and
- Ensure the rights of older people and prevent their abuse, neglect and exploitation.

Hawaii's population profile is shifting toward one with a larger share of older adults than has been seen in the past. This shift presents challenges for predicting care needs as well as for estimating and planning for the workforce to provide care.

Finally, Hawaii is an archipelago state. Each county must create its own long-term services and support delivery system. Even with national funds from the Administration on Aging (AOA), it is difficult to deliver to those in one county the AOA services presented in another county. Likewise, the cost of creating comprehensive LTSS delivery systems in the areas of the State with sparse populations is substantial.

Partitioning the Risk: The Impracticality of Attempting to Cover All the LTC Risk

A proposed benefit program should effectively partition the risk of long-term care into two pieces, a front portion and a back portion. The proposed programs cover the front portion—starting 30 days from the onset of services (once the disability trigger has been reached). The service package does not run so long as to make other, longer-term support unnecessary. This division and the restriction of the benefit period reinforce the role of the individual's own planning in covering his or her long-term needs. Complete public financing is not seen as feasible in most of the United States. Public financing that leaves an area to be covered by private LTC insurance, by family savings, or by other family efforts provides substantial private opportunities to protect family well-being. Program benefits will delay the possible reliance on Medicaid for home and community services, thus bringing much-needed assistance to the families with frail members.

John O'Leary, noted the dimensions of public support for social insurance to fund long-term services and supports:

> Social insurance is needed as part of the solution. The most surprising finding of the survey is the overwhelming degree to which the panelists agreed on the need for a social insurance component as part of the ultimate LTC financing solution. It appears that panelists felt that private insurance and savings, while essential components of the LTC financing solution, would not be sufficient by themselves to satisfy all the financing requirements without a supplementary social insurance component. The government needs to take an active role in the LTC financial solution. Over 90 percent of panelists agreed on the need for the government to take an active role developing and implementing LTC financing solutions.

John O'Leary, Land This Plane: A Delphi Research Study of Long-Term Care Financing Strategies. Society of Actuaries, 2014.

How would an existing LTC insurance policy fit into this program? An existing LTCI policy that starts benefits after 100 days of paid services would begin payments a good way through the benefit period offered by these proposed packages. The proposals discussed in this report offer a level of benefits that can be delivered in the home or in community settings. For persons with no private LTCI policy, the 365-day benefit may be stretched by not using services every day.

For the person with a private LTCI policy, the nursing home portion of the benefits provided may have to be deferred because a nursing home bed may not be available. The proposed programs here start early in the care sequence and enable a more financially secure stay at home.22 The most important coordination, though, is with Medicaid. Since the proposed Hawaii social insurance package provides benefits without setting income or asset limits, it may reduce the pressure for spending down or disposing of income and assets to qualify for Medicaid benefits.23 The proposed social insurance program is not primarily intended to create a Medicaid offset. Any offset would be limited because the program has a limited quantity of 365 service days. The greatest number of users of the program will be the large segment of the population, which is not Medicaid eligible, and would generally not meet both the asset and the income limitations of Medicaid.

Limiting Benefit

Limiting the size of a prospective benefit accomplishes several goals. One is that it forces attention to the level of care we may need, as opposed to a level of care that is on a cost-free "wish list." The proposed benefit size and duration must address the services most people use. The length of benefit must also be based on some sense of how long a benefit is likely to be used in the insured population

The image we often have of the need for care is that "I need maximum benefits for life" or "I need care for at least five years," or perhaps, "We need to cover ourselves until at least 100." These wishes, however, are at best described as wants, not needs. For events that occur in the future, we really do not know what our actual needs may be. We can say something about what we expect them to be. When we look at a whole population, or a really big sample, we can tally those who reach some particular level of frailty (and thus may need assistance) for every age.

Hurd, Michaud and Rohwedder point out the life forces—death and frailty-- that drive home care and nursing home risks:

> There are two competing forces that affect lifetime risk: nursing home risk and mortality risk. Both depend in a non-trivial way on socio-demographic characteristics. For example, smokers have a higher risk of entering a nursing home conditional on being alive. But since they also face higher mortality risks, this reduces lifetime exposure to nursing homes. We find that females, white and non-smokers face the highest risks of ever entering a nursing home.
>
> Michael Hurd, Pierre-Carl Michaud and Susann Rohwedder. The Lifetime Risk of Nursing Home Use. Chapter in NBER book Discoveries in the Economics of Aging (2014), David A. Wise, editor (p. 81 - 109).

The lesson for us at this point is that most people will not experience the risk of disability at age 99, but many will face it at age 80 or 85. In addition, most people facing a disability will not experience it forever, and most not even for five or possibly three years. Many will experience a disability for a year or less. It is psychologically comforting to think of having insurance coverage for a disability that might last five years, but most will not. It is comforting to think of having some kind of protection until age 100—but only 5% of females and 2% of males are likely to see that age.

It is also comforting to think of obtaining a large amount of insurance coverage, in the hundreds of thousands of dollars per year, to provide for a long nursing home stay. Yet the bed may not be there for a part of that potential stay—someone else is using it. The idea of a nursing home may sound clean and inviting when we are negotiating a long and complex insurance document—but the reality may be that we prefer our own house, with mangos and papayas in the backyard.

The goal of these prospective programs is to propose a limited length of benefit that will "capture" the largest share of the population. This shorter than lifetime benefit—365 days of services—will not cover lifetime care and is not targeted at covering the costs of nursing home care. It is intended to bridge the family's ability to adjust schedules, arrange work hours, and keep caregivers' regular jobs and benefits safe—especially those of women in the labor force who are not yet ready or able to retire.

Why social insurance? Why not simple general funds financing? Why not plain private long-term care insurance?

The goal of all insurance programs is to spread risk. We generally cannot ensure things that incur constant costs. There is no insurance that families can buy to cover the risk of their children's pizza bill. There is no insurance to cover the cost of the auto owner's tank of gasoline every week. In an imaginary economy, we might find someone willing to write the pizza or the gasoline policy, but that insurer would have to charge at least the average price of pizza for a year or the total of gasoline purchases, plus an amount to run the imaginary insurance company. This would be in fact, more than the cost of the pizza or the gasoline, because the pizza and gasoline purchases are not rare events, but steady streams of use. There is no real way to share the risk of these costs

The situation is completely different if an insurance program takes everyone. In the long run, the risk pattern of the population becomes that of the youngest members. This means that the risk of providing care, and the cost of care are substantially less than the risks faced in a pool in which the people applying for insurance can choose when they wish to seek coverage. In that pool, many seek coverage when they have some concerns about not being able to escape the insured event. Many of these will not be offered coverage. Those who secure coverage, to keep it, must pay the premiums regularly. To pay the premiums they must have the funds available for years into the future.

A serious flaw in the design of the CLASS Act long-term care provision of the Affordable Care Act brought about termination of the provision. Because the proposed program was voluntary, and targeted toward older people, but did not underwrite applicants, it faced the risks of higher usage, higher premiums after a short experience period, and then flight of healthy members when premiums were raised. The result would have been increasing disability levels among the insured population.

A serious flaw in the design of the CLASS Act long-term care provision of the Affordable Care Act brought about the termination of the provision. Because the proposed program was voluntary, and targeted toward older people, but did not underwrite applicants, it faced the risks of higher usage, higher premiums after a short experience period, and then flight of healthy members when premiums were raised. The result would have been increasing disability levels among the insured population. Taking everyone in the population allows accounting for the increasing age profile that Hawaii is expected to experience.

At what level of benefit does the program maximize the sharing of risk?

This question forces us to ask two different questions. One, is the level of disability that should be set as a trigger for benefits? Two, what should the size of the benefit be? The lower we set the trigger standard, of course, the more people will be covered at a low level of disability. Setting a disability trigger of the loss of just one of the activities of daily living (ADLs) will produce a large pool of eligible beneficiaries, but many with very little disability. This would be a very expensive program. Setting the trigger value at three ADL levels lost would be an exceptionally stringent standard—many persons at this level of care may be very hard to care for at home. The standard of requiring hands-on assistance with 2 ADL follows a HIPAA definition used by CMS (Center for Medicaid and Medicare Services).

A social insurance program can cover a population because it takes all of the cases, some high-risk and some low. Over time, the population comes to resemble the lowest risk cases. But this works only if the

program takes everyone. When it does so, it shares the risk across the entire group. Because we live in a population for a long time, we receive coverage for different levels of risk as we age.

It is admittedly hard to summarize the issues supporting a social insurance program for a specific kind of need—coping with frailty and inability to execute Activities of Daily Living. These remarks are an abstraction from the Report to the Hawaii State Legislature of December 14, 2014 It is clear that spending down to meet Medicaid qualifications creates many untenable situations for families, hoping to cover all frailty with private Long Term Care Insurance is tied to health at the time of application, and the ability to pay premiums for the rest of one's life. Planning to cover expenses with cash strains the credulity of a large share of the income distribution. Finally, relying on annual appropriations of general funds provides no basis for planning care. We come back to social insurance—covering everyone's risk at some level of benefit.

The full report is available from the following link:

https://drive.google.com/file/d/1cym-kwmX2vaoHRwd4DSf6D-VT3FDDfoJ/view?usp=sharing

IV. MEDICAID DIVERSION OF NURSING HOME PATIENTS BACK TO THE COMMUNITY

Health care is a fundamental need essential to the well-being of individuals, families, and society at large.[54] Ensuring equitable access to health services not only protects public health but also strengthens communities and sustains economic and civic participation.

Hawai'i's Unique Health Care Framework

Hawai'i has long been a leader in health care innovation. The Hawai'i Prepaid Health Care Act (PHCA)—enacted on June 12, 1974—requires employers to provide health insurance to eligible employees. This landmark legislation, codified in Hawai'i Revised Statutes, Chapter 393, mandates that:

- Employers must offer health insurance to employees who:
  - Work at least 20 hours per week, and
  - Earn at least 86.67 times the state minimum wage per month

Hawai'i remains the only U.S. state exempt from the federal Employee Retirement Income Security Act of 1974 (ERISA), allowing it to maintain stronger employer health coverage standards.[55]

Long-Term Services and Supports (LTSS): A National and Local Priority

Medicare provides limited coverage for long-term care:

- Covers up to 100 days of skilled nursing facility (SNF) care following a hospital stay
- Covers home health services for part-time or intermittent skilled needs
- Does not cover long-term custodial care (e.g., ongoing help with bathing, eating, dressing)

According to the Congressional Budget Office:

- Over 6 million Americans use paid LTSS in home and community-based settings
- Over 2 million receive LTSS in institutional settings (e.g., nursing homes)

[54] U.S. CONST. art. 1, §8.

[55] The Employee Retirement Income Security Act of 1974 (ERISA) (Pub. L. 93–406, 88 Stat. 829, enacted September 2, 1974, codified in part at 29 U.S.C. ch. 18).

Medicaid is the largest single payer of LTSS in the United States.

Medicaid Delivery System in Hawai‘i

In Hawai‘i, Medicaid services are delivered primarily through a managed care model. The five (5) Managed Care Organizations (MCOs) currently contracted by the state include:

- AlohaCare
- HMSA (Hawai‘i Medical Service Association)
- Kaiser Permanente
- ‘Ohana Health Plan
- UnitedHealthcare Community Plan

These MCOs are responsible for providing both medical and Long-Term Services and Supports (LTSS) to eligible members across the islands.

The Health Reform Imperative: Cost, Access, Quality

Any meaningful health care reform must balance the "three-legged stool" of:

1. Cost containment
2. Access expansion
3. Quality improvement

For Medicaid beneficiaries, especially those in nursing home settings, this balance requires strategies that:

- Reduce reliance on institutional care
- Expand access to high-quality community-based programs
- Lower costs by supporting independence and family reunification
- Enhance quality of life for older adults and persons with disabilities

Permitted Interactive Group (PIG) Proposed Initiatives to Improve LTSS Outcomes

To meet these goals, Hawai‘i proposes strengthening and expanding three key programs:

1. Going Home Plus (GHP) – A community reintegration initiative helping Medicaid beneficiaries transition from institutional settings to community living.
2. Stewardship of Skilled Nursing Facilities (SNFs) – A policy strategy to manage utilization of SNF services and promote timely discharge planning.
3. GRACE Program – [To be described separately—likely a model focusing on comprehensive care for elderly or chronically ill individuals.]

Together, these initiatives aim to divert individuals from long-term institutionalization, empower families, and reallocate resources to more sustainable, person-centered care settings.

A. Going Home Plus (GHP) Program

Purpose

The Going Home Plus (GHP) project helps Medicaid recipients who have been living in hospitals or nursing facilities to transition safely and successfully back into the community. Participants who no longer require institutional care but need ongoing support can receive housing assistance and a tailored package of home and community-based services.

Funding

GHP is funded by the Centers for Medicare & Medicaid Services (CMS) through the Money Follows the Person Rebalancing Demonstration Grant, with funding secured through September 30, 2028.

Participants

- Medicaid beneficiaries residing in hospitals, nursing homes, or intermediate care facilities.
- Must meet nursing facility level of care requirements.
- Must reside in an institutional setting for at least 60 to 90 continuous days.
- Desire and ability to live in the community with appropriate support.

Participants and families work with a Health Coordinator or Developmental Disabilities (DD) Case Manager to design a person-centered care plan tailored to the individual's needs.

Core Services Provided[56]

GHP offers a wide array of community-based services, including:

- Adult Day Health / Adult Day Care
- Assisted Living
- Attendant Care
- Case Management

[56] https://medquest.hawaii.gov/en/members-applicants/already-covered/going-home-plus/ghp-services.html

- Chore Services
- Community Care Foster Homes
- Counseling & Training
- Environmental Accessibility Adaptations (EAA)
- Home Delivered Meals
- Home Maintenance
- Medically Fragile Day Care
- Moving Assistance
- Personal Assistance Levels 1 & 2
- Personal Emergency Response System (PERS)
- Skilled Nursing
- Respite Care
- Special Medical Equipment & Supplies (SMES)
- Vehicular Modifications
- Transition Coordination
- Virtual Care / Telehealth
- Training Institute
- Non-Medical Transportation

Supplemental Services

Additional support services to aid with the transition may include:

- Housing coordination
- Housing deposits
- Utility hook-ups & deposits
- Essential furniture, appliances, household goods, and clothing
- Moving services

Opportunity

- Since its inception in 2009, 749 individuals have been successfully transitioned to the community.
- This equates to ~50 transitions per year—a figure that reflects significant underutilization.
- Many families are unaware of the GHP program, as Managed Care Organizations (MCOs) do not routinely inform members.
- Many residents in intermediate care facilities—especially those with low to medium nursing needs—could be suitable for transition to Community Care Foster Homes or similar community-based living arrangements.

Goals

1. Promote family reunification by enabling patients to return home or closer to loved ones.
2. Double the number of referrals to the GHP program from MCOs and institutional facilities.

Proposed Action Plan

Action 1. Mandate Routine Education:
Health Coordinators within MCOs should be required to inform patients and families about GHP during the annual DHS 1147 Level of Care (LOC) assessments.

Rationale:
The 1147 process is a natural touchpoint for identifying members who may be eligible for discharge from institutional settings and would benefit from a community-based transition.

Additional Recommendations:

- Implement a standardized GHP referral checklist embedded in LOC assessment protocols.
- Provide MCO staff with training on GHP benefits and eligibility criteria.
- Include GHP informational brochures in discharge planning packets.
- Track GHP referral rates by facility and MCO to identify engagement gaps.

Key Metrics to Monitor

Metric	Baseline	Target (12–18 mo)
Annual GHP Transitions	~50	100+
Annual Referrals from MCOs	TBD	2x increase
% of LOC Assessments with GHP Offer	TBD	100%

B. Stewardship of Skilled Nursing Facilities

Skilled nursing care refers to services provided or supervised by licensed professionals (nurses or therapists) for conditions requiring clinical monitoring and intervention. These services include:

- Nursing and therapy services that require medical expertise
- Condition monitoring and care evaluations

- Rehabilitation after hospitalization

Services: These include:

- Semi-private room
- Meals
- Skilled nursing care
- Physical, occupational, and speech therapy
- Medical social services
- Medical supplies and equipment used in the facility

Coverage: Medicare-Covered

- Days 1–20: Fully covered under Medicare Part A
- Days 21–100: Patient responsible for a daily copay
- Beyond 100 days: Coverage ends (unless a new benefit period is triggered)

Opportunity:

Unlike Medicare, Medicaid pays for long-term stays in SNFs if deemed medically necessary:

- No copayments for patients
- No defined limit on duration of stay
- Less frequent oversight due to high caseloads of health coordinators

Systemic Issues:

- Incentivized long stays: Patients may experience "secondary gain" from prolonged residence (e.g., stability, daily support), reducing motivation to return home. While nursing facilities may be incentivized to keep patients longer to avoid an empty bed.
- Downgrading of care: Patients often enter at a Skilled Nursing Facility level of care, but over time are downgraded to Intermediate Care Facility (ICF) level, while remaining institutionalized.
- Delayed discharge planning and underutilization of community options like GHP or Community Care Foster Homes.

Goals

1. Promote early discharge planning from SNFs to more appropriate and cost-effective care settings.
2. Ensure appropriate utilization of Medicaid-funded nursing home resources.

Proposed Action Plan

Action 1:

➞ Require Prior Authorization from Managed Care Organizations (MCOs) After Day 21

- Why Day 21? This is when Medicare coverage introduces cost-sharing, making it a natural intervention point for Medicaid and MCO oversight.
- Encourages reassessment of:
  - Current medical necessity for skilled care
  - Possibility of transitioning to lower levels of care
  - Community-based alternatives (e.g., GHP, Assisted Living)

Implementation Considerations:

- Develop standardized clinical criteria and workflows for prior authorization reviews
- Integrate transition coordinators or discharge planners into SNF workflows
- Align with existing 1147 LOC assessment timelines and data

Key Metrics to Monitor

Metric	Baseline	Target
% of SNF stays with discharge plan by Day 15	TBD	90%
% of SNF stays transitioning to community care	TBD	+25% increase
Avg. SNF length of stay (Medicaid population)	TBD	-15% reduction
% of stays requiring prior authorization post-Day 21	0%	100%

C. Geriatric Resources for Assessment and Care of Elders (GRACE)

The GRACE model, developed by the Indiana University, is a proven, evidence-based care coordination model designed to improve outcomes for frail older adults.[57] The model focuses on:

- Enhancing health and functional status
- Reducing hospitalizations and emergency department visits

[57] Counsell SR, Callahan CM, Buttar AB et al. Geriatric Resources for Assessment and Care of Elders (GRACE): a new model of primary care for low-income seniors. *J Am Geriatr Soc*. 2006 Jul;54(7):1136-41.

- Preventing long-term nursing home placement

A distinctive element of GRACE is the in-home assessment conducted by a dyad of a nurse practitioner and a social worker, working as a team during the same visit. This personalized, in-depth evaluation allows for early identification of issues and coordinated care planning.

Local Adaptation in Hawai'i

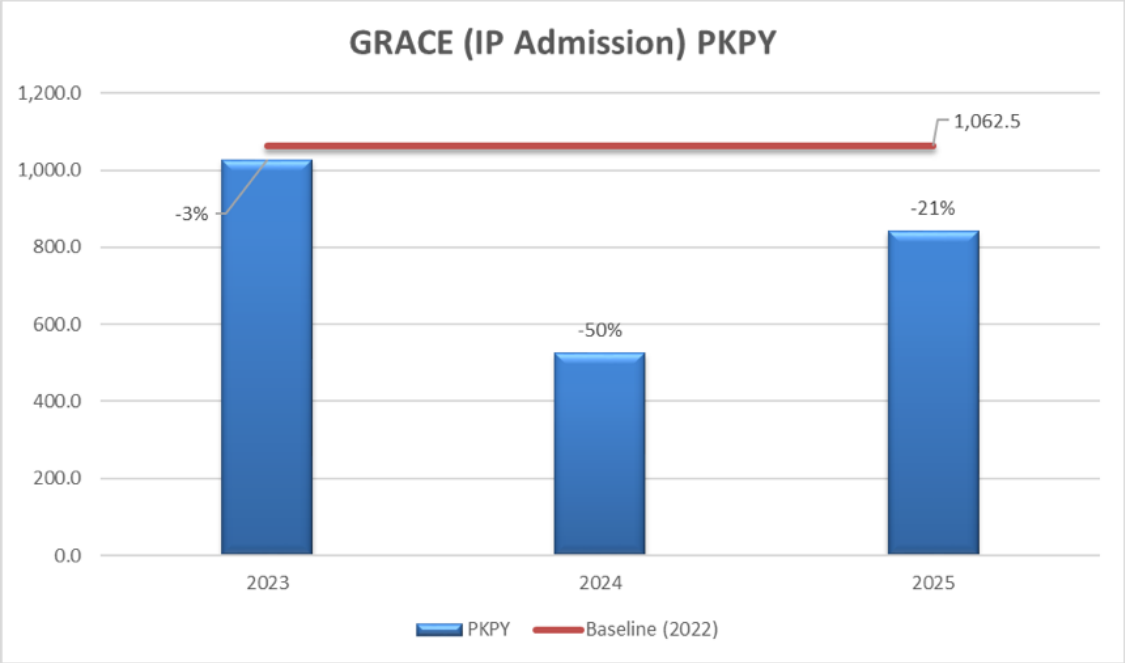
In Hawai'i, AlohaCare, a Medicaid Managed Care Organization (MCO), has successfully adapted and piloted the GRACE model. The program is implemented by a health coordination team consisting of registered nurses and social workers conducting:

- Home visits
- Monthly contact with members
- Ongoing collaboration with primary care providers and specialists

The interdisciplinary team includes input from:

- Pharmacists
- Behavioral health specialists
- Geriatricians
- Nurses and social workers

Preliminary data from the Hawaii pilot indicates a reduction in inpatient hospitalizations, affirming the model's effectiveness in managing complex, chronic geriatric care in the community.



Key Geriatric Protocols Addressed

GRACE care coordination focuses on comprehensive geriatric syndromes and concerns, including:

- Advance Care Planning
- Health Maintenance
- Medication Management
- Falls and Mobility Issues
- Depression
- Dementia
- Caregiver Burden
- Chronic Pain
- Malnutrition / Unintended Weight Loss
- Urinary Incontinence
- Visual and Hearing Impairment

Opportunity

Currently, MCOs are required to perform an annual Health Risk Assessment (HRA) or Health and Functional Assessment (HFA) to create individualized care plans. However, these assessments often lack geriatric-specific protocols critical to the aging population.

By incorporating GRACE:

- MCOs can enhance clinical depth and geriatric relevance of their assessments
- The model provides a structured framework for delivering targeted, high-touch care coordination.
- It complements existing requirements and fulfills broader aging-in-place goals of the state Medicaid program

Goals

1. Prevent institutionalization of frail elderly members by implementing geriatric-focused care coordination
2. Promote healthy aging in place through proactive, home-based interventions

Proposed Action Plan

Action 1:
➞ Include GRACE in the Med-QUEST Request for Proposals (RFP):
Future Medicaid MCO contracts should require offering the GRACE model to frail dual-eligible (Medicare-Medicaid) members.

Action 2:
➞ Use Predictive Analytics to Target High-Need Members:
MCOs should apply predictive modeling algorithms to identify 10–20% of Dual-Eligible Special Needs Plan (DSNP) members who would benefit most from GRACE.

Predictive Modeling Criteria for GRACE Enrollment

The following criteria can be used by MCOs to identify high-risk dual-eligible members who would benefit from GRACE. These factors can be incorporated into claims-based algorithms, risk stratification tools, or EMR alerts:

Demographic Risk Flags

- Age ≥ 75
- Living alone (documented in care management notes or self-reported)
- Limited caregiver support

Clinical Risk Indicators

- ≥ 2 hospital admissions in past 6 months
- ≥ 2 ER visits in past 6 months
- Recent discharge from skilled nursing facility
- ≥ 5 active medications (polypharmacy)

- Diagnoses of:
    - Dementia or cognitive impairment
    - Falls / gait instability
    - Depression or behavioral health needs
    - Malnutrition or significant weight loss
    - Chronic conditions (e.g., CHF, COPD, diabetes, CKD)
    - Urinary incontinence

Functional Risk Indicators

- Needs assistance with ≥ 2 Activities of Daily Living (ADLs):
    - Bathing
    - Dressing
    - Toileting
    - Transferring
    - Eating
- Documented frailty, homebound status, or mobility limitations

Social & Environmental Factors

- Frequent missed appointments or difficulty accessing care
- Lack of transportation
- Unsafe home environment (e.g., hoarding, fall hazards)
- Recently evicted or at risk of homelessness
- Caregiver burnout or change in caregiving situation

Potential Impact

Metric	Expected Outcome
Hospitalizations (inpatient)	↓ Decrease
Emergency room utilization	↓ Decrease
Nursing home placements	↓ Decrease / Delay
Member satisfaction	↑ Increase
Caregiver stress	↓ Decrease
Functional status (ADL/IADL)	↑ Stabilization or Improvement

V. JAPAN'S LONG-TERM CARE FINANCING SYSTEM: 25 YEARS OF EXPERIENCE TO LEARN FROM

1. Background

Japan is known for having one of the world's most rapidly aging populations. This year, more than 30% of the Japanese population is 65 or older, presenting a significant challenge for long-term care (LTC) services. In some rural towns, the percentage over 65 is in excess of 50%! In response, Japan implemented its Long-Term Care Insurance (LTCI) system in 2000 to address the growing demand for elderly care services. Back in the 1960s, it was already pioneering active aging programs to moderate the demand for hospital and long-term care services. Japan's Long-Term Care *(Kaigo)* Financing system was designed to provide financial support for long-term care services, ensuring that older adults could live with dignity and support while also alleviating the burden on families and the public healthcare system. This new system aimed to address these issues by combining elements of social insurance, public assistance, and private sector involvement.

2. Structure of Japan's LTC Financing System

Japan created a public, mandatory long-term care insurance (LTCI) program to address its "super-aged society." The LTC Insurance *(Kaigo hoken*) system in Japan operates as a public insurance scheme that is mandatory for all citizens aged 40 and older. It covers a range of services, including home-based care, nursing home care, and rehabilitative services. When it was introduced, middle-aged 40-year-olds were targeted as the age for participation, given the likelihood that many in this cohort were experiencing parents with long-term care needs. The financing system is structured as follows:

- Funding and Premium Contributions:
    - 50% public funds (national, prefectural (25% - National; 12.5% Prefecture; 12.5% Municipal taxes)
    - 50% insurance premiums ispaid by everyone 40+ from income or pension. The amount covered is split between the individual payor and the secondary insurer (eg. company)
    - Co-pay: Usually between 10 to 30%
- Benefits: Covers institutional care (nursing homes, special facilities) and community-based/home care services. Services are categorized into a standardized five (5)

levels of care. Depending on their level of need, beneficiaries are entitled to receive a combination of in-home care, institutional care, and community-based care services.
- Universal Access: Eligibility is based on need, not income or family status.
- Goal: Reduce family caregiving burden, support aging in place, and stabilize financing as the population ages.

Changes and Modifications

Over the past 25 years, Japan's LTC insurance system has undergone several changes and modifications to adapt to evolving demographic trends, increasing demand for services, and financial sustainability concerns declining fertility rates and a burgeoning older adul population:

- Revisions in Eligibility and Benefits:
  - Early revisions focused on adjusting the eligibility criteria and the type of services covered. For example, in 2006, the system introduced stricter eligibility requirements and a more refined needs assessment process.
- Integration of Health and Long-Term Care Services:
  - In the 2010s, Japan began integrating long-term care services with health services, aiming for better coordination and efficiency. This helped streamline care delivery and reduce the administrative burden on hospital providers.
- Cost-Sharing Mechanisms:
  - To address rising costs, there have been modifications to the cost-sharing mechanisms, including increases in co-payments for certain services and stricter eligibility criteria for institutional care.
- Shift Toward Community-Based Care:
  - Recent reforms have emphasized promoting community-based care options, such as home care, day care services, and respite care, to reduce the reliance on institutional care and foster aging-in-place strategies.

4. Challenges for the Future

While Japan's LTC financing system has successfully provided coverage for elderly care, when it began and has attempted to revise its services and policies over time, it will continue to face ongoing challenges:

- Aging Population:
  - The demographic shift towards a rapidly growing elderly population and a shrinking workforce, given a chronic sub-par fertility rate, Japan will continue to face challenges with system sustainability. The decrease in its working-age

population will result in a decrease in premiums, further exacerbating funding gaps.

- Increased Care Demand:
  - As life expectancy increases, the demand for long-term care services is projected to grow, putting pressure on the availability of services and the ability to meet the diverse needs of elderly individuals.
- Financial Sustainability:
  - The growing fiscal burden on both national and local governments is a significant concern. The current funding structure may not be adequate to support the system in the long term, especially as costs rise and contributions from the working-age population shrink.
- Quality of Care:
  - There is a need for continued improvement in the quality of long-term care services. Despite the significant increase in the number of available services, issues related to care standards, workforce shortages, and caregiver training remain persistent challenges. Eldercare workers are generally less well compensated making it difficult to attract the dwindling supply of the working age population into this job market.

5. Other Non-American Models Worthy of Review

In addition to the U.S. system, several countries have adopted unique approaches to long-term care that may offer insights for improving Japan's system. Some notable examples include:

- Germany: Germany's LTC system, established in 1995, is also a social insurance-based model that combines both public and private funding. A key feature is the high degree of coordination between healthcare and long-term care providers, ensuring a more integrated and efficient service delivery. Germany's system is often viewed as a successful example of sustainability through its balance of contributions, subsidies, and tax-funded support.
- Sweden: Sweden offers a largely public system with universal coverage, financed through taxes. The Swedish system focuses on home-based care and community services, with a strong emphasis on preventing institutional care. Sweden's strong focus on quality assurance and citizen rights could offer valuable lessons in assuring quality care.
- Netherlands: The Dutch model is a hybrid of social insurance and private insurance. It has a strong focus on personal care plans for individuals, allowing for greater personalization of services. The Netherlands has also developed a well-functioning home-care system, which helps reduce the need for institutional care.

- South Korea: South Korea introduced its own LTC insurance system in 2008, modeled in part after Japan's. Like Japan, LTC in South Korea is a mandatory public insurance system. However, the government is providing a larger share of funding compared to Japan. South Korea faces an even more dire demographic challenge with its aging population and 0.78 fertility rate. However, South Korea does attempt to keep its costs sustainable by adjusting benefits and premiums more frequently than Japan. Will that be enough? Regarding care integration, South Korea, like Japan, has focused on integrating healthcare services with long-term care, ensuring that people can seamlessly access both medical and care services through the same framework. Both Japan and South Korea's systems prioritize equity and access to care, but Japan has had a longer time to refine its system, whereas South Korea is still in the process of adapting and scaling its approach.

6. Implications of Japan's Model for Hawai'i

Hawai'i faces rising LTC demand that will overwhelm Medicaid and even more so under the present federal administration. Given the existing situation, Japan's mixed public-premium financing could inspire a state-level LTC social insurance program to spread costs more equitably across generations There a number of areas where Japan's policies are consistent with Hawaii's. First, its LTC insurance program is aimed at easing caregiving pressure on families (especially women). The direction of Hawaii state policy is consistent with that approach to help working caregivers, reduce burnout, and keep seniors at home longer. Secondly, regarding workforce development, Japan is investing in training. Hawaii faces a severe shortage in professional, paraprofessional, and family caregivers. A mandatory LTC insurance system could provide stable funding to attract, adequately compensate, and retain workers. Thirdly, Japan's Kaigo LTC System is now emphasizing home and community-based care to avoid premature institutional placements. This aligns with Hawai'i's values of keeping kūpuna (elders) connected to family and community. And fourthly, there are differences in the political and financial feasibility. Japan's national program enhances the viability of its system. On the other hand, Hawai'i would need to adapt at a state level, balancing costs with federal Medicaid and Medicare structures. Perhaps a payroll deduction LTC trust fund similar to Washington State's might be an incremental step.

7. Challenges for Hawai'i

Hawai'i's economy is smaller than Japan's, making the financing of a universal LTC system require careful design. We are also dependent on tourism and federal dollars for the Department of Defense. International and national economic downturns and fluctuations could affect tourism and, therefore, stable funding. On the other hand, Hawaii can anticipate an ongoing stable flow of funds from the US Department of Defense (War),

given its pivot from the European to the Asian theatre of conflicts. In addition, given Hawaii's high cost of living, premiums and taxes will need to account for higher employment at livable wages and issues related to income disparities. Finally, Hawai'i's system must integrate its multi-ethnic/multi-cultural family caregiving traditions rather than replacing them.

Conclusion

Japan's LTC financing system has made substantial progress since its inception in 2000, providing essential support to the aging population. However, as demographic shifts continue, Japan faces significant challenges in maintaining the system's sustainability and quality of care. Drawing insights from international models like those of Germany, Sweden, and the Netherlands may offer pathways to improving efficiency, care quality, and financial sustainability in Japan's long-term care framework. There is a lot of work that needs to be done to develop a universal, publicly structured LTC insurance to create an affordable means of addressing its cost, reduce caregiver burden and promote aging in place. But Hawai'i would need to adapt the model carefully to its smaller economy, unique cultural context, and reliance on federal programs. This will require the development of an information-driven, self-adjusting, self-improving system of long-term care financing.

VI. The False Mythology of Home & Community-Based Care As a Panacea for the LTC Financing Crisis

N.B.: The following is not intended as an indictment but rather a “reality check” and roadmap for addressing what is required to transform the foundational premise and functional role of HCBS care as it exists today so that it supports care in a community setting that is equitable, resilient, sufficiently resourced, and not fundamentally reliant on unpaid caregiving.

As used in this Addendum, the terms “unpaid caregiver,” “unpaid HCBS community caregiver,” “unpaid family caregiver, “family caregiver,” and the like are used interchangeably and are inclusive of a spouse, adult child, other relative, partner, or friend who has a personal relationship with and provides a board range of unpaid assistance for a person with chronic or disabling impairments.

Whereas the true total cost of institutional care is, for the most part, visibly and transparently baked into pricing schedules, the true cost of home and community-based care is not readily apparent with a multitude of hidden, neglected, and overlooked costs that can make the actual total cost of HCBS much higher than it might otherwise appear after closer more rigorous inspection.

A prevailing policy development narrative has largely emphasized HCBS as a cost-saving alternative to institutional nursing home care but persistently fails to adequately account for the substantial and often hidden costs borne by unpaid caregivers as well as other hidden or overlooked direct and indirect costs.

Virtually every HCBS model cannot effectively function without such unpaid informal support and active unpaid caregiving and as a result the “rebalancing” deinstitutionalization push has transferred a substantial portion of the burden of care onto unpaid family caregivers.

Fortunately, there is growing acknowledgment and recognition of this reality in both the scholarly published research and policy analysis literature.

Here's a detailed consideration of the issue, drawing on peer-reviewed scholarly research and trusted-source policy insights.

The "False Mythology" of HCBS as Less Expensive

While many reports and policy discussions present HCBS as inherently less expensive, a rigorous critical look reveals the failure of “incomplete analysis” and oversimplification of a more complex picture. These failures often manifest in the following oversights:

- Incomplete and faulty accounting of total true costs[58]: Most comparison studies cited as evidence of HCBS costs being less expensive than institutional care will focus solely on the *paid* services within HCBS versus the comprehensive suite of care services and costs in a nursing home. Nursing home rates are typically "all-inclusive," covering room and board, ADL/IADL assistance, medical care, as well as facility/infrastructure costs (building, maintenance, insurance, financing, etc.) and technology support (monitoring, medication, treatment machinery and technology).

  In contrast, HCBS cost comparisons will typically only consider the cost of direct formal services (e.g., a few hours of home health aide and attendance or therapy visits) and omit the significant cost-value of unpaid family caregivers, as well as other direct and indirect costs like home modifications, medical equipment, and transportation, enhanced technology (e.g., remote monitoring).

- Level of Need Matters—a Distorted View[59]: The use of “average/mean” costs that do not account or control for patient acuity inevitably distorts the cost comparison picture because such averages are significantly influenced by the higher volume of low-level services for low need patients in community settings (e.g., congregate day care). While HCBS is highly appropriate for such low need patients, their inclusion will skew cost comparisons if not properly risk adjusted. Comparing the cost of HCBS with a significantly lower-acuity patient census to the cost of a nursing home with a more uniformly higher-acuity patient census is not an "apples-to-apples" comparison.

  For individuals with very high needs or requiring specialized care (e.g., those with advanced dementia or complex behavioral needs), requiring continuous oversight, 24/7 care, or specialist treatments, the cost of replicating the appropriate licensed medical care, skilled nursing, therapy (physical, occupational, speech), and complex medical procedures in the home with paid HCBS can quickly surpass and far exceed that of institutional care.

  In addition, there is evidence that high need home health care recipients who are not adequately supported by trained caregivers and sufficient levels of care can experience more and elevated hospitalizations as a result. This collateral harm and cost are a significant policy planning oversight.

The Central Role and Overlooked Toll of Unpaid Caregiving: An Ethical and Economic Dilemma[60]

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[58] Cohen, M. A., & Weinrobe, M. (2014). *The role of informal care in long-term care policy.* Journal of Aging & Social Policy, 26(2), 127-143. Konetzka, R. T., & Gilsenan, B. (2018). *Nursing home and home health spending: Implications for rebalancing long-term care.* Health Affairs, 37(1), 115-122. Urban Institute. (2013). *The True Costs of Long-Term Care: What it Means for the Middle Class*.

[59] Sorensen, S., et al. (2016). *The Link Between Home Health Care and Hospital Readmissions*. Journal of Applied Gerontology. Grabowski, D. C., & Feng, Z. (2013). *The effects of Medicaid home- and community-based service expansions on nursing home use.* Health Services Research, 48(2 Pt 1), 384-406. Harris-Kojetin, L., et al. (2019). *Long-Term Care Providers and Services Users in the United States: Data from the National Study of Caregiving*. NCHS Data Brief, no 346.

[60] Otsuka US (2025), *New Report Shows Nearly Half of U.S. States Are on the Threshold of a Caregiving Emergency*. The New School SCEPA (2023), *Reducing the Unequal Burden of Unpaid Eldercare Work*., ASPE (2020). *Economic Impacts of Programs to Support Caregivers: Final Report.* Nursemagic.ai (2025), *The Hidden Costs of Ignoring Caregiver Stress in Home*

The perceived cost-effectiveness of HCBS hinges on the scarcely acknowledged and uncompensated labor of unpaid family caregivers:

- The Functional Foundation for HCBS Models Rests Squarely on Unpaid Caregivers: Virtually every HCBS care coordination model relies on unpaid caregivers to execute essential tasks, including:

    - Transportation to appointments.
    - Routine monitoring of health conditions.
    - Medication management.
    - A sizable portion of Activities of Daily Living (ADLs) assistance (e.g., feeding, toileting, ambulation, personal hygiene beyond what a paid aide might provide with limited hours). This inherent reliance means that the "success" of HCBS is often predicated on the availability and willingness of family members to fill these gaps, effectively shifting the burden from the formal system to the informal one—as well as creating inequities for those who do not have such ready, able, and WILLING informal support resources.

  It is open to question as to whether most existing HCBS service models are even viable absent unpaid care.

- Unpaid Caregivers Provide the Majority of HCBS care[61]: Unpaid family caregivers provide most of the long-term care in the United States, with estimates suggesting they contribute 75-80% of total care hours for older adults (The New School SCEPA, 2023). The economic value of this unpaid labor is staggering, estimated in the hundreds of billions of dollars annually (e.g., $552 billion in 2015, per Johnson and Wang, cited in ASPE, 2020; $340 billion for dementia care alone, per Otsuka US, 2025). From Tables 2 and 4 of the LTSS Primer, we can see that there are an estimated 154,000 unpaid caregivers in Hawai'i who provide 144,000,000 hours of care annually with an estimated value of $2,325,600,000 (billion) accounting for an estimated 74.1% of Hawai'i's total LTSS annual bill (virtually all of it in HCBS settings).

- Hidden Costs and Exploitation of Unpaid Caregivers[62]: The "hidden costs" of relying on unpaid caregiving extend far beyond the direct financial outlay. As discussed in Section 5 of the LTSS Primer, the hidden costs for unpaid caregivers include:

    - Foregone Income and Career Impacts: Caregivers often reduce work hours, switch to part-time, or leave the labor force entirely, resulting in lost earnings, reduced retirement savings,

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Health Care Agencies. CEPR (n.d.), *The overlooked economic value of adult informal care*. ResearchGate (PDF) - *The economic burden of informal care*.

[61] AARP Public Policy Institute. (2023). *Valuing the Invaluable 2023 Update: A Brief Look at the Economic Value of Family Caregiving*. National Alliance for Caregiving and AARP. (2020). *Caregiving in the United States 2020*.

[62] Feinberg, L. F., et al. (2011), *The Economic Impact of Caregiving on Caregivers*. AARP Public Policy Institute. Pinquart, M., & Sörensen, A. (2000), *Correlates of physical health problems in caregivers of relatives with dementia: A meta-analysis*. Journal of Gerontology: Psychological Sciences, 55B (3), P138-P144. Zarit, S. H., Rechel, B., & Hu, B. (2018), *Caregiving and health: Evidence from across Europe*. The Lancet Public Health, 3(4), e167-e168. National Academies of Sciences, Engineering, and Medicine. (2016), *Families Caring for an Aging America*. The National Academies Press.

truncated/compromised careers, and diminished Social Security benefits (ASPE, 2020; The New School SCEPA, 2023). Low-income and minority caregivers are disproportionately affected by these economic burdens (The New School SCEPA, 2023).

- Physical and Mental Health Deterioration: Caregiving is physically and emotionally demanding, leading to increased stress, burnout, depression, and poorer physical and mental health outcomes for caregivers (Nursemagic.ai, 2025; CEPR, n.d.).

- Opportunity Costs: The time spent on caregiving comes at the expense of leisure, social activities, and personal well-being (CEPR, n.d.; ResearchGate PDF, "The economic burden of informal care").

- Out-of-Pocket Expenses: While not always acknowledged in official cost analyses, caregivers often incur out-of-pocket expenses for medical supplies, transportation, and other care-related needs.

- Creating a New Cohort of Potentially Destitute and Injured: The burden of caring for high and constant-need patients is enormously taxing and can easily result in chronic debilitating injuries for the untrained caregiver that often exacerbates existing frailties such as Osteoporosis. Community spousal impoverishment Med Quest spend-down rules are often a pathway toward homelessness for many unpaid caregivers (see Section 7 Med-QUEST Means Test and Spend Down Rules for details).

  This is an especially vexing and troubling aspect of program designs that cannot fully function without transferring a significant amount of the care burden to unpaid family caregivers and placing them at risk of destitution and physical injury/impairment.

Other Hidden/Often Overlooked HCBS Costs

Inefficiencies & Lack of Economies of Scale[63]: In addition to relying on unpaid caregiving to function, there are other direct and indirect costs associated with HCBS care that are often neglected or overlooked. Many stem from the inherent inefficiency of providing high intensity and/or individualized care in non-congregate settings that manifests as the lack of economies of scale:

- Individualized Staffing vs. Shared Resources: For HCBS care, custodial and skilled care must generally be provided on a one-on-one basis in an individual's home. If a person needs intermittent assistance throughout the day, this often requires multiple visits from different caregivers, or a single caregiver for extended periods, even if active assistance is only needed for short bursts. This "idle time" or fragmented service delivery drives up costs. Most typically, the burden of continuous care gets transferred to overburden unpaid family caregivers because of payment limits and restrictions.

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[63] Wiener, J. M., et al. (2013). *The Challenge of Paying for Long-Term Services and Supports*. AARP Public Policy Institute. Kaiser Family Foundation (KFF). (2020), *Medicaid Home and Community-Based Services: An Overview*.

The diffusion of care resources can also significantly deteriorate health outcomes due to lags in emergency response when unforeseen events arise for higher need patients.

In a nursing home, a single registered nurse or nursing assistant can oversee multiple residents, responding to needs quickly as they arise. This allows for efficient deployment of a shared workforce.

- Facility Overhead vs. Distributed Costs: While HCBS programs can provide assistance with infrastructure and facility expenses required for the provision of care in community settings (e.g., home modifications) a portion of that cost must often be borne by the patient or caregiver. For a true picture of costs, such "operating" or "room and board" expenses as utilities, maintenance, and food preparation are relevant—and not generally covered or reimbursed by HCBS programs. Even when HCBS programs cover services like meal delivery, the cost per meal for a single individual in their home is often higher than the per-meal cost in a large institutional kitchen. And, as with staffing, these facility and operating expenditures lack the economies of scale that would lower costs by being spread across many patients.

- Procurement and Inventory: HCBS relies on individual or small agency procurement which cannot generally leverage bulk purchasing and discounts for medical supplies, equipment, and food; resulting in generally higher per-unit costs to be borne by patients and their unpaid caregivers.

Coordination, Administrative, and Quality Assurance Costs[64]: Functional operating and logistical challenges are another source of inefficiency driven costs that are often neglected or overlooked:

- Case Management Intensity: Case management is essential for HCBS and is often a source of inefficiency. Coordinating multiple providers (personal care, skilled nursing, therapy, transportation, durable medical equipment, etc.) for a single individual in the community is complex and labor-intensive. Excessive or inefficient case management can consume a sizable portion of HCBS budgets without directly providing actual hands-on care. Incompetent and uncaring case management can wreak havoc on both patients and their families.

- Fragmented Service Delivery: Ideally, patients needing LTSS should receive a continuum of coordinated care. In HCBS settings, services are most often delivered by various disconnected/unrelated agencies and individuals, potentially leading to communication gaps, delays, and a lack of holistic understanding of the individual's needs, which can result in poorer outcomes and higher costs (e.g., causing preventable hospitalizations).
  The link with preventable hospitalizations is a serious and discouraging issue with obvious ramifications for patients as well as being a significant direct cost driver for the acute care hospital system.

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[64] Grabowski, D. C. (2010). *The long-term care industry: Firm structure and policy effects. Annual Review of Public Health*, 31, 357-372. Eiken, S., Saucier, P., & Polverini-Boswell, F. (2011), *The Case for Enhanced Federal HCBS Funding*. National Association of State Medicaid Directors. National Quality Forum. (2014), *National Quality Strategy for Long-Term Services and Supports*.

- Transportation Costs: For HCBS recipients, especially those with significant medical needs, transportation to appointments, adult day care, or other community resources can be a substantial and often overlooked cost, adding another layer of coordination and expense (often borne by unpaid caregivers directly or in the form of time).

- Quality Oversight and Monitoring: Ensuring quality and preventing fraud and abuse in a highly dispersed HCBS system is more challenging and administratively demanding than in a centralized institutional setting, requiring robust oversight mechanisms that add to system costs and complexity.

Reforms and Other Cost Considerations

- Adequate Hours and Comprehensive Services: Fully meeting complex needs in a home setting generally requires far more hours of paid care than typically provided, often necessitating 24/7 coverage for high-need individuals, which can quickly exceed the cost of nursing home care. Continuous custodial aid and attendance services that now rest on unpaid caregivers can be costly as well.

- Support for Unpaid Caregivers: This includes direct financial compensation, robust respite care, and comprehensive training and support programs. Employer engagement and flexibility are also essential support measures, perhaps in the form of incentives for employers to offer caregiver-friendly policies, including flexible work arrangements, more robust and flexible paid family leave, and access to on-the-job caregiver support resources—all of which entail additional costs. This acknowledges the reality that many caregivers are also employed and directly responds to workforce issues of recruitment retention and especially productivity.

- Infrastructure and Technology: Investment in care coordination, technology, and accessible housing modifications are also necessary. Leveraging technology (e.g., constant remote health monitoring) can help extend the reach of a limited workforce to some extent—but that technology is not free. There are costs for the technology itself (often new with limited economies of scale) as well as personnel costs for monitoring and response dispatching.

  Leverage Technology Wisely: While technology is not a panacea, it can be a powerful tool for extending the reach of the workforce and improving care coordination. Public funding is needed to support the development and adoption of technologies for remote health monitoring, care plan management, and communication between providers, caregivers, and recipients.

- Medicaid's Limits: As documented in Section 7 of the LTSS Primer, Medicaid serves only those who meet stringent income and asset tests, often after they "spend down" their life savings. This means it's a safety net for impoverishment, not a comprehensive solution for the middle class.[65] (Urban Institute, 2016 - Consensus Framework; Congress.gov, 2023).

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[65] Urban Institute, (2003), *A Consensus Framework for Funding Long-Term Services and Supports,* 2016. Congress.gov., *Medicare Long-Term Services and Supports Act*.

- "Woodwork Effect"[66]: The "woodwork effect" is a significant policy consideration for every public health benefit program as it adds costs. The woodwork effect refers to the phenomenon where an increase in supply or accessibility leads to an increase in consumption or participation that would not have otherwise manifested but for the increase in supply of accessibility.

  When HCBS programs become more widely available and desirable, individuals who might have otherwise relied solely on informal (unpaid) family care or who suffered unmet needs, will "come out of the woodwork" to access these new expanded covered services. While this addresses unmet need and improves quality of life, it can lead to an overall increase in total spending because the *volume* of people served increases.

  It is imperative that HCBS expansions actuarially factor in woodwork effect forecasts and there be realistic expectations about current costs remaining unaffected or even reduced.

- Public Awareness Campaigns: A concerted funded public awareness campaign is essential for educating the public and policymakers about the true economic and personal costs of unpaid caregiving. Hawai'i can build on the existing legislative awareness and willingness to act that resulted in passage of the Kupuna Caregiver Program Act 102 in 2017 (discussed further below)—a support program for working caregivers. A public awareness and education campaign is also crucial to enfranchise and empower unpaid caregivers to not let social "norms" and cultural mores entrap them into what for some is seen as "involuntary servitude" because of feelings that societal pressures leave them no alternatives but to assume the role quietly and resignedly.

Dispelling the False Mythology: Functional Non-Exploitative HCBS is Not Inexpensive[67]

The historical push for **"Rebalancing"** deinstitutionalization, while driven by laudable goals of promoting independence and community integration, has, in practice, simply transferred much of the burden and cost to unpaid caregivers in homecare settings. This is unsustainable, inequitable, and exploitative of unpaid caregivers. A substantial body of scholarly and policy research makes the case that relying on unpaid caregivers constitutes a significant, and often unacknowledged, subsidy of the entire LTSS system, and policies that fail to account for this value are fundamentally flawed and unfair.[68] The foregoing discussion illustrates that while HCBS care is depicted as less expensive and often posed as a cost-effective alternative to institutional care, that is a questionable narrative because it does not fully

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[66] Liu, K., & Manton, K. G. (1995), *The potential impact of long-term care insurance on Medicare and Medicaid expenditures.* Journal of Gerontology: Social Sciences*,* 50(5), S248-S261. Congressional Budget Office (CBO), (Ongoing reports on long-term care financing). The CBO frequently analyzes the potential costs of expanding long-term care programs, often accounting for the "woodwork effect" in their projections.

[67] A Place for Mom (n.d.). *Cost of Home Care vs. Nursing Homes*. Sorensen, L., et al. (2016). *Comparison of Long-term Care in Nursing Homes Versus Home Health: Costs and Outcomes in Alabama.* The Gerontologist*, 56*(2), 215-225. ResearchGate (PDF) - *Comparative Costs of Home Care and Residential Care*.

[68] Urban Institute. (2016). *A Consensus Framework for Long-Term Care Financing Reform.*

account for hidden and neglected costs (including the very consequential financial, physical, and emotional toll for unpaid family caregivers) and inefficiencies .

Building a Fully Functional, Resilient, and Adequately Resourced HCBS System That Does Not Rely on Exploiting Unpaid Caregivers Requires Additional Financing to Deal with the True Cost of HCBS Care[69]

While states have made progress in rebalancing Medicaid LTSS spending towards HCBS, the pace has been slower for older adults compared to individuals with intellectual and developmental disabilities.[70] Furthermore, merely shifting spending doesn't guarantee quality or access or fairness. As KFF observes, "rebalancing is not necessarily a panacea to achieve this goal" and requires a detailed strategy with financial incentives.

A more accurate and equitable understanding of LTSS costs must incorporate the full economic and social value of unpaid informal caregiving, including the substantial opportunity costs and negative health outcomes experienced by caregivers. Policy discussions need to move beyond simply comparing paid service costs and address how to truly support and sustain the informal care infrastructure, rather than implicitly exploiting it as a hidden subsidy for the formal LTSS system.

This will demand not only a transformative re-thinking about the structure and role of HCBS but also acceptance that such a transformation to financially support and relieve the transferred burden of care for caregivers will require adequate additional financing that is simply not there right now.

The expectation that simply “rebalancing" from institutional to community care will automatically yield significant cost savings or that fixing the HCBS model won't be expensive is not reasonable. Building a fully functional HCBS system that is not heavily reliant on and explicitly accounts for unpaid care will demand several fundamental reforms—including a significant re-evaluation of how HCBS is funded, organized, and delivered. This will entail significant financial investments well beyond nominal and ultimately inconsequential tax credits or limited intermittent respite for a fraction of the unpaid care burden.[71]

Dealing with the True Cost of Functional HCBS Care—Investing in the Direct Care Workforce[72]

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[69] **Kaiser Family Foundation (KFF).** (2015), *Medicaid Home and Community-Based Services: Rebalancing and Financial Incentives*. **HHS ASPE**. (2025), *Long-Term Services and Supports: A Data and Trends Report*.

[70] **U. S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation**, (January 14, 2025), *Actuarial Analysis of Long-Term Services and Supports Reform Proposals.*

[71] **KFF (Kaiser Family Foundation).** (2015, January 21). *Medicaid and Long-Term Services and Supports: A Primer*. **HHS ASPE (U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation).** (2025, January 14). *Actuarial Analysis of Long-Term Services and Supports Reform Proposals*. **KFF (Kaiser Family Foundation).** (2017, June 20). *Strategies to Reduce Medicaid Spending: Findings from a Literature Review.*

[72] PHI (Paraprofessional Healthcare Institute), (Ongoing reports). *Direct Care Workers: Key Facts*. KFF. (2024), *Medicaid Home and Community-Based Services (HCBS) Workforce*. KFF. (2021), *Medicaid Spending on Home and Community-Based*

When the full scope of needs and the economic role and value of unpaid care and requisite supports are taken into consideration it becomes apparent that **untethering from the reliance on unpaid caregiving or replacing a meaningful share of institutional care with HCBS, especially for individuals with high needs, will require substantial and meaningful investments in the direct care workforce**.

An effective and robust strategy to address the chronic shortage and exceedingly high turnover in the LTSS and especially the HCBS workforce must address both the pipeline of new workers as well as factors that contribute to job dissatisfaction and attrition.

- **Investing in the Direct Care Workforce: Competitive Wages, Career Paths, Benefits, & Training**: To attract and retain a skilled workforce, wages for home health aides and other direct care workers would need to significantly increase, making HCBS more expensive than current models.[73] As highlighted in Section 4 of the Primer, the Hawai'i LTSS workforce is woefully under compensated to the point that most direct care workers do not earning a minimum living wage. Nationally, the median pay for home health and personal care aides was $16.12 per hour or $33,530 per year in 2023, with 65% making less than $35,000 annually. [73]

  Inadequate and non-competitive pay and the associated absence of meaningful career development paths is a direct driver of the recruitment and retention issues that leave the current LTSS and HCBS system substantially under-staffed.[74]

  The criticality of rectifying the compensation disparity cannot be over-stated. Research consistently shows a direct correlation between higher wages and better benefits and lower turnover and higher retention. Perhaps even more importantly, a stabilized workforce can have **enormous quality of care impacts** as well as broader economic impacts[75]:
  - **Reducing Turnover Costs**: High turnover rates among direct care workers (DCWs) is incredibly expensive. Recruitment, hiring, and training a new employee can cost thousands of dollars per person. The 2004 ASPE study found that increasing wages, offering better benefits, and creating career ladders, reduced turnover rates by 11% to 44%.

  - **Improving Quality of Care**: A stable, well-trained, and motivated (vs. beleaguered) workforce leads to better health outcomes. Research shows a correlation between higher hourly wages for assistive staff and higher quality ratings for nursing homes. Better-staffed facilities experience fewer adverse events, such as falls, and lower rates of hospital readmissions, which generates substantial cost savings and efficiencies for the entire

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Services (HCBS). **National Association of State Health Policy (NASHP)**. (Ongoing reports, *State Innovations in Long-Term Services and Supports*. **Urban Institute**. (2016), *Financing Long-Term Services and Supports: A Consensus Framework*.

[73] **KFF,** *Medicaid's Direct Care Workforce: A Key to HCBS and a System Under Strain, (*March 14, 2024); *Medicaid's Role in Addressing the Direct Care Workforce Crisis.*
[74]**Paraprofessional Healthcare Institute (PHI),** *Direct Care Workers Face Persistent Wage Gap Across All 50 States, 2024*

[75] **IOM,** (2008), *Retooling for an Aging America: Building the Health Care Workforce*. National Academies Press. **The Council of State Governments.** *Expanding the Pipeline – Long Term Care.* **ASPE**, (2004), *State-Based Initiatives to Improve the Recruitment and Retention of the Paraprofessional Long-Term Care Workforce*. **Medicaid.gov**. (2009), *Strategies for Improving DSW Recruitment, Retention, and Quality*.

healthcare system. There is no reason that this relationship will not translate for the HCBS service system as well.

It is unquestionable that an inadequately trained, overworked, and underpaid direct care workforce cannot provide the preventative care that is crucial for managing chronic conditions and preventing health crises in HCBS settings. The resulting cascade of negative outcomes for patients and the associated unnecessary increase in total LTSS costs has to be understood and rectified[76]:

* Failure to Manage Chronic Conditions: An underpaid, poorly trained, unmotivated, or overworked caregiver may miss subtle changes in a person's condition—such as signs of a urinary tract infection, a worsening of diabetes symptoms, or early signs of a pressure ulcer. Without timely intervention, these manageable conditions can quickly escalate into a medical emergency requiring an expensive and often traumatic hospital visit.

* Avoidable Hospitalizations: The lack of proper and sufficient in-home support—for everything from medication management to fall prevention—directly contributes to avoidable hospitalizations. The Centers for Medicare & Medicaid Services (CMS) found that inadequate care coordination and a lack of support for chronic conditions were major drivers of hospitalizations among Medicaid beneficiaries. These hospital stays are not only costly but can also lead to a decline in a person's functional abilities and independence, making it more difficult to return to community living.[77]

* Avoidable Increased Need for Institutional Care: Once a person's condition deteriorates due to inadequate community care, they often require a higher level of care than what can be provided at home. This inevitably leads to the need for more expensive elevated levels of institutional care that ratchet up the total LTSS bill.

Cost Estimate: Rectifying the direct care workforce compensation disparity is the most significant cost driver. A study on wage pass-throughs to CNAs found an 8.7% increase in wages. The cost of increasing wages for the entire LTSS workforce would be in the billions of dollars nationwide, but even modest increases have a positive impact. A state could implement targeted wage increases, with costs ranging from tens of millions to hundreds of millions depending on the scope of the program.

Paying DCWs a living wage not only improves their financial security and motivation but also has a broader economic impact. Higher wages lead to increased consumer spending in local economies

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[76] Genet, K., et al. (2021), *Outcomes of Medicaid Home- and Community-Based Long-Term Services Relative to Nursing Home Care Among Dual Eligibles,* Journal of the American Geriatrics Society, 69(12), 3469-3478. Mor, V., et al. (2010), *The Revolving Door of Rehospitalization from Skilled Nursing Facilities,* Health Affairs, 29(1), 57-64. Stone, R., & Harahan, M. (2010), *The Role of Direct Care Workers in Preventing Avoidable Hospitalizations,* The Gerontologist, 50(4), 433-441.

[77] Centers for Medicare & Medicaid Services (CMS), (2017), *Chronic Care Management Toolkit*. Agency for Healthcare Research and Quality (AHRQ), *Transforming Care for People with Multiple Chronic Conditions: AHRQ's Research Agenda*. *Health Services Research*, *56*(5), 972-976, 2021

and can reduce reliance on public assistance programs (caused by not making a minimum living wage), further generating a positive fiscal impact. One study on New York's home care workers projected that paying workers between $30,000 and $40,000 annually (which would be a minimum living wage in Hawai'i) generated a net economic gain of $3.7 Billion.[77]

It is noteworthy that low Medicaid payment rates are a contributing factor, and rate-setting reforms are in order with "wage pass-through" mechanisms to assure that additional funding actually reach workers.

- Recruitment and Retention—Creating a Structured Pipeline for *Meaningful* LTSS Careers: The direct care HCBS workforce exhibits high turnover as a result of inadequate wages, limited benefits, and challenging high demand working conditions with no meaningful career advancement paths. This constant churn increases recruitment and training costs for agencies, erodes the level and quality of care, and can disrupt continuity of care for recipients, potentially necessitating more expensive interventions if care becomes inconsistent.

  Building and funding the development of career ladders that offer opportunities for advanced training, specialization, and supervisory roles will require the infusion of additional financing. In addition, providing essential benefits like health insurance and paid time off to professionalize the workforce and improve job performance will help recruitment and retention in an industry with a high prevalence of "independent contractor" arrangements (both individual/private-sector and Medicaid "Self-Directed" models) that deny workers Federal minimum wage and overtime protections under the Fair Labor Standards Act (FLSA) and access to employee health insurance, retirement plans, and workers' compensation.[78]

  "Independent Contractor" HCBS workforce abuse: Independent contracting is a deeply ingrained and widespread aspect of the HCBS workforce, driven by a combination of consumer choice, provider economics, and the structure of many publicly funded care models. The practice, while sometimes a legitimate arrangement, is also a source of ongoing concern regarding worker protections and benefits.

  The use of independent contractors is a central feature of Medicaid Waiver self-directed HCBS programs. These models allow consumers the autonomy to hire, train, and manage their own care providers. This arrangement by its nature often involves the worker being classified as an independent contractor or a "household employee," rather than a traditional employee of a large agency.

  In fact, the prevalence of independent contracting in HCBS has led to a significant and ongoing concern about worker misclassification. As highlighted by reports from the National Employment Law Project (NELP), some home care agencies mislabel their employees as independent contractors to avoid legal obligations like minimum wage, overtime pay, and social security taxes.

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[78] National Employment Law Project (NELP. *Independent Contractor Misclassification in Home Care* (2015). Bureau of Labor Statistics, (2023), *Contingent and Alternative Employment Arrangements News Release*. Economic Policy Institute, (2025), *Misclassifying workers as Independent Contractors is Costly for Workers and States.* PHI, (2024), *Understanding the Direct Care Workforce*. Centers for Medicare & Medicaid, *HCBS Self-Direction Series.* KFF, (2022), *Ongoing Impacts of the Pandemic on Medicaid Home & Community-Based Services (DCBS) Programs: Findings from a 50-Sate Survey*.

The Department of Labor (DOL) has issued and revised rules to clarify the distinction between employees and independent contractors, specifically mentioning industries like healthcare as being impacted by these regulations.[79]

Creating a Structured HCBS Workforce Pipeline: The foundation for creating a structured workforce pipeline rests fundamentally on additional financing to fund rectifying the negative pay disparity for direct care workers and focusing tactically on introducing and recruiting young people to LTSS/HCBS careers early in life, providing educational and hands-on experience, and supporting professional development. These tactics aren't new or novel—but they are not cheap either:[80]

- High School LTSS Career & Technical Education (CTE) Programs: Partnering with high schools to create dedicated CTE curriculums in LTSS to include coursework on topics like gerontology, disability studies, and basic healthcare, as well as opportunities for job shadowing and volunteering in local care facilities or with HCBS providers.

  Cost Estimate: As a general cost reference, the initial design/setup, classroom materials, simulation equipment, and teacher training for a new CTE program can range from $50,000 to $150,000 per site with ongoing costs per student typically ranging between $5,000 to $10,000 per year.

- Paid Apprenticeships and Internships: Creating paid apprenticeship programs that combine classroom learning with on-the-job training can help bridge the gap with nursing homes offering ongoing, on-site training for their staff, ensuring consistent training and specialized skills for a dispersed HCBS workforce to effectively serve individuals with complex medical needs as well as offer a clear path to certification (e.g., Certified Nursing Assistant or Home Health Aide) and a living wage.

  Cost Estimate: As a general cost reference, a state-level apprenticeship program could cost $450,000 or more annually, as seen in Washington's investment in direct care worker apprenticeships (The Council of State Governments). The cost per apprentice would include wages (which can be a pass-through from the employer), administrative fees, and training costs, potentially ranging from $10,000 to $20,000 per student annually. State and federal grants may be available to subsidize these programs—working with the Hawai'i State Department of Education's Office of Curriculum and Instructional Design.

- Tuition Assistance and Loan Forgiveness: Tuition assistance, scholarships, and loan forgiveness programs can help attract and support students who pursue degrees or certifications in LTSS and commit to working in the field for a set number of years.

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[79] Bureau of Labor Statistics, (2023), *Contingent and Alternative Employment Arrangements News Release.*

[80] IOM, (2008), *Retooling for an Aging America: Building the Health Care Workforce.* National Academies Press. The Council of State Governments, (n.d.), *Expanding the Pipeline – Long Term Care*. ASPE, (2004), *State-Based Initiatives to Improve the Recruitment and Retention of the Paraprofessional Long-Term Care Workforce*. Medicaid.gov, (2009), *Strategies for Improving DSW Recruitment, Retention, and Quality*.

Cost Estimate: The cost of scholarship and subsidy support program depends on the number of recipients and the award amount. As a general cost reference, a program awarding 3,000 scholarships for training and testing could cost millions of dollars, as seen in a past initiative referenced in the footnote. These costs can be substantial but justified as a necessary and unavoidable long-term investment in a stable workforce.

- Career Ladders and Mentorship Programs: Implementing clear career ladders that allow direct care workers to advance into higher-skilled and better-paying roles (e.g., from CNA to LPN to RN) is crucial for recruitment and retention of the HCBS workforce. Pairing new workers with experienced mentors can help reduce turnover and burnout.

  Cost Estimate: As a general cost reference, mentorship and career ladder initiatives can typically be cost-effective. One study found a significant 18-point increase in retention among mentored workers (ASPE 2004). The costs are primarily administrative, involving staff time for training and program management, and could be estimated at $1,000 to $3,000 per new employee to implement a robust program.

Dealing with the True Cost of Functional HCBS Care—Building Robust Care Coordination and Infrastructure[81]

- Establish a "No Wrong Door" Single Coordinated Point of Entry for HCBS[82]: A single, easy-to-access, patient-centered point of entry for all LTSS/HCBS care, regardless of an individual's specific needs or funding source will greatly simplify the process of accessing Hawai'i's fragmented, highly siloed, and often funding-source demarked jumble of almost ad hoc community-based care services for individuals and families to ensure they are connected to the right services from the start.

  Establishing a single access point system is a key policy mechanism designed to alleviate the confused navigation of a complex and fragmented system with multiple agencies and eligibility criteria and sometimes opaque visibility for patients in need. This approach is widely recognized as a best practice for improving consumer experience and ensuring appropriate service matching. More efficient and person-centered system access aim to reduce the administrative burden, prevent individuals from being shuffled between different agencies, and ensure they receive timely and accurate information about their options and clarity about eligibility. The Centers for Medicare & Medicaid Services (CMS) has promoted this model through various initiatives, recognizing its potential to improve care coordination and reduce institutional bias in LTSS.

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[81] MACPAC (n.d.). *Care Coordination in Integrated Care Programs Serving Dually Eligible Beneficiaries – Health Plan Standards, Challenges and Evolving Approaches*.

[82] Kaiser Family Foundation (KFF), (2015), Long-*Term Services and Supports for Seniors: A State-by-State Look*. Administration for Community Living (ACL), (2022), *Aging and Disability Resource Centers Program/No Wrong Door System* Kaiser Family Foundation (KFF), (2021) *How Could $400 Billion New Federal Dollars Change Medicaid Home and Community-Based Services?*

Public Awareness Campaigns are an integral part of building public awareness about the existence of a single point of entry coordination program. Additionally, it is vital to establish critical Data Integration with existing state databases, such as those for Medicaid, housing, and transportation as well as standardized comprehensive coordinated care treatment protocols for all practitioners.

Costs: Implementing a robust "No Wrong Door" system is a significant and potentially disruptive upfront investment that can lead to long-term savings by improving efficiency and effectiveness as well as patient outcomes that can delay the need for higher intensity care. Grants from the Administration for Community Living (ACL) can support Hawai'i's effort to develop or enhance NWD systems with Federal matching funds covering up to 90% of the costs for building the necessary IT infrastructure—if such funding sources survive Federal budget cuts.

The Executive Office on Aging's No Wrong Door Initiative could be a promising start (with appropriate statutory authorities to affect and mandate a functioning care plan coordinated care protocol—rather than be ineffectively "voluntary" or "advisory") but is currently moribund and needing full supported activation.[83]

Dealing with the True Cost of Functional HCBS Care—Relieving the Burden of Transferred Care and Compensating Unpaid Caregivers[84]

- Relieving the Burden of Transferred Care and Compensating Unpaid Caregivers: The current HCBS system operates on the *implicit assumption that unpaid family care is an unlimited free resource*. There is need to fundamentally shift that thinking to one that recognizes caregiving as valuable labor and addresses the systemic failures that force individuals into care roles (often involuntarily). The almost quaint "solutions" offered about acknowledging and supporting the role of unpaid family caregivers with respite, training, and a modicum of direct financial compensation

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[83] Executive Office on Aging, *Report to the Thirty-Third Hawai'i State Legislature 2025 Session*, December 2024,

[84] Administration for Community Living (ACL), (July 2025), *National Strategy to Support Family Caregivers*, July 2025; *National Family Caregiver Support Program,* August 2025. ARCH National Respite Network & Resource Center, (August 2025), *Types of Respite*. Brandeis University, Community Living Policy Center, (March 2022), *Reducing Costs for Families and States by Increasing Access to Home- and Community-Based Services,* March 2022*; Medicaid Home and Community-Based Services: How Consumer Access Is Restricted by State Policies,* October 2014. CareScout, (August 2025), *Cost of Long-Term Care by State | Cost of Care Report,* August 2025. Kaiser Family Foundation (KFF), *How do Medicaid Home Care Programs Support Family Caregivers,* January 2025; *Payment Rates for Medicaid Home Care: States' Responses to Workforce Challenges,* February 2025; *Voices of Paid and Family Caregivers for Medicaid Enrollees Receiving HCBS*, August 2025. Medicaid.gov (Centers for Medicare & Medicaid Services - CMS), *Long-Term Services and Supports Rebalancing Toolkit*, August 2025, *Leveraging Family Caregivers for Personal Care Services in 1915(c) Waiver Programs*, February 2024. Medicaid and CHIP Payment and Access Commission (MACPAC), *Examining the Potential for Additional Rebalancing of Long-Term Services and Supports*, March 2021; *Chapter 4: Access to Home- and Community-Based Services,* June 2023. National Academy for State Health Policy (NASHP), (2021), *Using Research, Data, and Evidence-Informed Practices to Support Family Caregivers.* National Health Law Program (NHELP), (2023), *Paying Family Caregivers: State Options, Limitations, and Policy Considerations*. RTI International, (August 2025),
Respite Care: A Vital Component of the Caregiver Support System. US Aging, (August 2025), *Caregiver Services and Supports*. VA Caregiver Support Program, (August 2025), Home Page August 2025. VNA & Hospice Monterey, CA, (July 2025), *Respite Care for Family Caregivers: A Guide to Support & Relief*.

seldom, almost never, demonstrates a full appreciation or understanding of the enormous level of effort and cost required to truly and honestly support unpaid caregivers by both (1) **meaningfully relieving the transferred burden of care** and (2) **fairly and equitably compensating for the direct and indirect costs of rendering unpaid care.**

We already know that the conservatively estimated value of unpaid care in Hawai'i is $2.356 Billion annually—and that does NOT include the negative economic caregiving impacts on employment and retirement as well as risks of physical injury already documented in Section 5, LTSS Primer.

Significant additional financing resource investments are needed to fix the HCBS system to offset even a fraction of that unpaid bill. A societal commitment is needed to invest in financing and paying for the true cost of building a robust, adequately resourced, and non-abusive HCBS system that does not force untenable caregiving on individuals due to a lack of affordable, accessible, and high-quality support services for community care. The elements of such a commitment are wide-ranging and not inexpensive; some of these are already in the works but lack reliable sustained funding (payment):

- **Relieving the Burden of Transferred Unpaid Caregiving—Universal Access to Affordable, High-Quality Paid HCBS benefits:**

  - **Adequate Funding of the Direct Care Workforce**: As already discussed, this is foundational. Until there are enough well-paid, well-trained direct care workers, families will continue to be the default. This requires additional funding to significantly increase reimbursement rates for HCBS providers to support (with enforced pass-through) livable wages, benefits, and career pathways for direct care workers.

  - **Expanded HCBS Eligibility and Scope**: Loosening restrictive financial and functional eligibility criteria for HCBS programs and expand the types and hours of services covered so that individuals with diverse needs can access comprehensive paid professional care. This reduces the gaps that family caregivers are currently forced to fill.

  - **Focus on Workforce Development and Training:** Investing in programs that recruit, train, and retain direct care workers, including immigration pathway initiatives for care workers (with fair and equitable compensation), apprenticeships, and specialized training for complex care needs.

  - **Enhanced Medicare HCBS Benefits**: Minnesota's ***Own Your Future Initiative*** is looking at embedding significant HCBS coverage in all Medicare Advantage and Medigap policies sold in Minnesota.[85] California's ***Master Plan for Aging*** LTSS Financing Initiative has a pilot component focused on leveraging the Medicare Advancing Home & Community Care (MAHCC) program to build expanded

[85] **Minnesota Department of Human Services, Own Your Future Initiative (John Cutler Consulting)**, (December 2018), *Enhanced Home Care Benefits in Medicare Supplemental Plans, Final Report*.

Medicare HCBS services and benefits for the “overlooked middle” (with incomes between 139% - 500% of the Federal poverty benchmark).[86]

- Robust and Accessible Respite Care – True Relief, Not Just Once-in-a-While Breaks:
    - **Substantial Funding for Extended Respite:** Instead of a few thousand dollars for a few hours—shift to thinking in terms of weeks or months of respite per year, tailored to the caregiver's need, not a fixed, minimal amount. Moving from a $2,500 annual limit (as recommended by the GUIDE model[87]) to, for example $10,000 - $20,000annually for comprehensive respite would allow for weeks of regularly recurring relief—which could take the form of "respite vouchers" of significant value that allow the purchase of hands-on in-home care, adult day services, or short-term facility stays.
    - **Emergency Respite:** Establishing readily available emergency crisis respite services (e.g., to address caregiver illness, family emergencies, burnout, etc.) to prevent forced institutionalization or extreme caregiver distress.
    - **Integrated Respite into Care Plans**: Making respite a core, non-negotiable component of every HCBS care plan, proactively offered and easily accessible, rather than a crisis intervention.
- "Caregiver-as-Client" Model:
    - Expand and reinforce the paradigm shift from focusing primarily on supporting care recipients to recognizing the caregiver as a distinct client with their own needs for support, training, and well-being. This would involve independent assessments of caregiver needs and the allocation of resources directly to them, not solely tied to the care recipient's plan.
    - **Legal Protections and Rights for Caregivers**: Beyond employment leave, explore establishing legal recognition for family caregivers, potentially granting them certain rights or protections akin to employed workers, especially when fulfilling roles traditionally performed by paid professionals.
- Far More Equitable & Meaningful Financial Support Measures—Not Inconsequential Tokens

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[86] California Department of Aging, *Long Term Services and Supports (LTSS) Financing Initiative Overview and Next Steps,* Webinar, August 28, 2024; *Gap Analysis and Multi-Year Roadmap for Non-Medical Home and Community-Based Services,* Webinar, July 31, 2025.

[87] Center for Medicare and Medicaid Services, (July 1, 2024), *Guiding an Improved Dementia Experience (GUIDE) Model*, Commonwealth Fund (2017). *Use of Paid and Unpaid Personal Help by Medicare Beneficiaries Needing Long-Term Services and Supports*. NCBI (n.d.). *Transforming the Role of Payment System Incentives to Improve Quality - Mechanisms for Organizational Behavior Change to Address the Needs of People Living with Alzheimer's Disease and Related Dementias*.

Equitably and meaningfully compensating, even partially, for the deep financial costs of caregiving—career disruption, lost wages, depleted savings, and compromised careers—requires more than minimum hourly payments or small stipends.

Comprehensive Caregiver Compensation Models:

* "Caregiver Salary" or Living Wage Payments: Instead of hourly rates that may not reflect the 24/7 nature of care, explore models that provide a living wage or salary for intensive caregiving roles, especially for those providing extensive personal care and skilled tasks. This could be tiered based on the level of care required.

* "Opportunity Cost" Compensation: Payments that aim to offset lost wages, benefits, and career progression would be more substantial, commensurate with the lifetime economic damage incurred. This could involve income replacement schemes like unemployment benefits, but for caregiving.

* Pension/Retirement Contribution Mechanisms: Establishing government or state-funded contributions to caregivers' retirement accounts (e.g., 401k, IRA) to mitigate the long-term impact of attenuated employment participation on their financial security. This directly addresses the often-devastating effect on retirement savings resulting from truncated careers to accommodate the unpaid transferred burden of unpaid caregiving.

* Social Security Earnings Credits: Educate and raise awareness among our Congressional delegation about the plight of unpaid caregivers and work with them to advocate for policy changes that would grant Social Security earnings credits for periods of intensive family caregiving, ensuring that caregivers don't face reduced Social Security benefits in retirement due to time out of the paid workforce for unpaid caregiving.

* Health and Disability Insurance for Caregivers: Provide access to subsidized, affordable, high-quality health insurance and disability insurance for unpaid caregivers, particularly those who lose employer-sponsored benefits due to caregiving. This is crucial given the risk of physical injury.

Enhanced Tax Incentives and Financial Relief:

Educate and raise awareness among our Congressional delegation, Legislature and County jurisdictions about the toll suffered by unpaid caregivers and work with them to legislate Federal and State tax relief measures.

* Refundable Tax Credits: Significant, refundable tax credits that directly reduce a caregiver's tax liability or provide a payment if they owe no taxes. These credits should be substantial enough to offset real caregiving expenses and lost income, not just token amounts that have no real and meaningful beneficial effect.

        - Expanded Deductions for Care-Related Expenses: Broadening the scope of deductible expenses beyond medical, to include home modifications, specialized equipment, transportation costs, and even "wear and tear" on personal property due to unpaid community caregiving.

        - Property Tax Relief/Deferral: For caregivers who remain in their homes to provide care, offering property tax relief or deferral programs.

    - Targeted Financial Assistance:

        - Housing Assistance: Develop and fund programs that help caregivers afford housing that accommodate the needs of their care recipients or that provide financial support (loans, stipends, grants, etc.) for necessary home modifications (e.g., ramps, accessible bathrooms).

        - Transportation Vouchers/Assistance: A significant part of the transferred burden and cost of unpaid caregiving relates to transporting care recipients to appointments, day programs, or for community engagement. While subsidized para-transport services like Honolulu's The Handi-Van are available, service is limited and navigating advanced reservations can be frustrating and difficult.

        - Technology Subsidies: Expanded funding and eligibility for assistive technologies, remote monitoring devices, and smart home solutions that can ease the physical and supervisory burden on caregivers somewhat.

Costs: The argument for more meaningful and equitable direct compensation and indirect support of unpaid caregivers is both ethical as well as economic. The HCBS system and associated policy planning as it exists today is "penny-wise and pound-foolish" relying of uncompensated care that almost inevitably leads to deleterious outcomes for those involved and higher costs in other related areas.

The "Cost" of Inaction is Enormous: The collateral economic harm and consequences of unpaid caregiving are considerable.

- Lost Productivity: The estimated value of unpaid family caregiving is staggering, often cited in the range of hundreds of billions of dollars annually (e.g., AARP estimates it at $600 billion in 2021). For Hawai'i, the estimated value of unpaid caregiving is $2.356 Billion. This is essentially a massive subsidy to the LTSS system. Also, when caregivers leave the workforce or reduce hours, it impacts the Hawai'i GDP, tax revenues, and business productivity—especially in small-business dominated Hawai'i.[88]

- Increased Healthcare Costs: Caregiver burnout, stress, associated physical and mental health problems, and physical injury lead to increased healthcare utilization by caregivers

[88] AARP Public Policy Institute, (2021), *Valuing the Invaluable 2021 Update: Charting a Path Forward in the Economic Value of Family Caregiving.*

themselves. There are also direct negative implications for patients when stressed or overwhelmed caregivers may be less able to prevent crises for their care recipients, leading to emergency room visits and avoidable hospitalizations (the "pop drop" phenomenon), which unnecessarily increase healthcare costs in general.[89]

- The Next Cohort of Destitute LTSS Users: As noted previously, it is a cruel irony that unpaid and inadequately supported home caregivers are themselves at elevated risk of physical injury or exacerbation of existing chronic conditions as well as impoverishment resulting from the punishing Medicaid "spend-down rule" that helps to create the next crop of potentially homeless LTSS users.

Dealing with the True Cost of Functional HCBS Care—Providing Fair and Equitable Compensation for Unpaid Caregivers Will Not be Inexpensive

Paid Family Caregiving (PFC): As previously documented, an estimated 155,000 Hawai'i residents now provide roughly 144 million hours of unpaid (predominantly HCBS) care. It is patently obvious that directly compensating these caregivers, even at a minimum living wage of $31/hr. (for Hawai'i), would be unfeasible at a cost of roughly $4.464 Billion.

Innovative, workable, and equitable options and strategies are needed to provide a measure of meaningful (not token) compensation for the direct and indirect costs borne by unpaid community caregivers.

Targeted Compensation for High-Needs Caregiving

A workable tiered approach might involve targeting compensation for High-Needs Caregiving. This approach would focus on compensating caregivers who provide the most intensive care, where the burden is highest, and the care recipient is most at risk of institutionalization.

- Direct Compensation Tiered by Level & Intensity of Care Rendered: Instead of a single, universal payment, a tiered approach links compensation directly to the intensity and nature of the care provided. This allows for a more fiscally responsible and sustainable program that gives priority to the most burdensome and medically complex assistance rendered. Compensation could be tied to the number of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) that a caregiver assists with—possibly more heavily weighted for deficits demanding 24/7 aid and attendance (e.g., continence, ambulation, etc.). A standardized assessment could be used to determine the level of assistance rendered, and a higher hourly rate could be paid for a greater number of ADL and IADL assistance. This is similar to models already in use by programs like Medicaid and several other existing programs, notably the U.S. Department of Veterans Affairs (VA) Program of Comprehensive Assistance for Family Caregivers (PCAFC). The core idea is to assess the care recipient's needs and assign them to a tier, which in turn determines the stipend amount for the caregiver. For example:

[89] Michigan Medicine, (2017), *How Caregiver Fatigue, Stress & Burnout Increase Health Care Costs*.

- Tier 1: Instrumental Activities of Daily Living (IADLs): This tier would be for caregivers assisting with less intensive, but still crucial, tasks. This could include things like managing medications, meal preparation, shopping, transportation, and light housekeeping assistance that is *readily pre-scheduled and does not require constant attention*. A caregiver in this tier might receive a lower monthly stipend or an hourly rate tied to a percentage of the minimum wage (e.g., 25% to 50% of the Hawai'i minimum wage).

- Tier 2: Activities of Daily Living (ADLs): This tier would compensate caregivers who assist with more hands-on, direct care. ADLs include bathing, dressing, toileting, and eating. A caregiver in this tier would receive a higher stipend or an hourly rate based on a larger percentage of the minimum or living wage. *While higher intensity, this level of assistance is still largely pre-schedulable.* The VA model, for example, ties its stipend to the hourly wage of a home health aide in the specific geographic area.

- Tier 3: High-Acuity or Medically Complex Care: This highest tier would be for caregivers providing constant supervision and hands-on care for individuals with significant cognitive impairment (e.g., advanced dementia) or other severe medical conditions. This care is often required around the clock, *not readily pre-schedulable, is emotionally and physically exhausting, and carries a substantial risk of burnout and physical injury*. The compensation in this tier should be the highest, potentially a stipend that approximates a full-time, living wage equivalent, recognizing that the caregiver is often unable to hold a paying job.

Other Direct Compensation Options:

- Case-by-Case Assessment: Rather than a blanket hourly rate, a case manager could work with families to determine a reasonable number of compensated hours per week based on the care recipient's specific needs and the caregiver's availability. This would avoid paying for every single hour of caregiving, which often includes less-intensive tasks.

- Stipends for Specific Conditions: Caregivers for individuals with severe cognitive impairments (like advanced dementia) or other high-acuity medical needs could receive regular tiered monthly stipends. The level of the stipend could be tier-based on the severity of the condition and the resulting caregiving burden. This is an approach used in the federal "Guiding an Improved Dementia Experience" (GUIDE) model.

- Capitated Payment Model: Under a capitated payment model providers (in this case, unpaid caregiver) receive a fixed, periodic payment for each patient cared for, regardless of how many services are provided in that period. This model is more commonly used in healthcare provider settings and organizations, but it can be adapted for unpaid family caregivers.

  Caregivers are paid a set amount each month for a specified period (e.g., six months or a year). The amount is "risk-adjusted" based on the care recipient's health status and needs. This is similar to the tiered stipend model but with a crucial distinction: the payment is a single lump sum per period rather than an hourly rate. Advantages include providing caregivers a predictable monthly payment, which can be essential for financial planning. It also reduces the administrative burden of

tracking every single hour of care, as is required in a fee-for-service model. The focus shifts from logging hours to managing the care recipient's overall well-being.

In healthcare organization settings there is the risk that capitated payments can incentivize care **"rationing"** or **"stinting"** where the volume and quality of services is limited to maximize income from fixed payments. Within the realm of compensating unpaid caregivers (given the close/personal relationship with patients) a robust assessment and risk-adjustment system can ensure that capitated payments accurately reflect the level of care required and provided.

- **Kupuna Caregivers Program (KCGP), Act 102 (Session Laws 2017).** The Hawai'i Kupuna Caregivers Program Act of 2017, codified in HRS §349-18, constitutes a promising if currently modest but **legislatively significant** platform for building a program to compensate unpaid community caregivers because it **demonstrates Legislative awareness and recognition of the toll on unpaid caregivers as well as the political will to act**.

  HB607 CD1 (Session Laws 2017) establishing the Kupuna Caregivers Program (signed into law in 2017 by Governor David Ige as Act 102) was a direct response to a growing legislative recognition of the need for home- and community-based long-term care options in Hawai'i. Act 102 was specifically aimed at helping **employed/working caregivers** by providing support services that would allow them to remain in the workforce.

Key Features of the Original Legislation:

* **Program Goal**: Provide direct payments to cover the cost of care services for impaired recipients that would otherwise be provided by unpaid qualified working caregivers to help the caregiver remain in the workforce.

* **Caregiver Eligibility:** "Qualified caregivers" had to be employed for at least 30 hours per week.

* **Care Recipient/Patient Eligibility:** Eligible care recipients had to be U.S. citizens, age 60+, not covered for HCBS services, not residing in any long-term institutional setting, with chronic disabling conditions, including 2 ADL, 2 IADL, 1 ADL + 1 IADL, or a substantive cognitive impairment.

* **Funding Mechanism**: The KCGP is funded by State General Fund appropriations. A modest initial sum of $600,000 was appropriated for FY 2017-18 to establish and implement the program—but on-going funding is left, ". . .subject to the availability of funding. . ." (HRS §349-B(c)). The program initially awarded a maximum of **$70 per day** for covered services. This was subsequently amended in 2019 by **Act 126** that significantly **reduced the benefit amount** to a maximum of **$210/week** (a mere pittance relative to actual real-world costs at the equivalent of only $30/day).[90]

[90] **SB1025** (Session Laws 2019): This bill, and its associated committee reports, detail the proposed changes to the program's funding allocation cap.

* KCGP does not directly compensate unpaid caregivers but reflects the intent to off-load some of the unpaid care burden by directly paying contracted service providers for services that would otherwise have been provided by the unpaid caregiver.

* Covered Services: As amended, payments remitted directly to contracted service providers for care services that would otherwise be performed by an unpaid caregiver are allowed for:
    - Care coordination or case management
    - Adult day care
    - Assisted transportation
    - Chore services
    - Home-delivered meals
    - Homemaker services
    - Personal care
    - Respite care
    - Transportation.

* Administration: The program is coordinated and administered by the Hawai'i Executive Office on Aging (EOA) and implemented through the county-level Area Agencies on Aging.

Subsequent Amendments and Evolution: Since its inception, the KCGP has seen some adjustments, most notably Act 160 (Session Laws 2022) repealed HRS §435-18 and consolidated the Kupuna Caregiver Program with the Kupuna Care Program under HRS §435-17 by the rather vague inclusion of a reference to "Services for the employed caregiver; . . ."[91] Not unexpectedly, funding for Caregiver benefits has become murky.

Building a Fair and Equitable Compensation Program for Unpaid Caregivers on the Kupuna Caregiver Foundation

Building a program on KCGP that would directly and equitably compensate unpaid caregivers can be accomplished by:

* Enacting legislation that would re-establish the KCGP as an autonomous stand-alone program (effectively reversing provisions in Act 160 that resulted in merging KCGP in an undifferentiated manner with the Kupuna Care Program). The expected funds that would be channeled through this program demand explicit visibility and accountable administration. In addition, the expectation will be to establish a different funding source for the program and move away from annual General Fund appropriations (see below).

* Adding a provision for direct caregiver payments (retaining the provision for paying service contractors). The core limitation of the current KCGP is that the money goes to a service provider, not the caregiver. A revised program could allow for a portion of the benefit to be paid directly to the caregiver. This moves the program from a glorified respite service to a

[91] SB 3113 (Session Laws 2022).

true direct compensation model. This is an approach used in some other state and federal programs (like certain Medicaid waivers) that recognize family caregivers as legitimate providers of care services.

* Align the caregiver payment structure with equitable tiered compensation principles discussed previously).

* Significantly reforming the benefit amount. The current weekly benefit of $210 is inadequate for a meaningful and equitable compensation since it barely covers a few hours of professional care. The weekly benefit must be significantly increased to be a truly meaningful supplement to a caregiver's lost wages or as a direct stipend. This could be tired up based on the care recipient's needs, as discussed earlier. For example, a low-acuity tier might receive a stipend of $500/month, while a high-acuity tier could receive a more substantial stipend of $2,000/month, better reflecting the lost income from full-time work. (By comparison, the current maximum Hawai'i Unemployment benefit is $835/week for up to 26 weeks; or $3,340/month.[92])

* If Hawai'i enacts legislation to establish a Long-Term Care Financing mechanism (e.g., a mandatory income tax funded earned benefit plan and Trust Fund)—discontinue funding the KCGP by annual General Fund appropriations and move funding to the LTC Financing Program.

* Evaluate placement of the KCGP in EOA with implementation by county-level Area Agencies on Aging. The current arrangement has the advantage of an existing and experienced administrative structure. However, significant staffing upgrades and the promulgation of detailed Hawai'i Administrative Rules as required by HRS Title 8, Chapter 91 are required for optimum results.

Proposed New Program Framework. Building a new, comprehensive caregiver compensation program structured as a modified and expanded Kupuna Caregivers Program might entail the following components:

(1) Needs-Based Assessment: A trained assessor would evaluate the care recipient's needs to determine their acuity level (e.g., Tier 1, 2, or 3) and the associated severity of care service needs.

(2) Tiered Compensation: Based on the assessment, the caregiver will receive a monthly stipend tied to the determined tier. The amount would be a meaningful benefit, not a token payment.

(3) Fiscal Intermediary: The program would mandate the use of a fiscal management service provider to manage all payroll, tax withholding, and administrative tasks that may be

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[92] Hawai'i Department of Labor & Industrial Relations, (2025), *Tax Rate Schedule and Weekly Benefit Amount,*

associated with stipend payments. This ensures the caregiver is treated as an employee and receives all necessary protections without the family having to navigate complex legal and tax requirements.

(4) Integration with Existing Resources: The program could be administered by the Executive Office on Aging and the county-level Area Agencies on Aging, possibly integrating it with existing Kupuna Care services, respite vouchers, and other caregiver support programs—pending a determination of capabilities and appropriateness as mentioned above.

This framework would move beyond the current KCGP's limitations to create a truly meaningful, equitable, and sustainable program that provides direct compensation while protecting the rights and financial well-being of family caregivers.

Synthesis: A Combined Approach. A stepwise implementation plan could involve a combination of:

(1) Immediate Relief: Immediately expand the existing Kupuna Caregivers Program to include a direct-to-caregiver stipend for the highest-acuity cases, using a tiered system. This provides a fast, targeted response to the most acute needs.

(2) Long-Term Strategy: Simultaneously, begin the policy and legislative work to create a public universal long-term care social insurance program, like Hawai'i Family HOPE or Washington's WA Cares.[93] This would establish a sustainable funding mechanism for caregiver compensation and supports that, over time, would provide a far more comprehensive and equitable solution for the entire state.

(3) Holistic Support: As part of both programs, ensure that funding is also dedicated to the "Tier 2" and "Tier 3" solutions mentioned earlier: expanded tax credits, respite care vouchers, and caregiver training/support services. Direct financial compensation is essential, but it is most effective when part of a broader, more holistic ecosystem of support.

Strong Demand, Negligible Reach/Impact—A Compelling Empirical Validation of the Need and Necessity to Expand and Overhaul KCGP

The Kupuna Caregiver Program can be a significant, valuable, and relevant element for the HCBS reform transformation needed—but substantial expansion and overhaul of the program is an imperative for full functionality.

With an estimated 155,000 unpaid family caregivers across the State, one would expect significant interest and demand for KCGP benefits. In fact, results have been modest at best. During SFY 2018, the first program year, there were only 1,704 unduplicated inquiries with merely 171

[93] Littler, (2025, June 15), *WA Cares Gets a Makeover: What's Changing in 2026*, provides an updated summary of the WA Cares Fund, its structure, and recent amendments. Milliman, (2022, October 19), *2022 WA Cares Fund Actuarial Study*. The detailed actuarial analysis of the WA Cares Fund, providing the financial projections for its sustainability.

applying caregivers qualifying for the program. Of the 159 program enrollees, a negligible 101 received support services.

Despite two legislative appropriations of $1.2 million for SFY 2019 and $1.5 million for SFY 2020, and a legislative requirement to maximize the number of caregivers supported, the program reach and impact continued to be negligible with just 112 caregiver served in SFY 2019 and 121 in SFY2020 (affected by COVID isolation mandates). Most support expenditures went toward basically supervisory Adult Day Care and Care Coordination/Case Management with little or no direct hands-on care despite the advanced median age and elevated levels of impairment of care recipients being cared for by family caregivers.[94]

A prominent underlying premise for this Addendum is the beleaguered and overburdened state of unpaid caregivers and the ethical necessity of fairly and equitably compensating these caregivers. Early results for the KCGP provide some very stark empirical validation of that premise. Based on the small sample of 112 supported working caregivers during SFY 2019 we can glean the following disturbing and deeply concerning observations[95]:

- 38.4% are working caregivers aged 60 and older
- 40.2% have been providing care for more than 5 years
- 51.8% are providing more than 40 hours of care per week, effectively the equivalent of another full-time job's labor
- 26.8% are providing between 20 – 40 hours of care per week, effectively the equivalent of another half-time job's labor
- Montgomery Borgatta Caregiver Burden (MB) assessments[96] indicated elevated MB scores for Objective Burden (interference with a caregiver's life) and Stress Burden (caregivers feeling anxious and depressed). MB Demand Burden scores (caregiving perceived as overly demanding and caregivers feeling taken advantage of) were slightly less than the MB Reference High Value.

Dealing with the True Cost of Functional HCBS Care—Social Insurance is Very Likely the Only Reasonable and Equitable Means of Effectively Grappling with The Magnitude of Remedial Costs

While HCBS can be cost-effective for individuals requiring modest levels of support compared to institutional care, a fully functional HCBS system capable of serving higher levels of acuity that is comprehensive, sufficiently resourced, provides meaningful respite and equitably compensates family caregivers, and builds a robust paid professional care

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[94] Executive Office on Aging, Department of Health, *Executive Office on Aging Annual Report for SFY2017; SFY2018; SFY 2019; SFY 2020; SFY 2021; SFY 2022.*

[95] Executive Office on Aging, Department of Health, *Executive Office on Aging Annual Report for SFY 2019.*

[96] Montgomery, R. J. V. (2006), *Using and Interpreting the Montgomery Borgatta Caregiver Burden Scale,* http://www4.uwm.edu/hbssw/PDF/Burden20Scale.pdf ; Savundranayagam, M. Y. (2010), *A Dimensional Analysis of Caregiver Burden Among Spouses and Adult Children,* https://academic.oup.com/gerontologist/article-abstract/51/3/321/559666

workforce will likely incur a *higher aggregate societal cost* than the underfunded system heavily reliant on uncompensated family care we have now, and potentially more than a strictly institutional model relying on economies of scale.

After many decades of avoidance and deflection, there is growing recognition of the need to explore social insurance models for long-term care as perhaps the only reasonable and equitable means of providing universal benefits to reduce the reliance on means-tested Medicaid and the unpaid labor of families in community settings. Such explorations and reconsiderations are already taking place in a host of other states (California, Massachusetts, Minnesota, etc.) with Washington state having taken the lead by establishing a first in the nation mandatory payroll taxed financed LTC social insurance program, WA Cares.[97]

These explorations are serious moves to action—well beyond mere academic or philosophical discussion.

[97] Commonwealth Fund, (2023), *U.S. and Global Approaches to Financing Long-Term Care: Understanding the Patchwork*, HHS ASPE (U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation), (2025, January 14), *Actuarial Analysis of Long-Term Services and Supports Reform Proposals*; *Evaluating Long-Term Services and Supports Reform Options from Front to Back,* National Academy for State Health Policy (NASHP). (n.d.). *State HCBS Spending: Trend Over Time.* Littler, (2025, June 15), *WA Cares Gets a Makeover: What's Changing in 2026,* Milliman, (*2022), WA Cares Fund Actuarial Study*. Tax Policy Center, (n.d.), A *Tax on Income to Finance Long-Term Care*. PubMed Central (PMC), (2021, December 19), *Reimagining Financing and Payment of Long-Term Care*. California Department of Aging, (August 28, 2024), *Long Term Services and Support (LTSS) Financing Initiative, Overview and Nest Steps,* Massachusetts Executive Office of Health & Human Services, Milliman, *(*April 2025), *Long-Term Services and Supports Feasibility Study* Minnesota Department of Human Service Agency on Disability Service Administration, FTI, ARC, Altarum, (October 2023), *The Own Your Future LTSS Funding and Services Initiative.*

Appendix

Appendix 1
Nursing Home Patient Acuity

This Addendum seeks to address the speculation that there is a sizable number of MedQUEST nursing home resident patients who could be appropriately and cost-effectively diverted to community care settings to yield substantial MedQUEST expenditure savings.

Medicaid "Rebalancing"—Unlikely There Are Significant Numbers of Resident Medicaid Nursing Home Patients Who Do Not Require Institutional Care

To establish a realistic framing context, consider the decades-long Medicaid "rebalancing" policy shift that has fundamentally re-aligned and altered how LTSS is funded and delivered. The rebalancing shift from institutional facility-based care to HCBS care has resulted in HCBS now accounting for the majority of Medicaid LTSS spending nationally since 2013. (From Table 2 of the Primer, we can see that Hawaii still lags with 49.8% of total Medicaid LTSS spending for HCBS.) That shift in patients to HCBS care has not been without significant challenges (as discussed in Primer Addendum 1), including long waiting lists for HCBS placements and persistent workforce shortages for direct care workers.

Accordingly, it is highly likely that most, if not all, patients who might otherwise be marginally qualified for nursing home/intermediate care facility placement (due to relatively lower requisite levels of care) will have been diverted to community care even before admission.

Medicaid Rebalancing History

- Institutional Bias: Medicaid has had an "institutional bias" since its inception in 1965 because it mandated coverage for nursing facility care but made most HCBS services optional. States were required to pay for institutionalization but could limit or refuse to fund care in a person's home or community resulting in a disproportionate amount of spending on nursing homes. As a result, institutional care was often the only viable option for many individuals needing long-term services and supports (LTSS).

- Beneficiary Preference & the False Mythology of Cost Saving: The push for rebalancing was driven by beneficiary preference for receiving care at home, the provision of more person-centered care, as well as growing program cost concerns that sought to contain expenses by shifting care to HCBS—which was seen as less

expensive than institutional care, but actually transfers a substantial portion of the cost burden to unpaid family caregivers as discussed in Addendum 1.

The strong financial cost reduction incentive for Federal and state government is a major reason that it is unlikely there are currently many Medicaid nursing home patients who could otherwise be cared for in community settings.

- **HCBS Waiver Program (Section 1915(c)):** The **Medicaid HCBS waiver program**, authorized under Section 1915(c) of the Social Security Act in was the first major step toward rebalancing. This provision allowed states to "waive" certain Medicaid rules and offer a defined set of HCBS to specific populations as an alternative to institutional care, if the cost was no more than the cost of institutional care. This program gave states a new tool to expand community-based services, but it was limited by strict rules and a requirement for a federal waiver for each program.

- **The *Olmstead* Decision:** The 1999 U.S. Supreme Court decision in ***Olmstead v. L.C.*** held that the unnecessary institutionalization of individuals with disabilities is a form of discrimination under the **Americans with Disabilities Act (ADA)**. The ruling required states to provide services in the **"most integrated setting"** appropriate to an individual's needs, if it is not an undue financial or administrative burden, and the individual does not oppose it. This decision created a legal obligation for states to actively move people out of institutions and into community-based settings.[98]

  Outgrowths of the Olmstead Decision include:

  - **The Money Follows the Person (MFP) Demonstration Program:** Authorized by the Deficit Reduction Act of 2005, provides enhanced federal funding to help states transition Medicaid beneficiaries from institutions—like acute hospitals, nursing homes and psychiatric hospitals—back into the community. The program aims to remove barriers to community living and has **already transitioned tens of thousands of people to HCBS settings**.[99]

    Hawaii "Going Home Plus" (GHP)/CMS Money Follows the Person (MFP) Demonstration Grant[100]: Hawaii's GHP project is an expansion of the original

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[98] *Olmstead v. L.C.*, 527 U.S. 581 (1999).

[99] Deficit Reduction Act of 2005 (P.L. 109-171), Section 6071.

[100] **Hawaii Medicaid "Going Home Plus" Official Page:** https://medquest.hawaii.gov/content/medquest/en/members-applicants/already-covered/going-home-plus.html

"Going Home" project that ran from 2003 to 2007 and aimed to transition patients from acute hospital beds to alternate community residential settings. Beginning in 2007, "Plus" expanded the target population to include patients who were in long-term care facility beds for an extended period (60 or more continuous days) who met MedQUEST nursing home level of care criteria.

Key GHP transition services include a Transition Coordinator who works with the families of transitioned patients to provide:

* Transition coordination
* Housing coordination and locator services
* Moving assistance
* One-time housing transition services (e.g., utility hook-ups, essential furniture, initial food stocks, etc.)
* Ongoing HCBS services such as attendant care, home-delivered meals, private duty nursing, and supportive housing services.

While the original Going Home project appears to have transitioned 838 Med-QUEST beneficiaries between July 2003 and December 2007, no performance report metrics for nursing facility transitions could be found for the Going Home Plus project—despite project operation protocols indicating the intent to conduct evaluations (quarterly and annual CMS reports, various status data collection, etc.). Anecdotal information suggests that there have been only an inconsequential number of GHP nursing home transitions. A fuller picture of program effectiveness and cost savings is needed:

* Number of Med-QUEST nursing home patients transitioned
* The LOC scores of transitioned patients
* A distribution of the annual bundle of HCBS services/per patient and associated costs
* Total Med-QUEST nursing home cost savings resulting from the transition to HCBS
* Estimation of the remaining potential nursing home census eligible for cost-effective transitioning
* HBCS resource shortages affecting transition placements

- The Balancing Incentive Program (BIP): Part of the Affordable Care Act (ACA), the BIP provided states with enhanced federal funding for a limited time to increase their share of LTSS spending on HCBS. States were required to meet

Hawai'i Going Home Plus Operational Protocols: https://medquest.hawaii.gov/content/dam/formsanddocuments/med-quest/going-home-plus/ghp-operational-protocols/D_Evaluation.pdf

specific spending benchmarks and implement key infrastructure reforms, such as creating a **"No Wrong Door/Single Entry Point"** system to streamline access to information about LTSS for consumers.[101]

- **The Community First Choice (CFC) Option:** Authorized under Section 1915(k) of the Social Security Act, the CFC option allows states to offer a wide range of HCBS as a state plan service with a 6-percent point increase in the federal matching rate. This is a notable change because state plan services are generally not subject to the same caps or limitations as HCBS waivers, making them a more robust and permanent alternative.

Given Medicaid's decades long rebalancing push and strong financial drivers for HCBS, it is hard to imagine there are a significant number of current MedQUEST nursing home residents who do not objectively require institutional level of care and could be appropriately and cost effectively diverted to care in a community setting to yield meaningful Medicaid cost savings that can be captured for Hawaii.

Objective Measures of Nursing Home Patient Acuity

There are at least two objective measures of patient acuity we can look at to assess whether the disability level/level of care need for a current Med-QUEST nursing home patient can be appropriately and cost-effectively served in a community care setting: **CMS Minimum Data Set (MDS) 3.0/Patient-Driven Payment Model (PDPM)** and Hawaii Med-QUEST **Form 1147 Level of Care (LOC) Evaluations.**

MDS 3.0/PDPM Nursing Home Patient Condition Assessment[102]

MDS 3.0: The Minimum Data Set (MDS) 3.0 is a standardized patient condition assessment tool used in all Medicare and Medicaid-certified nursing homes. It measures a patient's health status and functional capabilities to ensure they receive appropriate, individualized care. The MDS is a key component of the Resident Assessment Instrument (RAI) and serves multiple purposes, including informing care planning, determining Medicare reimbursement, and monitoring the quality of care provided.

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[101] Affordable Care Act (P.L. 111-148), Sections 10202 and 2401

[102] **MDS 3.0 RAI Manual**: https://www.cms.gov/medicare/quality/nursing-home-improvement/resident-assessment-instrument-manual; **Skilled Nursing Facility (SNF) Prospective Payment System (PPS)**: https://www.cms.gov/medicare/payment/prospective-payment-systems/skilled-nursing-facility-snf. **Patient-Driven Payment Model (PDPM) Technical Report**: https://www.cms.gov/medicare/medicare-fee-for-service-payment/snfpps/downloads/pdpm_technical_report_508.pdf; **American Association of Post-Acute Care Nursing (AAPACN)**: https://www.aapacn.org/
Office of Inspector General (OIG) Reports: https://www.oig.hhs.gov/reports-and-publications/workplan/summary/wp-summary-0000575.asp

Detailed information is captured to provide a holistic picture nursing home resident condition. MDS 3.0 added direct patient interviews to version, MDS 2.0. The key measures of patient condition include:

- Physical and Functional Status: Assesses a resident's ability to perform Activities of Daily Living (ADLs) such as dressing, eating, and personal hygiene. It also assesses mobility, including the ability to walk, transfer, and use a wheelchair.

- Cognitive and Behavioral Status: These measures screen for cognitive impairment, including memory issues and the presence of delirium using tools like the Confusion Assessment Method (CAM). It also evaluates behavioral symptoms and psychosocial functioning, such as mood, anxiety, and social engagement.

- Medical and Clinical Conditions: A resident's active diagnoses, chronic illnesses, and any new or worsening health conditions is documented as well as the specific treatments and therapies they are receiving, like oxygen therapy, dialysis, or physical, occupational, and speech therapy.

- Sensory and Communication Abilities: A resident's vision, hearing, and ability to communicate their needs and understand others is assessed to measure potential barriers to communication and provide effective care.

- Pain and Nutrition: The MDS includes items that directly ask the resident about their experience with pain and pain management and also assesses nutritional status and risks, such as weight loss or dehydration.

MDS 3.0 assessments are conducted by trained nursing home clinicians within 14 days of admission and quarterly for long-stay residents with a more comprehensive annual assessment conducted once a year. When there is a significant decline or improvement in the condition of a patient, a new assessment is triggered.

These assessment data are electronically transmitted to a national database maintained by the Centers for Medicare & Medicaid Services (CMS). The data are used to create Individualized Care Plans and determine facility reimbursements based patient acuity groupings.
PDPM: Effective October 1, 2019, the Centers for Medicare & Medicaid Services (CMS) replaced the RUG-IV system patient acuity grouping methodology with the Patient-Driven Payment Model (PDPM) to establish reimbursement rates based on DMS 3.0 assessment data. This significantly shifted how Medicare reimburses nursing homes, moving away

from a system based on the volume of therapy minutes provided and towards one that focuses on the patient's specific clinical needs.

Key Differences Between PDPM and RUGs

The fundamental difference lies in the payment drivers:

- RUGs: Reimbursement was heavily tied to the amount of therapy minutes a resident received. This created a financial incentive for facilities to provide a high volume of therapy, sometimes regardless of whether it was clinically necessary for the patient.

- PDPM: Payment is determined by a resident's clinical characteristics and care needs. This "patient-driven" model is designed to align reimbursements with the actual costs of caring for a complex patient.

PDPM Classification of Resident Care Needs

PDPM classifies each patient into five different payment component groups, each with its own per diem rate:

- Physical Therapy (PT) and Occupational Therapy (OT): The classification for these components is based on the resident's primary diagnosis and their functional status using specific items from the MDS 3.0 (Section GG).

- Speech-Language Pathology (SLP): This component's classification is based on the resident's primary diagnosis and the presence of certain comorbidities or cognitive impairments.

- Nursing: The nursing component is based on a wide range of factors documented in the MDS, including complex medical conditions, extensive services like ventilator care, and physical or cognitive impairments.

- Non-Therapy Ancillaries (NTA): This component accounts for the cost of supplies, drugs, and services that are not part of the other four categories. It's driven by the presence of specific medical conditions or comorbidities (e.g., chronic kidney disease, HIV/AIDS) that require more resources.

- Non-Case Mix Component: A fixed per diem rate that covers general overhead costs for the facility.

Each of these five groping components has a specific case-mix index (CMI) that is multiplied by a national base rate to determine a portion of the daily payment. These rates are then summed to calculate the total per diem rate for the resident's stay. This model aims to create a more accurate and comprehensive payment system that reflects the total resource needs of the patient, rather than just one aspect of their care.

Limited access

The public facing MDS database is massive with limited access.[103] State level summary reports are not readily available. Direct contact with analysts at the Brown University LTC Focus project have been made to ask for assistance compiling a state level summary of Hawaii nursing home patient acuity.

Med-QUEST Form 1147 Level of Care (LOC) Evaluation

The Level of Care (LOC) Evaluation Form 1147[104] is used by Med-QUEST to assess an individual's need for long-term care services and to determine their eligibility for various Medicaid-funded programs, including nursing facility care, home and community-based services (HCBS), and other forms of long-term support.

Form 1147 is completed by a healthcare professional, physician or Advanced Practice Registered Nurse (APRN), and is a central component of assessing the clinical eligibility criteria for Medicaid long-term care in Hawaii.

LOC Assessment Criteria

Form 1147 provides a detailed snapshot of a person's medical and functional status. It differs from the Federal MDS 3.0 assessment tool in that it is Hawaii state-specific and tailored to Hawaii's long-term care programs.

The form is structured to gather information across several domains:

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[103] Centers for Medicare & Medicaid Services, U.S. Department of Health and Human Services (2025). *Minimum Data Set (MDS) Frequency Data*. CMS MDS Frequency Reports page: https://data.cms.gov/quality-of-care/minimum-data-set-frequency; Facility-Level MDS Frequency Reports: https://data.cms.gov/quality-of-care/facility-level-minimum-data-set-frequency

[104] Hawaii Department of Human Services, Med-QUEST Division. (2023). *DHS 1147 Level of Care (LOC) and At-Risk Evaluation*. https://medquest.hawaii.gov/content/dam/formsanddocuments/provider-forms/1147-level-of-care---at-risk-evaluation/DHS_1147_Form_Rev_06_2023-PRINT.pdf

- Patient Demographics and Background: This section includes basic information such as the patient's name, birthdate, sex, present address, and their attending physician or primary care provider. It also asks about their Medicare and Medicaid eligibility status.

- Medical and Clinical Information: The form requires a list of the patient's significant current diagnoses, both primary and secondary. This provides a medical context for their need for care.

- Functional Status Assessment: This is the core of the LOC assessment. It assesses a person's ability to perform Activities of Daily Living (ADLs) and other daily tasks. This data uses a numerical scoring system to quantify the level of assistance required for each evaluated activity.[105] Key areas include:

    - Mobility: The ability to walk, use a wheelchair, and transfer.

    - Bathing and Grooming: The level of assistance needed for personal hygiene.

    - Dressing: The ability to get dressed with or without help.

    - Eating/Feeding: The level of assistance required with meals.

    - Toileting and Continence: The patient's bowel and bladder function.

- Cognitive and Behavioral Status: This section evaluates a person's mental state. It includes items on:

    - Memory: Assessing for short- and long-term memory impairment.

    - Mental Status/Behavior: Determining if the patient is oriented, disoriented, or exhibits behaviors such as aggression or wandering.

    - Communication: Assessing the ability to communicate needs and wants.

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[105] For example, for Dressing and Personal Grooming:
[0] a. Appropriate and independent dressing, undressing and grooming
[1] b. Can groom/dress self with cueing
[2] c. Physical assistance needed on a regular basis
[3] d. Requires total help in dressing, undressing, and grooming

- Health-Related Services: The form documents the need for specific medical and nursing services, such as medication administration, wound care, and specialized diets. It also assesses the amount of supervision required for these tasks.

- Level of Care Determination: Based on the data collected, the form is used to determine the appropriate level of care, which can include:

    - Adult Residential Care Home (ARCH) Level

    - Intermediate Care Facility (ICF) Level

    - Skilled Nursing Facility (SNF) Level

    - Other long-term care settings (e.g., hospice, expanded adult residential care home)

Purpose and Function[106]

Form 1147 data serves several critical functions:

- Eligibility Determination: The most important use of Form 1147 assessment data is to determine if a patient meets the clinical criteria for a "Nursing Facility Level of Care," which is a prerequisite for receiving Medicaid long-term care benefits in Hawaii. Med-QUEST nursing home patients have been objectively assessed to have levels of impairment that meet clinical requirements for placement and are not there as a matter of circumstance.

  Nursing Facility Level of Care (NF LOC): Individuals assessed as needing nursing facility LOC have medical and functional needs so significant that they require 24-hour skilled nursing care, rehabilitative services, and/or extensive assistance with daily activities that can typically be safely and appropriately provided only in a licensed nursing home.

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[106] Official Form and Technical Guidance: https://medquest.hawaii.gov/content/dam/formsanddocuments/provider-forms/1147-level-of-care---at-risk-evaluation/DHS_1147_Form_Rev_06_2023-PRINT.pdf
Medicaid Long-Term Care Eligibility: https://www.medicaidlongtermcare.org/eligibility/hawaii/
Hawaii Department of Human Services, Med-QUEST Division. (Current Year). *Provider Handbook: Nursing Facility*. https://medquest.hawaii.gov/content/dam/formsanddocuments/plans-and-providers/fee-for-service/Chapter_12_Update%20Final%20V4_L%20kk%20lp.pdf.
Hawaii Department of Human Services, Med-QUEST Division. (Current Year). *Hawaii Administrative Rules: Title 17, Chapter 1717*.

While Medicaid is required to provide nursing home care for those who qualify, waivers can be used to allow persons with nursing facility LOC needs to receive care at home, in an assisted living facility, or in a Community Care Foster Family Home (CCFFH) instead of a nursing home.

"At-Risk" Level of Care (AR LOC): AR LOC is a lower level of need compared to NF LOC. Individuals are considered "at-risk" if they do not yet meet the full criteria for a nursing facility placement but are likely to deteriorate to that level of need without the assistance of long-term services and supports (LTSS).

At risk Individual are typically assessed as needing a significant amount of assistance with Activities of Daily Living (ADLs) or having complex medical conditions. Med-QUEST AR LOC benefits aim to prevent or delay the need for institutional care and often include adult day care, personal care services, and home-delivered meals.

Sub-acute Care: Sub-acute care is a more intensive level of care than NF LOC but less than acute care (e.g., a hospital stay). Sub-acute care patients are medically stable but still require a higher level of skilled nursing and/or rehabilitative services than a standard nursing facility can provide, often requiring short-term, post-hospital stays in a sub-acute hospital unit or specialized section of a nursing home for intensive wound care, IV therapy, and physical therapy.

- Care Planning: The development of individualized care plans based on the assessment of functional and clinical need, whether patients are in a facility or receiving services at home.

- Programmatic Oversight: The Med-QUEST Division uses Form 1147 data to ensure that individuals are placed in the most appropriate and cost-effective care setting that meets their needs. It is also used to monitor ongoing eligibility.

- Regulatory Compliance: The form is used for annual reviews or when a resident's condition undergoes a significant change, ensuring that the level of care and services provided remain appropriate.

Restricted Limited access

There does not appear to be any public facing Form 1147 database and no state level summary reports available from Med-QUEST or other sources. Direct contact with the

Administrator of the Med-QUEST Health Analytics & Information Office has been made to ask for assistance compiling a state level summary of Hawaii nursing home patient acuity.