STATE OF HAWAII **DEPARTMENT OF HEALTH** P. O. BOX 3378 HONOLULU, HI 96801-3378

In reply, please refer to:

December 26, 2019

The Honorable Ronald D. Kouchi, President and Members of the Senate Thirtieth State Legislature State Capitol, Room 409 Honolulu, Hawaii 96813

The Honorable Scott K. Saiki, Speaker and Members of the House of Representatives Thirtieth State Legislature State Capitol, Room 431 Honolulu, Hawaii 96813

Dear President Kouchi, Speaker Saiki, and Members of the Legislature:

For your information and consideration, I am transmitting the Executive Office on Aging, "Annual Report on Elder Programs" for the Governor and the Legislature pursuant to §349-5(b)(2) of the Hawaii Revised Statutes (HRS).

In accordance with Section 93-16, HRS, I am also informing you that the report may be viewed electronically at:

https://health.hawaii.gov/opppd/department-of-health-reports-to-2020-legislature/

Sincerely,

Bruce S. Anderson, Ph.D. Director of Health

Truck anderson

Enclosures

REPORT TO THE THIRTIETH HAWAII STATE LEGISLATURE 2020 SESSION

Executive Office on Aging Annual Report for SFY 2019

IN ACCORDANCE WITH THE PROVISIONS CHAPTER 349-5(b)(2), HAWAII REVISED STATUTES, REQUIRING THE EXECUTIVE OFFICE ON AGING TO PROVIDE AN ANNUAL REPORT ON ELDER PROGRAMS FOR THE GOVERNOR AND THE LEGISLATURE



"E Loa Ke Ola" May Life Be Long

Prepared by Department of Health Executive Office on Aging State of Hawaii

December 2019

EXECUTIVE SUMMARY

The Executive Office on Aging (EOA) is submitting this annual evaluation report on elder programs in accordance with Section 349-5(b)(2), Hawaii Revised Statutes (HRS). The report covers the EOA's activities in State Fiscal Year (SFY) 2019.

In SFY 2019, the EOA received \$11,900,000 from State funds and \$6,729,550 from federal funds for a total of \$18,629,550 in appropriations. The EOA contracted with the county Area Agencies on Aging to procure, manage, and coordinate the delivery of long-term supports and services in their respective counties. State funds were used to support the Kupuna Care and Kupuna Caregiver services: adult day care, attendant care, case management, chore, homemaker, personal care, assisted transportation, KC transportation, and home-delivered meals. Federal funds were used to support family caregiver support services, access services, home and community-based services, and nutrition services. The services reached 8,878 older adults.

In addition to other programs such as the Long-Term Care Ombudsman Program (LTCOP), Hawaii State Health Insurance Program (SHIP), and Senior Medicare Patrol (SMP), the EOA continued to undertake, or initiate, special initiatives such as Hawaii Healthy Aging Partnership (HHAP), Participant Direction (Community Living Program and Veteran-Directed Choice Program (VDC)), No Wrong Door initiative (NWD), and the Hawaii Alzheimer's Disease Supportive Services program (HADSSP).

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Part I. Background Information

A. Statutory Basis, Mission, and Goals

The re-authorization of the 2016 Older Americans Act (OAA) as amended through P.L. 114-144 is to promote the development and implementation of a comprehensive and coordinated state system of long-term services and supports (LTSS) in home or community-based settings to enable older adults and persons with disabilities to live in their homes and communities.

The U.S. Administration on Community Living (ACL) of the U.S. Department of Health and Human Services (DHHS) is charged with implementing the statutory requirements of the OAA. To implement the OAA, the ACL works with the State Unit on Aging (SUA) of each state. The OAA requires the states to designate a SUA to carry out the OAA mission. Chapter 349, Hawaii Revised Statutes (HRS) created the Executive Office on Aging (EOA) to function as the SUA in the State of Hawaii and carry out the responsibilities of an SUA as described in the OAA. Chapter 349, HRS, also created the Policy Advisory Board on Elder Affairs (PABEA) to advise the Director of the EOA.

B. Hawaii State Plan on Aging

The State Plan on Aging describes how the EOA will use federal and State funds to pursue statewide activities related to meeting the needs of Hawaii's older adults and persons with disabilities by developing and fostering a coordinated and accessible system on long-term services and support through strategic community-based partnerships and alliances.

In SFY 2019, the EOA, in collaboration with the Area Agencies on Aging (AAAs) and advocates for older adults and persons with disabilities, developed the Hawaii State Plan on Aging covering the period from October 1, 2019 to September 30, 2023. The State Plan on Aging was approved by the ACL, and implementation began on October 1, 2019.

The 2019 - 2023 State Plan on Aging establishes the following five goals:

Goal 1: Maximize opportunities for older adults to age well, remain active, and enjoy quality lives while engaging in their communities.

Goal 2: Forge partnerships and alliances that will give impetus to meeting Hawaii's greatest challenges of the aging population.

Goal 3: Strengthen the statewide Aging and Disability Resource Center system for persons with disabilities, older adults, and their families.

Goal 4: Enable older adults to live in their communities through the availability of and access to high-quality long-term services and supports, including supports for families and caregivers.

Goal 5: Optimize the health, safety, and independence of Hawaii's older adults.

Part II. State and Federal Funding

In SFY 2019, the total operating budget for the EOA was \$18,629,550. Table 1 shows a breakdown of the source of funding between State (64%) and Federal (36%) monies.

Table 1. EOA's State and Federal Funding for SFY 2019

SOURCE	SFY 2019	PERCENT
State	\$11,900,000	64%
Federal	\$6,729,550	36%
Total	\$18,629,550	100%

Part III. Long-Term Services and Support

A. Aging and Disability Resource Center

Chapter 349-31 of the Hawaii Revised Statutes assigns the EOA the authority to allow each AAA the ability to provide information and access to aging and disability services and supports in their respective counties. Through its Aging and Disability Resource Center (ADRC), the EOA helps older adults, persons with disabilities, and family caregivers find options for long-term supports and services available in the State of Hawaii. The number of contacts decreased by 12.7%; however, the number of registered clients increased by 24.5%.

Table 2. Outcomes of Consumer Contacts with the ADRC (SFY 2018 and SFY 2019)

Outcomes	SFY 2018	SFY 2019
Total Contacts Received by the ADRC*	60,281	52,613
Received an assessment	4,980	4,648
Received at least one service	7,129	8,878

^{*}Contacts include phone calls, emails, and walk-ins.

B. Kupuna Care Program

In SFY 2019, the Hawaii State Legislature appropriated \$8,731,368 for the Kupuna Care Program (KC). To qualify for the KC, the individual must be:

- Sixty (60) years of age or older;
- A citizen of the United States or a qualified alien;
- Not covered by any comparable government or private home and community-based services:
- Not living in a long-term care facility or institution; and
- Has impairments of at least:
 - o Two (2) Activities of Daily Living¹ (ADLs) or
 - o Two (2) Instrumental Activities of Daily Living² (IADLs) or
 - One (1) ADL and one (1) IADL or
 - Substantive cognitive impairment requiring substantial supervision because the individual behaves in a manner that poses a serious health or safety hazard to the individual or another person.

KC monies are allocated to the AAAs using a federally-approved funding formula. KC funds provide for the following nine core home and community-based services (HCBS). The service definitions are based on the Older Americans Act definitions. The service unit for each service is in parentheses:

- Adult Day Care (hour). Personal care for dependent elders in a supervised, protective, and congregate setting during some portion of a day. Services offered in conjunction with adult day care/adult day health typically include social and recreational activities, training, counseling, and services such as rehabilitation, medications assistance and home health aide services for adult day health. "Dependent elders" are individuals 60 years old or older with 2 or more functional impairments (ADLs/IADLs.)
- Attendant Care (hour). The service provides primarily stand-by assistance, supervision or cues, and may include other activities to help maintain the independence of older adults.
- Case Management (hour). Assistance either in the form of access or care coordination in circumstances where the older person is experiencing diminished functioning capacities, personal conditions or other characteristics which require the provision of services by formal service providers or family caregivers. Activities of case management include

¹Impairment in Activities of Daily Living (ADL) --The inability to perform one or more of the following six activities of daily living with personal assistance, stand-by assistance, supervision or cues: eating, dressing, bathing, toileting, transferring in and out of bed/chair, and walking.

²Impairment in Instrumental Activities of Daily Living (IADL) – The inability to perform one or more of the following eight instrumental activities of daily living without personal assistance, or stand-by assistance, supervision or cues: preparing meals, shopping for personal items, medical management, managing money, using telephone, doing heavy housework, doing light housework, and transportation ability (refers to the individual's ability to make use of available transportation without assistance).

such practices as assessing needs, developing care plans, authorizing and coordinating services among providers, and providing follow-up and reassessment, as required.

- *Chore* (hour). Assistance such as heavy housework, yard work or sidewalk maintenance for a person.
- *Homemaker* (hour). Assistance such as preparing meals, shopping for personal items, managing money, using the telephone or doing light housework.
- *Home Delivered Meals* (1 meal). A meal provided to a qualified individual in his/her place of residence. The meal is served in a program administered by the AAAs and meets all of the requirements of the OAA and State/Local laws. (Note: A qualified individual is an individual 60 years old or older who is frail, homebound by reason of illness or incapacitating disability or otherwise isolated, and the spouse of such a person even if younger.)
- Personal Care (hour). Personal assistance, stand-by assistance, supervision or cues.
- Assisted Transportation (one-way trip). Assistance and transportation, including escort, to a person who has difficulties (physical or cognitive) using regular vehicular transportation.
- *KC Transportation* (one-way trip). Transportation from one location to another; may involve a helpful driver. Does not include any other activity.

C. Kupuna Caregivers Program

The Kupuna Caregivers Program (KCGP) is delivered by the Aging and Disability Resource Center (ADRC) of the Area Agencies on Aging (AAAs) and administered by the EOA. In SFY 2019, the EOA was appropriated \$1,200,000 to implement the KCGP. To be eligible, caregivers must be working 30 or more hours a week and be the primary caregiver for a care recipient who qualifies for the Kupuna Care Program. Care recipients were allocated up to \$70 a day for contracted services.

On June 2019, Act 126 was signed into law and appropriated \$1,500,000 to the Kupuna Caregivers Program for SFY 2020. In addition, it required the inclusion of detailed outcomes of the program. The Report on Outcomes of the KCGP, Appendix A, as attached, examines whether the stress levels of working caregivers have increased or decreased as a result of participating in the KCGP and describes the outcomes of the Kupuna Caregivers Program in SFY2019.

Act 126 modified the program funding allocation cap from \$70 a day to \$210 per week, authorized the EOA to adopt administrative rules to implement and administer the program, and required EOA to develop and implement a plan to maximize the number of caregivers served in

the Kupuna Caregivers Program (Appendix B: The State of Hawaii Kupuna Caregivers Program: A Plan to Maximize the Number of Caregivers Served).

Table 3. Kupuna Caregivers Program (SFY 2018 and SFY 2019)

	SFY 2018	SFY 2019
Total Inquiries about the KCGP	2,706	1,018
Number of Working Caregivers served	101	112
Number of Contracted Providers	22	28
State Appropriations	\$600,000	\$1,200,000

D. Title III Older Americans Act Services and Legal Services

In addition to Kupuna Care and Kupuna Caregivers programs, older adults and caregivers may qualify to access other services and supports through the federal Title III funds. Older American Act programs and services represent a significant federal investment in developing a comprehensive, coordinated, and cost-effective system of home and community-based services (HCBS) that enables adults to live independent and healthy lives in their homes and communities. Below are the types of services OAA funds support.

• Title III-B: Supportive Services.

Title III-B funds a broad array of services that enable seniors to remain in their homes for as long as possible. These services include but are not limited to: Access services, such as transportation, case management, and information and assistance; in-home services, such as personal care, chore, and homemaker assistance; and community services such as legal services, mental health services, and adult day care. This program also funds multi-purpose senior centers that coordinate and integrate services for older adults such as congregate meals, community education, health screening, exercise/health promotion programs and transportation.

Legal Services:

- Under Title IIIB of the Older Americans Act, the EOA is mandated to fund the provision of legal assistance through the four (4) Area Agencies on Aging. The purpose of legal assistance is to assist older adults in securing their rights, benefits, and entitlements.
- In April 2019, there was an Elder Abuse Training for First Responders conducted by Paul Greenwood, a retired San Diego Prosecutor with 25 years of experience in elder abuse cases, including physical and financial abuse. There were over 70 attendees including firefighter, public health

nurses, social workers, attorneys, and state employees from the EOA, Department of Commerce and Consumer Affairs, and DHS Adult Protective Services.

- In SFY 2020, the EOA Legal Services Developer will collaborate with the AAAs, the State Long-term Care Ombudsman, legal service providers (i.e. Legal Aid Society of Hawaii, University of Hawaii Elder Law program, etc.) to develop statewide standards for legal services provided to older adults.
- *Title III-C: Nutrition Services*. Congregate nutrition services and home-delivered nutrition services provide meals and related nutrition services to older individuals in a variety of settings including congregate facilities such as senior centers; or by home-delivery to older individuals who are homebound due to illness, disability, or geographic isolation. Services are targeted to those in greatest social and economic need with particular attention to low-income individuals, minority individuals, those in rural communities, those with limited English proficiency and those at risk of institutional care. Nutrition Services Programs help older individuals to remain independent and in their communities.
- *Title III-D: Disease Prevention and Health Promotion Services.* Title III-D of the OAA provides grants to States based on their share of the population aged 60 and over for education and implementation activities that support healthy lifestyles and promote healthy behaviors. Health education reduces the need for more costly medical interventions. Priority is given to serving elders living in medically underserved areas of the State or who are of greatest economic need.
- *Title III-E: National Family Caregiver Support Program (NFCSP)*. The NFCSP offers a range of services to support family caregivers. Under this program, States shall provide five types of services: information to caregivers about available services, assistance to caregivers in gaining access to the services, individual counseling, organization of support groups, and caregiver training, respite care, and supplemental services, on a limited basis.

E. Service Utilization Statewide

This section covers the utilization of state and federally funded services in SFY 2019. Table 4 shows the number of unduplicated persons served, service units delivered and the unit measure. See page 7.

Table 4. Utilization of Services in SFY 2019

SERVICES*	PERSONS SERVED (Unduplicated Count)	UNITS OF SERVICE	MEASURE
Case Management	5,324	30,318	Hours
Assisted Transportation	184	7,577	One-way trips
Transportation	Not Available	89,909	One-way trips
Attendant Care	74	2,840	Hours
Personal Care	827	54,634	Hours
Homemaker	752	23,913	Hours
Adult Day Care	339	187,739	Hours
Chore	82	1,334	Hours
Home Delivered Meals	3,032	462,043	Meals
Congregate Meals	2,779	185,833	Meals
Legal Services	1,536	5,973	Hours
Caregiver Services			
Respite Care	304	54,010	Hours
Counseling/Support Groups/Training	520	3,349	Sessions

^{*}These services are funded with State and/or Federal funds.

Part IV: Other Programs and Special Initiatives

The EOA offered several programs and undertook several special initiatives that enhanced the health, independence, safety, and well-being of older adults in Hawaii, and improved their access to these services. This section describes those programs and special initiatives and their performance in SFY 2019.

Other Programs

1. Long-Term Care Ombudsman Program (LTCOP)

Both federally and state mandated, the LTCOP serves as advocates for residents of nursing homes, adult residential care homes (ARCH), expanded adult residential care homes (E-ARCH), community care foster family homes (CCFFH), and assisted living facilities. There are 1,610 long-term care facilities statewide with 12,661 beds.

In SFY 2019, the LTCOP staff included: 2 full-time Ombudsman and 3 half-time contracted Ombudsmen.

Long-Term Care Ombudsman Volunteer Program

The Long-Term Care Ombudsman Program (LTCOP) is a volunteer-based program utilizing volunteers who are trained and certified to visit residents in licensed or certified nursing homes, care homes, community care foster family homes, and assisted living facilities. Volunteer ombudsman representatives focus on residents' quality of life and quality of care by advocating that their rights be honored and protected. In SFY2019, there were 9 volunteers who provided 1,248 volunteer hours (valued at \$31,737).

Table 5. Accomplishments for LTCOP Program

Activity	SFY 2019
Cases Opened	132 Cases
Cases Closed	125 Cases
Consultations provided to facility staff	2,086 consultations
Consultations provided to individuals	1,991 consultations
Training session hours for 9 LTCOP Volunteers	388 hours
In-service training sessions to facility staff	19 sessions
Guest Speaker for Resident and Family Councils	29 presentations
Community education presentations	72 presentations
Media Interviews	15 interviews

2. Hawaii State Health Insurance Assistance Program (SHIP)

Hawaii SHIP is a federally-funded volunteer-based program helping Hawaii's beneficiaries, their families and caregivers, and soon-to-be retirees with a comprehensive review of plans, benefits and costs. Local Medicare counselors on each island provides unbiased information and one-on-one help at no cost, the service is free.

Table 6. Accomplishments for Hawaii SHIP

Activity	SFY 2019
Medicare Beneficiaries Counseled	2,264 Persons
Outreach - Community Fairs and Exhibits	14,335 Persons
Outreach - Digital, Social, and Print Media	1,420,000 Persons
Help Line and Website Inquiries	3,000+ Contacts

3. Hawaii Medicare Improvements for Patients and Providers Act (MIPPA)

The purpose of the federally-funded MIPPA program is to enhance State efforts to provide application assistance to Medicare beneficiaries who are likely to be eligible for the Low-Income Subsidy (LIS) program, Medicare Savings Program (MSP), or other forms of public assistance. The MIPPA program, in alignment with Hawaii SHIP, focuses on intensified outreach to beneficiaries through statewide and local coalition building involving volunteers, community agencies, non-profit organizations, benefit enrollment centers, and the county Area Agencies on Aging/Aging and Disability Resource Centers (AAA/ADRC).

Table 7. Accomplishments for MIPPA

Activity	SFY 2019
Individual Application Assistance	183 Persons
Outreach - Community Fairs and Exhibits	8,146 Persons
Beneficiaries under 65	26 Persons
Rural Beneficiaries	65 Persons
Native Hawaiian Beneficiaries	28 Persons
Beneficiaries with English as a Second Language	27 Persons

4. Senior Medicare Patrol (SMP)

SMP Hawaii is a federally-funded program that provides local outreach, education, and assistance to Medicare beneficiaries through a trained volunteer workforce. The SMP teaches Medicare beneficiaries to protect their Medicare numbers, to detect billing discrepancies on their quarterly Medicare Summary Notice statements, and to report suspicious activity for further investigation. In addition, the SMP actively disseminates fraud prevention and identification information through the media, outreach campaigns, and community events.

Table 8. Accomplishments for SMP

Activity	SFY 2019
Individual Interactions	156 Persons
Outreach - Community Fairs and Exhibits	10,595 Persons
Public Service Announcements (PSA)	179 PSAs
Kupuna Alert Partner Presentations	284 Participants
Outreach through Media	350,000+ Persons

A. Special Initiatives

1. Hawaii Healthy Aging Partnership

Hawaii Healthy Aging Partnership (HHAP) is a cooperative endeavor by the DOH Diabetes

Prevention and Control Program and the University of Hawaii at Manoa, Office of Public Health Studies to improve the health of Hawaii's kupuna.

In SFY 2019, HHAP did not receive state funding; however, Maui county and Hawaii county provided funding to sustain current HHAP classes in their counties. During SFY 2019, the HHAP Steering Committee had a face-to-face Strategic Planning meeting. The priorities identified for SFY 2020 are marketing, revenue, and partnerships. HHAP is also continuing to work on developing their own website, looking for potential funding opportunities, and expanding partnerships with medical entities.

Table 9. Accomplishments for HHAP

Activity	SFY 2019
EnhanceFitness Program	606 Participants
Living Well with Chronic Conditions Workshops	74 Participants

In June 2019, Act 124 was signed into law which appropriated \$550,000 to fund HHAP activities in SFY 2020.

2. Community Living Program

The Community Living Program (CLP) is a participant-directed program with the same eligibility requirements as the Kupuna Care Program. However, the CLP differs from the Kupuna Care Program, in that the care recipients are their own case manager. To be enrolled in CLP, participants must be willing and able to self-direct their own care which means hiring their own care workers, who may be friends of family members, who will provide care. The care recipient is responsible for explaining the job duties needed to provide the care that is needed and must adhere to a monthly budget and complete required paperwork on a timely basis.

In SFY 2019, a total of 36 qualified individuals were enrolled in the CLP statewide.

3. Veteran-Directed Choice Program

The Veteran-Directed Choice Program (VDC) program is a participant-directed program administered by the Veteran's Administration (VA) for eligible veterans of all ages. The VDC participants must have a functional level that makes them eligible for nursing home placement. The VDC allows veterans to control the care they receive, the provider of their care, and the quality of their care, rather than being dependent on a VA facility or community facility that is reimbursed by the VA for their care.

In SFY 2019, a total of 48 veterans were referred to EOA and are receiving VDC services.

4. No Wrong Door (NWD) Initiative

The "Doors" of the *No Wrong Door Initiative* are State and County agencies that provide long-term services and supports. The Hawaii NWD implementation grant seeks to: (1) expand the ADRC to incorporate a NWD network that enables older persons and persons with a disability to access all publicly-funded LTSS; and (2) build an infrastructure to offer all individuals Person-Centered (PC) counseling. Under the NWD system, the Doors collaborate and coordinate with each other to streamline older persons and persons with disabilities access to LTSS options by creating a single, standardized entry process.

In SFY 2019, an online referral tool was developed to help the Doors streamline referrals to each other. The referral tool also notifies the agency who initiated the referral when the referral was worked on by the receiving agency.

In July 2019, Act 89 was signed into law which established a special fund within the EOA to receive reimbursements from Medicaid for activities conducted by the Aging and Disability Resource Center (ADRC) that supports eligibility, intake, and referral. This special fund will enable EOA to have quicker access to funds received from the Center for Medicare and Medicaid and in turn EOA will be able to distribute it to ADRC sites statewide.

In SFY 2020, the EOA is currently working with Med-QUEST, the state Medicaid office, to finalize and submit the paperwork to the Center for Medicare and Medicaid Services (CMS) for federal financial participation (FFP).

5. Hawaii Alzheimer's Disease Supportive Services Program Grant

EOA is in the third year of a three-year grant award from the ACL for the Hawaii Alzheimer's Disease Supportive Services Program (HADSSP): Creating and Sustaining Dementia-Capable Services System. The goals of this project are to: 1) build and sustain dementia-capability within the NWD Network; and 2) provide better access to services for persons with dementia and their caregivers.

In SFY 2019, statewide dementia capability training was conducted by Dr. Ritabelle Fernandes; the Care Transitions model was piloted at Straub Medical Center; and trainings for caregivers for persons with dementia were taught by Dr. Poki'i Balaz and Dr. Lucas Morgan.

In June 2019, Act 127 was signed into law and appropriated funds to EOA to fund the Alzheimer's Disease and Related Dementias (ADRD) Services Coordinator. The ADRD Services Coordinator will update the *Hawaii 2025: State Plan for Alzheimer's Disease and Related Dementias* and coordinate the various projects that have been established since the Hawaii 2025 State Plan was written in 2013. Due to a technicality, the monies in the first year will be contracted to the UH to perform the updating and coordination.

In SFY 2020, the EOA was awarded an Alzheimer's Disease Program Initiative (ADPI) expansion grant. This grant will expand on some of the activities in the HADSSP grant. Specifically, the ADPI grant will enable EOA to: 1) extend dementia capability training to Community Health Workers (CHW); 2) enhance dementia care transitions within Queen's Medical Center and integrate CHWs and homeless providers in the transition and support of homeless individuals with dementia; and 3) expand the availability of a culturally tailored Savvy Caregiver program in Hawaii's rural communities.

6. EOA Disability Initiatives

The EOA Disability Specialist (DS) provides training, technical assistance, and participates on boards and committees to advocate for the needs of older adults and individuals with disabilities. The AAAs can request training and technical assistance from the DS to better serve and support older adults and those with disabilities, and their family members.

In SFY 2019, the DS became a co-chair of a committee that is looking at the implementation of ABLE Account. An ABLE Account is like a 529 college savings account designed for the needs of individuals with disabilities and their families. It allows an individual with disabilities or their family to save money to pay for their costs of living. The DS, through the EOA, will be working with other members of the Council to provide technical assistance and training to interested individuals.

In SFY 2020, the EOA and DS are planning to review and update its language access plan and provide at least 4 trainings to ADRCs in the areas of customer service, how to communicate effectively with individuals with disabilities, and resource awareness.

APPENDIX A

Kupuna Caregivers Program (KCGP) Report on the Outcomes of the KCGP (SFY 2019)

as required by Act 126 (2019 Legislative Session, SB1025, SD1, HD2)

Introduction

In July 2017 Governor David Ige signed into law the Kupuna Caregivers Program (*Act 102, 2017 Legislative Session*). The purpose of Act 102 was for the Executive Office on Aging (EOA) to establish and implement the Kupuna Caregivers Program (KCGP). The purpose of the KCGP is to assist employed caregivers to remain in the workforce. In SFY 2017, the legislature appropriated \$600,000 in State funds; then in SFY 2018 and 2019, \$1.2 million dollars and \$1.5 million dollars, respectively.

As mentioned in Act 102 and Act 126, caregivers often experience high levels of stress and care recipients worry that they will become a burden on their family members. To measure this, the EOA, in partnership with the county Area Agencies (AAA) on Aging implemented a scale to measure caregiver burden. This report examines the effects of the KCGP program on caregiver burden for State Fiscal Year 2019.

Description of the Kupuna Caregivers Program (KCGP)

The KCGP is administered by the EOA through the county Area Agencies on Aging (AAA). The EOA, an attached agency to the Department of Health, receives both Federal and State funds. The EOA then contracts with the county Area Agencies on Aging to procure, manage, and coordinate the delivery of long-term supports and services in their respective counties. The KCGP monies appropriated by the Hawaii State Legislature were used to pay for only KCGP services. Program administrative and operational expenses are not included in KCGP appropriation by the legislature.

To be eligible for the KCGP, the caregiver must have verified employment of 30 or more hours per week and their care recipient must be eligible to receive Kupuna Care services.³ Once eligibility is met, two standardized assessment tools are administered: 1) An assessment to determine the care recipient's need for long-term services and supports, and 2) An assessment to determine the caregiver's burden score. The assessment responses are self-

¹Kupuna Care Program eligibility: A citizen of the United States or a qualified alien; sixty (60) years of age or older; not covered by any comparable government or private home and community-based care service, except for kupuna care services; not residing in a long-term care facility. Participant must also have impairments of at least:2 activities of daily living (ADLs); or 2 instrumental activities of daily living (IADLSs); or 1 activity of daily living and 1 instrumental activity of daily living; or substantive cognitive impairment such as Alzheimer's Disease or related dementias and requiring substantial supervision.

reported; therefore, the data received are subjective and not based on clinical assessments.

The care recipients of working caregivers who qualify for the KCGP are eligible to receive the following services: adult day care, assisted transportation, chore service, home delivered meals, homemaker services, personal care, respite care, and transportation.

KCGP Caregiver Data

1. Demographics

There were 112 active working KCGP caregivers in State Fiscal Year 2019. Table 1 indicates that a majority (44.6%) of the working caregivers participating in the KCGP are in the age 45 to 60 age group, with the average age of the caregiver being 57 years old. There is also a large number of working caregivers (38.4%) that are 60 years and over. This phenomenon of seniors caring for seniors while still employed is an area of interest for the EOA and the State.

Table 1. Characteristics of Kupuna Caregiver Program Caregivers
State Fiscal Year 2019
N=112

KCGP CAREGIVER CHARACTERISTICS	PERCENT	NUMBER
Age Group		
< 45 Years Old	9.8%	11
45 to 60 Years Old	44.6%	50
60 and Older	38.4%	43
Unknown/Missing	7.1%	8
Gender		
Male	23.2%	26
Female	76.8%	86
Race/Ethnicity		
Japanese	47.3%	53
Part Hawaiian	14.3%	16
Filipino	8.0%	9
White	8.9%	10
Other	4.5%	5
Unknown/Missing	17.0%	19
Living Arrangements		
Lives with Care Recipient	69.6%	78
Sometimes lives with Care Recipient	1.8%	2
Does not live with Care Recipient	15.2%	17
Unknown/Missing	13.4%	15

2. KCGP Caregiver Caregiving Responsibilities

During the assessments of the caregivers, the amount of time KCGP caregivers spent on caregiving was documented. About 78% of caregivers provided at least 20 hours of caregiving per week (See **Table 2**). At the time of their KCGP application, approximately 40% of the caregivers were caregiving for 5 or more years; of which, 64% of these were the only caregiver for their care recipient. In contrast, approximately 45% of KCGP caregivers that provided less than 5 years of caregiving were the sole caregiver.

Table 2. KCGP Caregivers Caregiving ResponsibilitiesState Fiscal Year 2019

N=112

CAREGIVING RESPONSIBILITIES	PERCENT	NUMBER
Length of Caregiving		
Less than 7 months	1.8%	2
7 months – 1 year	6.3%	7
13 months – 2 years	13.4%	15
25 months – 5 years	25.9%	29
More than 5 years	40.2%	45
Missing	12.5%	14
Hours Caregiving during the Past Week		
0 – 19 hours	8.9%	10
20 – 40 hours	26.8%	30
More than 40 hours	51.8%	58
Missing	12.5%	14
Caregiving Support		
Receive support	47.3%	53
Does not receive support	40.2%	45
Missing	12.5%	14

Evaluation of Caregiver Burden Among KCGP Caregivers

The Montgomery Borgatta Caregiver Burden Scale (MB) was administered to KCGP caregivers to assess the effects of caregiving on their lives (Montgomery, 2006). The MB is a valid and reliable tool that measures the following three (3) types of caregiver burden:

1) **Objective Burden** is defined as the extent in which caregiving tasks interfere with a caregiver's life, such as caregivers who no longer have time for recreational activities since their free time is occupied by caregiving duties.

- 2) **Demand Burden** is defined as the extent to which the caregiver perceives caregiving tasks to be overly demanding such as feelings of being taken advantage of by the care recipient.
- 3) **Stress Burden** is defined as the emotional impact of caregiving responsibilities on the caregiver, such as the caregiver feeling that caregiving makes them anxious or depressed.

A reference burden value was determined for each of the three types of caregiver burden. Burden scores greater than the reference value indicates the caregiver needs more supportive services. Low caregiver burden scores indicate the caregiver can simultaneously take care of their care recipient and themselves. (Montgomery 2006).

The t-test for paired samples was conducted to determine if the differences between the initial and follow-up assessment caregiver burden scores were statistically significant at the .05 level. In other words, if the KCGP program decreases the care burden for caregivers.

During the state fiscal year 2019, 80 KCGP caregivers received an initial assessment, a KCGP service, and a follow-up assessment. In general, KCGP caregivers were given the follow-up assessment between 6 months to a year after the initial assessment was administered. However, not all SFY 2019 KCGP caregivers were given a follow-up assessment because some caregivers were in the process of scheduling their follow-up assessments, while others had a care recipient who no longer qualified for the KCGP (i.e., death, placed in a care facility, or moved).

Table 3 shows the comparison of KCGP caregivers burden scores to the Montgomery Borgatta Caregiver burden reference value. On the follow-up assessments, the Objective burden and Stress burden scores were lower, indicating that the KCGP services received by the care recipients may have lessened the burden on their caregivers. The Demand burden score was not significant, so we do not know if the KCGP influenced the caregiver's perception of their relationship with their care recipient (i.e., does the caregiver feel that the care recipient is overly demanding).

Table 3. Initial and Follow-up Assessments Among KCGP Caregivers using the Montgomery Borgatta Caregiver Burden Tool SFY 2019

Montgomery Borgatta	MB	ASSI	ESSMENT
Caregiver Burden (MB)	Reference High Value	INITIAL	FOLLOW-UP
Objective ¹ (n=79)	>23.0	24.5	20.5
Demand (n=79)	>15.0	12.4	12.5
Stress ¹ (n=80)	>13.5	14.9	13.5

Differences between the initial and follow-up burden scores are statistically significant at the .05 level.

Other Factors that May Affect Caregiver Burden

Two other factors, 1) the amount of time caregiving, and 2) the average number of hours per week a KCGP caregiver provided care for a specific care recipient, were examined to determine if KCGP services helped reduce caregiver burden.

Amount of Time Caregiving

Table 4 shows the effects that the amount of time spent caregiving had on the KCGP caregivers. The length of time was divided into three groups: 1) KCGP caregivers who have been caregiving for the care recipient for less than 2 years; 2) KCGP caregivers who have been caregiving for the care recipient between 2 years and 5 years; and 3) KCGP caregivers who have been providing caregiving for over 5 years. A majority of the KCGP caregivers (53.8%) had more than 5 years of caregiving, followed by KCGP caregivers with 2 years to 5 years of caregiving (31.3%) and finally, KCGP caregivers with less than 2 years (15%).

The sample sizes of the KCGP caregivers were small, so many of the differences between the care burden scores from the initial assessment to follow-up assessment (after a service was received) were not significant. However, three caregiving burden scores were significant. The Objective Burden decreased for KCGP caregivers providing over 2 years of caregiving thereby increasing their perceptions that they can now spend more time on activities of their choice. In addition, among KCGP caregivers with over 5 years of caregiving, the Stress burden showed a slight decrease in their emotional impact toward caregiving indicating that they were less stressed after receiving services for their care recipient.

Table 4. Length of Time Caregiving Among KCGP Caregivers using the Montgomery Borgatta Caregiver Burden Tool SFY 2019

Longth of Time	MB	ASSES	SMENT
Length of Time Caregiving	Reference Value	INITIAL	FOLLOW- UP
Less than 2 years			
Objective (n=12)	>23.0	22.6	19.4
Demand (n=11)	>15.0	11.5	11.4
Stress (n=12)	>13.5	12.8	12.0
2 years to 5 years			
Objective ¹ (n=24)	>23.0	24.3	20.1
Demand (n=25)	>15.0	11.8	12.9
Stress (n=25)	>13.5	14.8	13.7
More than 5 years			
Objective ¹ (n=43)	>23.0	25.1	21.0
Demand (n=43)	>15.0	12.9	12.5
Stress ¹ (n=43)	>13.5	15.6	13.8

¹ Differences between the initial and follow-up burden scores are statistically significant at the .05 level.

Average Hours a Week Caregiving

The average hours of caregiving a week, based on a 7-day, 24 hour a week, was divided into three groups: 1) Less than 20 hours; 2) 20 to 40 hours a week; and 3) More than 40 hours a week. Most of the caregivers (68.8%) averaged over 40 hour a week caregiving, followed by caregivers providing care for 20 hours to 40 hours a week (22.5%), and caregivers providing care for less than 20 hours a week (8.8%).

The sample sizes of caregivers were small, so many of the caregiver burden scores did not significantly change from the first initial assessment to follow-up assessment (after a KCGP service was received). However, two caregiver burden scores were significant. As shown in Table 5, those KCGP caregivers with over 40 hours of week caregiving showed a significant decrease in the Objective burden which indicates that when someone else delivers support services to their care recipient, the KCGP caregiver does experience less caregiver burden. In turn, the Stress burden score did decrease for the KCGP caregiver.

Table 5. Average Hours a Week of Caregiving Among KCGP Caregivers using the Montgomery Borgatta Caregiver Burden Tool

SFY 2019

Aviana a Hanna a Wash	MB	ASSES	SSMENT
Average Hours a Week Caregiving	Reference Value	INITIAL	FOLLOW- UP
Less than 20 hours a week			
Objective (n=7)	>23.0	18.1	16.9
Demand (n=7)	>15.0	10.6	10.7
Stress (n=7)	>13.5	12.6	12.0
20 to 40 hours a week			
Objective (n=18)	>23.0	25.0	21.7
Demand (n=18)	>15.0	12.9	13.6
Stress (n=18)	>13.5	15.2	15.0
Over 40 hours a week			
Objective ¹ (n=54)	>23.0	25.2	20.6
Demand (n=55)	>15.0	12.4	12.3
Stress ¹ (n=55)	>13.5	15.1	13.2

¹ Differences between the initial and follow-up burden subscale means are statistically significant at the .05 level.

A. DISCUSSION

The State Fiscal Year 2019 was the first year of complete data for KCGP caregivers. Though the sample size was small (n=80), the results show that KCGP caregivers do perceive less caregiver

burden after receiving a KCGP service. The Objective burden, the disruption of caregiving created in the caregiver's life, was found to have significantly decreased the most. The Stress burden which measures the emotional impact of caregiving also decreased significantly. However, the Demand burden, the extent which the caregiver perceives care responsibilities to be over demanding, did not show a significant change in the caregiver burden scores from their initial to follow up assessments.

B. CONCLUSION OF CAREGIVER BURDEN

The data presented shows a snapshot of the status of the KCGP caregiver's burden. Though the results show the caregiver burden has lessen, the EOA will continue to monitor the KCGP caregivers as more follow-up assessments are completed.

C. BREAKDOWN OF INDIVIDUALS SERVED

The number of caregivers and care recipients served by county during the state fiscal year 2019 is reflected in Table 6. In addition, the services provided to the caregivers by county during the same time period is outlined below. Care coordination and case management is provided by the Aging and Disability Resource Center in each county.

Table 6. Number of Caregivers and Care Recipients Served by County

KCGP SFY 2019

Unduplicated Served	EAD	НСОА	KAEA	MCOA	TOTAL
Caregivers (unduplicated count)	72	13	8	19	112
Care Recipients (unduplicated					
count)	74	13	8	19	114

	PERSONS SERVED IN STATE FISCAL YEAR 2019				
KCGP Serviced Provided	EAD	НСОА	KAEA	MCOA	TOTAL
Care Coordination or Case Management	74	0	8	17	99
Adult Day Care	74	4	8	19	105
Assisted Transportation	0	3	0	0	3
Chore	0	1	0	0	1
Home-Delivered Meals	5	0	2	1	8
Homemaker	0	8	2	0	10
Personal Care	1	4	0	7	12
Respite Care	0	0	0	3	3
Transportation	4	0	5	0	9

D. NUMBER OF SERVICE PROVIDERS

Table 7 reflect the unintended consequence of the Kupuna Caregivers Program which is the increase in the number of service providers, specifically in the City and County of Honolulu, who are contracted providers of the Elderly Affairs Division. Statewide a total of 28 service providers delivered services for the KCGP. Of the 28 service providers, 50% were new providers because of the KCGP. The County of Kauai and the City and County of Honolulu utilize Kupuna Care wrap around services to address the long-term services and supports needs of the caregiver.

Table 7: Kupuna Caregivers Service Providers by County in SFY2019

	KUPU	NA CAREGIVERS Service P	roviders by service and county in	SFY 2019
SERVICES	EAD	HCOA	KAEA	MCOA
Adult Day Care	Palolo Chinese Home	Hawaii Island Adult Care		Maui Adult Day Care
	Live Well Center (run by	Ho'onani Place		Na Pu'uwai
	Windward Senior Day Ca			
	Franciscan Care-Ewa			
	Franciscan Care-Manoa			
	Franciscan Care-			
	Diamond Head			
	Hale Hauoli			
	Seagull Schools			
	Malama			
	Lunalilo			
Adult Health & Day Care	Salvation Army		Kauai Adult Day Health Center	
	Central Union (run by Ar	cadia)		
	Maluhia			
	Leahi			
Assisted Transportation		Maxi Care Link		
·		Master Care		
		Metro Care		
		Seniors Helping Seniors		
		Ultimacare		
Chore		Maxi Care Link		Hale Mahaolu
		Master Care		
		Metro Care		
		Senior Helping Senior		
		Ultimacare		
Homemaker		Maxi Care Link		Hale Mahaolu
		Master Care		Ho'okele Caregivers Maui
		Metro Care		Na Hoaloha
		Seniors Helping Seniors		
		Ultimacare		
Personal Care		Maxi Care Link		CareResource
		Master Care		Hale Mahaolu
		Metro Care		Ho'okele Caregivers Maui
		Seniors Helping Seniors		Maui Adult Day Care
		Ultimacare		,
In-Home Respite				Hale Mahaolu
•				Ho'okele Caregivers Maui
				Na Hoaloha
Home Delivered Meals				Mom's Meals

E. WAITLIST INFORMATION

The waitlist information (**Table 8**) reflects the waitlisted services of the Kupuna Caregivers Program. The caregivers waitlisted for services is specific to the County of Kauai and the City and County of Honolulu.

Table 8: Caregivers Waitlists by KCGP Services per County

	PERSONS SERVED IN STATE FISCAL YEAR 2019				
WAITHET BY VCCD CEDVICE	- FAD	LICOA	1/A F A	NACOA	TOTAL by
WAITLIST BY KCGP SERVICES Care Coordination or Case	EAD	НСОА	KAEA	MCOA	service
Management	0	0	3	0	3
Adult Day Care	25	0	0	0	25
Assisted Transportation	0	0	0	0	0
Chore	0	0	0	0	0
Home-Delivered Meals	0	0	0	0	0
Homemaker	0	0	0	0	0
Personal Care	0	0	0	0	0
Respite Care	0	0	0	0	0
Transportation	0	0	0	0	0

F. CONCLUSIONS

The Kupuna Caregivers Program is in its infancy. The Executive Office on Aging, the Area Agencies on Aging, and the service providers need to continue to monitor and evaluate the effectiveness and sustainability of this program.

Appendix B reflects the Plan developed to serve more caregivers in SFY2020.

References:

Montgomery, R. J. V. (2006). "Using and Interpreting the Montgomery Borgatta Caregiver Burden Scale". Retrieved from http://www4.uwm.edu/hbssw/PDF/Burden20Scale.pdf

Savundranayagam, Marie Y. (2010). "A Dimensional Analysis of Caregiver Burden Among Spouses and Adult Children". https://academic.oup.com/gerontologist/article -abstract/51/3/321/559666

Appendix B

Kupuna Caregivers Program

A Plan to Maximize the Number of Caregivers Served

Kupuna Caregivers Program A Plan to Maximize the Number of Caregivers Served

as required by Act 126 (2019 Legislative Session, SB1025, SD1, HD2)

Background of the Kupuna Caregivers Program

The Kupuna Caregivers Program (KCGP) was established on July 6, 2017 by the enactment of ACT 102.

The purpose of Act 102 was for the Executive Office on Aging (EOA) to ensure that working caregivers remain in the workforce by providing additional resources to cover a variety of support services to qualified kupuna. The KCGP allows caregivers to continue to earn their own retirement benefits and helps businesses retain experienced workers. The program also provides peace of mind to the caregiver that their loved one is being cared for while they are working.

In SFY 2017, the legislature appropriated \$600,00 in State funds for the KCGP and then in SFY 2018, \$1.2 million dollars was appropriated.

Enactment of Act 126

In June 2019, Governor Ige signed into law *Act 126*, requiring the EOA to: 1) include in its annual report to the legislature a section detailing the outcomes of the KCGP (see EOA annual report HSL 2019); 2) develop and implement a plan to maximize the number of caregivers served by the program; 3) include additional services to be provided by the KCGP; and 4) appropriate funds for the implementation of the KCGP. Act 126 provided funding for the program in the amount of \$1.5 million dollars, an increase of \$300,000 from the previous state fiscal year. In addition, Act 126 amended the allocation of funds to cover costs for services that would normally be paid for by qualified caregivers from a maximum of \$70 a day to \$210 per week.

Administration of the Kupuna Caregiver Program

The KCGP is administered by the EOA through the county Area Agencies on Aging (AAA) who are the operating entities of the Aging and Disability Resource Center (ADRC).

Eligibility Requirements for the Kupuna Caregivers Program

- A Qualified Caregiver:
 - o Provides care for a care recipient;
 - o Is employed at least thirty hours per week by one or more employers

- A Care Recipient must be:
 - o A citizen of the United States or a qualified alien;
 - o Sixty (60) years of age or older;
 - Not covered by any comparable government or private home and community-based care service, <u>except</u> for kupuna care services;
 - o Not residing in a long-term care facility; and
 - o Has impairments of at least:
 - Two activities of daily living (ADLs); or
 - Two instrumental activities of daily living (IADLs); or
 - One activity of daily living and one instrumental activity of daily living; or
 - Substantive cognitive impairment such as Alzheimer's Disease or related dementias and requiring substantial supervision.

Assistance Provided

Many caregivers who qualify for the KCGP require long-term services and supports for their kupuna. Based on a holistic assessment of need, a qualified caregiver may receive up to \$210 per week of home and community-based services (subject to the availability of funds, paid directly to contracted providers, and not to the caregiver) to cover the costs for one, or more of the following services that are provided by the AAAs:

- Adult Day Care
- o Care Coordination or Case Management
- o Chore
- o Home-delivered Meals
- Homemaker
- o Personal care
- Respite care
- o Transportation and assisted transportation

Plan to Maximize the Number of Caregivers Served

Act 126 amended Section 349-18 HRS requiring EOA to "develop and implement a plan to maximize the number of caregivers served by the program."

EOA, in coordination with the AAAs, identified five components necessary to maximize the number of caregivers served in the KCGP.

These components include:

- 1) Education and Outreach
- 2) Eligibility
- 3) Targeted Criteria for Long-term Services and Supports
- 4) Program Development (partnerships, resources, etc.)
- 5) Evaluation

1. Education and Outreach

Education and outreach provide working caregivers of older adults a better understanding of the mission and purpose of the KCGP and reduces barriers and expands access to the KCGP.

Objective 1-1: Provide education and outreach to working caregivers to ensure a better understanding of the mission and purpose of the KCGP.

Strategy 1-1:1: Develop outreach strategies to address the needs diverse populations, which include but are not limited to caregivers, employers, community organizations, ethnic organizations, health professionals, churches and temples. Utilize communication venues through printed materials, newspapers, television stations, radio stations, that are translated in different languages.

Objective 1-2: Provide education and outreach to reduce barriers and expand access to the KCGP.

Strategy 1-2:1: Educate caregivers and their kupuna to navigate and access long-term services and supports to address their needs in a comprehensive and holistic manner.

Strategy 1-2:2: Target working caregivers who are currently employed in industries, occupations, and positions that have salaries at, or below the median income level, and employed at least 30 hours a week by one or more employers.

2. Eligibility

Development of standard eligibility criteria improves program efficiency, ensures program consistency and minimizes eligibility decisions based upon subjectivity.

Objective 2-1: Improve program efficiency and consistency through the redesign of the standardized eligibility criteria.

Strategy 2-1:1: Review and monitor intake and assistance to ensure timeliness of the eligibility process for caregivers in accessing the KCGP.

Strategy 2-1:2: Evaluate current procedures to improve the KCGP.

Strategy 2-1:3: Assess and streamline the eligibility and employment verification process of the caregiver to improve program efficiency.

3. Targeted Criteria for Long-Term Services and Supports

The EOA is guided by the 2016 Older Americans Act (OAA) Reauthorization Act (P.L. 114-144) and the Hawaii Revised Statutes (HRS), Chapter 349. The OAA states that

while program and services are open to all adults, age 60 and older, the Act contains numerous requirements that limited program and service resources to be targeted specifically to those of greatest economic or social need.⁴ In addition, the OAA, Section 315(b)(3) does not allow the AAAs or service providers to "means test". Means testing is defined as an examination into the financial state of a person to determine eligibility for public assistance.

Objective 3-1: Ensure that the program targets the limited resources of the KCGP, with a focus on caregivers with the greatest economic need (GEN)⁵ and who has a caregiver burden score that requires intervention.

Strategy 3-1:1: After a caregiver and their care recipient has been deemed eligible, EOA shall implement thru the AAA, the following targeting criteria to prioritize who may receive KCGP services and supports*:

(a) Caregiver

- (1) Caregiver Financial Status Target caregivers in the following tiered priority. Caregivers of GEN will be given first priority. Caregivers with low income will be given second priority. Caregivers of median income will be given third priority.
- (2) Caregiver Burden Scale: The Montgomery Borgatta Caregiver Burden Scale is an evidence-based tool used to assess the effects of caregiving on the lives of the KCGP applicants. ⁶

(b) Care Recipient

- (1) Care Recipient Financial Status Care recipients with "greatest economic need" will be given first priority.
- (2) Cognitive impairment and diagnosis of Alzheimer's disease or related dementia.
- (3) Deficits in ADLs/IADLs. Care recipients with higher deficits of ADLs and IADLs will be given higher priority
- (4) At risk of placement in a long-term care facility.

⁴ National Center on Law & Elder Rights, "Targeting Older Americans Act Services Without Means Testing: Meeting the Challenge", Issue Brief, January 2018 (Adapted from the Best Practice Notes by The Center for Social Gerontology, Inc., Vol. 15, Nos. 1 & 2 (July 2013)).

⁵ GEN is defined as the need resulting from an income level at or below the poverty line.

⁶ The burden scale consists of three subscales—objective, demand, and stress burden. The objective burden subscale measures the perceived infringement or disruption of caregiving on the caregiver's life, the demand burden subscale measures the extent to which the caregiver feels the care responsibilities are unreasonable and excessive, and the stress burden subscale measures the emotional impact of caregiving on the caregiver.

4. Program development:

Development of a program that focuses on supporting the working caregiver.

Objective 4-1: Provide eligible KCGP working caregivers with the support services needed by their kupuna to retain their employment of at least thirty hours per week by one or more employers, earn their own retirement benefits, and help their employers retain experienced workers.

Strategy 4-1:1: Explore ways to increase the number of service providers and their workforce capacity.

Strategy 4-1:2: Assess the types of resources, services and supports, and other forms of supports that are needed by the caregivers and care recipients.

Strategy 4-1:3: Research actual costs of providing services (staffing, case managers, etc.) needed by the caregivers and care recipients.

Strategy 4-1:4: Develop partnerships with businesses to promote investment in supporting employees that are caregivers.

Strategy 4-1:5: Ensure through the care coordination or case management, that LTSS identified in the care recipient's support plan are provided.

5. Evaluation:

Objective 5-1: On an annual basis, the EOA will evaluate the overall effectiveness of the KCGP.

Strategy 5-1:1: Assess the current data that is being collected on the KCGP at both the programmatic and individual levels. Data may include, but not be limited to, applicants that did not receive services (i.e. denied, waitlisted, no longer qualified, etc.), reasons for denials, follow-up with those denied to assess outcome of denial, health outcomes of those who received KCGP services, employment outcomes of caregivers participating in KCGP, referrals provided to caregivers for additional services, etc.

Strategy 5-1:2: Ensure AAAs update data (e.g. disclosure of changes to financial status of caregiver, type(s) of services provided, etc.) as needed.

Strategy 5-1:3: Identify any additional data that needs to be collected as well as any data that is currently being collected that is not needed.

Strategy 5-1:4: Develop a KCGP monitoring plan by developing outcome measures and performance measures for the KCGP.

Strategy 5-1:5: Develop strategies to evaluate the overall effectiveness and sustainability of the KCGP.

<u>Public Feedback Period (October 2019 – December 2019)</u>

From the time between October 2019 – December 2019, the plan set forth in this report was presented to the EOA Policy Advisory Board for Elder Affairs, the Kauai Committee on Aging,

the Honolulu Committee on Aging, Hawaii County Office of Aging (HCOA) Committee on Aging, the Board of AARP, Caring Across Generations, Maui Service Providers, and Hawaii County Committee of Aging. EOA solicited feedback from other stakeholders and community partner on the strategies outlined in this plan. The feedback period was open from November 19, 2019 thru December 6, 2019 to allow time for review and comments.

Comments were received from caregivers of older adults, service providers, and nonprofit organizations. After the public comment period ended, EOA in coordination with the AAAs reviewed the feedback, comments, and recommendations. EOA will then review and decide on items to be incorporated in the EOA final plan to maximize the number of Kupuna caregivers.

In addition, changes to the program that result from this plan shall influence the necessary changes to the guidelines. The revised guidelines will be included in the contract modifications with the AAAs.

Finally, the "Plan to Maximize the Number of Caregivers Served by KCGP" is only a part of ACT 126 requirements. Act 126 also requires EOA to include in its annual report to the Legislature a section detailing outcomes of the kupuna caregivers' program. The 2020 Annual Report to the State Legislature shall include the outcomes from SFY2019 and is attached as Appendix A.

APPENDIX C

Alzheimer's Disease and Related Dementias State Plan Report

as required by Act 146 (2018 Legislative Session, HB1916, HD2, SD2, CD1)

In 2013, Hawaii's State Executive Office on Aging (EOA, Hawaii's State Unit on Aging) published the Hawaii 2025: State Plan on Alzheimer's Disease and Related Dementias (ADRD). Implementation of the ADRD State Plan is based on a framework of **dementia capability**. A model described by the Administration on Community Living (ACL) and research on dementia progression and supportive services, states that **a dementia capable system would:**

- 1) Educate the public about brain health. This would include information about the risk factors associated with developing dementia, first signs of cognitive problems, management of symptoms if individuals have dementia, support programs, and opportunities to participate in research.
- 2) Identify people with possible dementia and recommend that they see a physician for a timely, accurate diagnosis and to rule out reversible causes of dementia or conditions that resemble it.
- 3) Ensure that program eligibility and resource allocation consider the impact of cognitive disabilities.
- 4) Ensure that staff communicate effectively with people with dementia and their caregivers and provide services that:
 - a) Are person- and family-centered
 - b) Offer self-direction of services
 - c) Are culturally appropriate
- 5) Educate workers to identify possible dementia and understand the symptoms of dementia and appropriate services.
- 6) Implement quality assurance systems that measure how effectively providers serve people with dementia and their caregivers.
- 7) Encourage development of dementia-friendly communities, which include characteristics of dementia-capability. ⁷

Strong community engagement was key to the development and implementation of the ADRD State Plan. The State Plan was completed in 2013 by the efforts of 125 dementia allies, advocates, and professionals, many of whom were involved in the implementation process as

⁷ Tilly, J., Wiener, J., Gould, E., (2014), *Dementia-capable States and Communities: The Basics*.

well. In 2018, the Legislature added a new section to Chapter 349, Hawaii Revised Statutes requiring the EOA to "prepare an update of the state plan on Alzheimer's disease and related dementias no less frequently than once per fiscal biennium. The EOA shall include information on progress made toward the goals of the state plan in its annual report to the legislature". The following reflects progress made between 2017 through 2019.

Progress Made Toward Each Goal:

The following update provides progress on the implementation of the **State Plan on ADRD five goals**:

Goal 1. Prevent and effectively treat Alzheimer's disease by 2025

Strategy 1. Develop a Hawaii research consortium to expand research and programs unique to Hawaii that have the potential to contribute to the science and understanding of ADRD worldwide.

Strategy 2. "Piggyback" on or build relationships with national research partners. **Strategy 3.** Convene an annual dementia care and research symposium with goals of fostering scientific collaboration and sharing of current dementia research with the Hawaii community.

Hawaii Pacific Neuroscience (HPN) - Hawaii Alzheimer's Research Team – Center for Aging, Memory and Brain Health is the only facility in Hawaii with a dedicated multidisciplinary team of geriatricians, neurologists, psychologists, neuropsychologists, nurse practitioners and brain health and wellness specialists trained in diagnosing and treating memory disorders and dementia. HPN has been a critical community resource to help Hawaii expand research to support persons living with Alzheimer's disease. In 2019, HPN established Hawaii's first Genematch program, a genetic database registry as part of global Alzheimer's Prevention Initiative sponsored by NIH NIA Genematch Alzheimer's Prevention Registry. Also in 2019, an HPN patient became the 8th person in the world to receive the first human study to potentially prevent Alzheimer's using Anti-Tau Humanized Monoclonal Antibody IV Infusion at HPN Alzheimer's Research Unit & Memory Disorders Center. With a large emphasis of the State Plan on ADRD implementation geared towards helping people gain access to early detection, diagnosis, and support, HPN also provides E-cheek swab genetic testing for Alzheimer's ApoEgenes to all Hawaii residents 55-75 years old through the global API (Alzheimer's Prevention Initiative) network.

Implementation efforts also found that policy changes were needed to effectively treat ADRD. For example, in 2019 Senator Brian Schatz cosponsored the <u>Younger-Onset Alzheimer's Disease Act of 2019</u> (H.R. 1903 / S. 901) to create access for people living with ADRD who are under the age of 60 years and do not have access to services and supports from programs provided by

the Older Americans Act, including nutritional programs, respite services for family caregivers, supportive services, the National Family Caregiver Support Program, and other services that enhance quality of life.

Goal 2. Enhance care quality and efficiency

Strategy 1. Be dementia capable.

Strategy 2. Create a one-stop resource of access to information and referral.

Strategy 3. Build a workforce with the skills to provide high quality care for people with ADRD.

Strategy 4. Ensure timely and accurate diagnosis.

Strategy 5. Educate and support people with ADRD and their families upon diagnosis.

Strategy 6. Identify high-quality dementia care guidelines and measures across care settings.

Strategy 7. Ensure that people with ADRD experience safe and effective transitions between care settings and systems.

Strategy 8. Advance coordinated and integrated health and long-term services and supports for individuals living with ADRD.

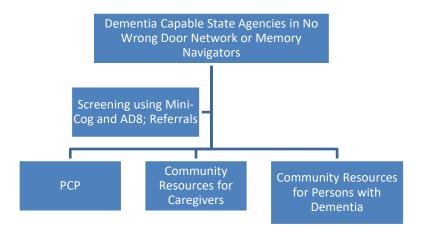
Strategy 9. Improve care for populations in Hawaii who are disproportionally affected by ADRD, and for populations facing care challenges.

During the past two years, EOA has provided dementia capability training to agencies in the No Wrong Door (NWD) network on all islands. Core access points for publicly funded long term services and supports are called "Doors" and include: the four county Area Agencies on Aging (AAAs) that operate the Aging and Disability Resource Center (ADRC), Med-QUEST Division (MQD, the state Medicaid agency), Developmental Disabilities Division (DDD), Children with Special Health Needs Branch (CSHNB), Division of Vocational Rehabilitation (DVR), Office of Veteran's Services (OVS), Veterans Health Administration (VHA), Centers for Independent Living (CIL), Adult Mental Health Division (AMHD), Office of the Governor's Coordinator on Homelessness (GOVH), Adult Protective Services (APS), and Assistive Technology Resource Center (ATRC). The intent of the NWD network is to provide a coordinated system of information and streamlined access for all persons needing long-term services and supports.

In 2017, through a grant from the ACL, staff at these agencies have been trained to utilize national best practice screening tools (i.e., Mini-Cog and AD8) and adopt a protocol to refer families to memory navigators or the county ADRC. The memory navigators or ADRC will connect families to their physician for further assessment and diagnosis as well as to long-term supports in the community (see Figure 1). This grant also trained hospital discharge planners at

Pali Momi and Straub to make referrals to services in the community (including Public Health Nurses, who provide memory care navigation).

FIGURE 1



Building a workforce with the skills to provide high quality care for people with ADRD is a big need as our kupuna population increases. The John A. Burns School of Medicine (JABSOM) received additional funding in 2019 from the Health Resources and Services Administration (HRSA) for the Geriatric Workforce Enhancement Program (GWEP). With this additional funding, GWEP will focus on building geriatric workforce capacity while improving patient access to specialty health care in Hawaii's rural communities. Training on dementia is a critical component of geriatric education and is a main grant objective.

Goal 3. Expand supports for people with ADRD and their families

- **Strategy 1.** Ensure that Hawaii care partners and families receive culturally sensitive education, training and support materials.
- **Strategy 2.** Enable Hawaii's family caregivers and families to continue to provide care while maintaining their own health and well-being.
- **Strategy 3.** Assist individuals and families in planning for future care needs, considering the cost and impact of dementia, inclusive of all levels of financial status.
- **Strategy 4.** Maintain the dignity, safety and rights of people with ADRD and their caregivers.
- **Strategy 5.** Assess and address the housing needs of people with ADRD.
- **Strategy 6.** Improve safety for people with ADRD and their caregivers.

Table 1. Federal Funding Given to Hawaii since 2013 to Support Implementation of the						
State ADRD Plan Title of grant	Title of grant Source of Dates Amount Recipient					
Title of grant	Funding	Dates	Amount	Recipient		
Building and	National	2014-2015	\$100,000	EOA		
Sustaining Public	Association of	2014-2013	\$100,000	EOA		
Health Partnerships	Chronic					
to make Hawaii	Disease					
Dementia-Capable	Directors					
and to Implement	Directors					
Hawaii 2025: State						
Plan on ADRD						
Hawaii Alzheimer's	Administration	2015-2019	\$969,000	UH Center on		
Disease Initiative	for	2013-2019	\$909,000			
Disease initiative				Aging		
	Community					
Hawaii Alzheimer's	Living Administration	2017-2020	\$647,324	Executive		
	for	2017-2020	\$047,324	Office on		
Disease Supportive						
Services Program	Community			Aging		
TT '' 41 1 ' 1	Living	2010 2021	Φ447.071	F .:		
Hawaii Alzheimer's	Administration	2019-2021	\$447,971	Executive		
Disease Program	for			Office on		
Initiative	Community			Aging		
TT '' G' 1 G	Living	2010 2021	Φ4 '11'	G .1 .1'		
Hawaii Circle of	Administration	2018-2021	\$1 million	Catholic		
Care for Dementia	for			Charities		
	Community			Hawaii		
	Living					
Geriatric Workforce	Health	2015-2019,	\$750,000 annually	UH Department		
Enhancement	Resources and	renewed to	(\$100,000 ADRD	of Geriatric		
Program (GWEP)	Services	2024	budget)	Medicine		
	Administration					
State Resource to Sup						
ADRD State	State Funds	2019	\$59,616	EOA		
Coordinator funding						

The University of Hawaii (UH) Center on Aging was awarded an ACL grant in 2015 that created the Hawaii Alzheimer's Disease Initiative (HADI). The HADI initiative was funded through 2019. The grant: 1) provided extensive dementia education and training to family caregivers and health professionals; and 2) created new support services for persons with dementia and their caregivers.

The HADI grant established three memory clinics currently operating in Federally Qualified Health Centers (FQHC) throughout the state: Kalihi-Palama Health Center (KPHC) on the island of Oahu; Molokai Community Health Center (MCHC) on the island of Molokai; and West Hawaii Community Health Center (WHCHC) on Hawaii Island. The memory clinic model employs an interdisciplinary team approach, offering comprehensive, coordinated care from dementia diagnosis through end-of-life. During the half-day, once per month memory clinic, persons with dementia and their caregivers are seen by an interdisciplinary team of providers (primary care provider, behavioral health specialist, social worker, care coordinator, and nutritionist) in a group visit setting.

The HADI grant also created a memory care navigator program, based on a national best practice model. Memory care navigators are trained to work with persons with dementia and their caregivers using a culturally appropriate approach, educating families about dementia, and connecting them to long-term services and supports (LTSS) in the community. HADI also adopted the evidence-based Savvy Caregiver program, a six-week program to empower ADRD caregivers to learn skills necessary to manage daily tasks and challenging behaviors. To date, 93 caregivers have benefited from the program and have shown improvements in caregiver self-efficacy and reductions in caregiver depression.

To further the creation of community-based supportive services, Catholic Charities Hawaii was awarded an ACL grant in 2018 to target gaps in services, particularly persons who live alone with dementia and those with intellectual disabilities who are at a higher risk of dementia. Catholic Charities Hawaii used the grant to train several community-based organizations in the evidence-based Resources for Enhancing Alzheimer's Caregivers Health (REACH) model, which provides one-on-one support to dementia caregivers in the home, teaching them practical caregiving skills. These trained organizations are currently working with dementia caregivers.

On a state level, a federal ACL grant was awarded in 2017 to the Hawaii Executive Office on Aging to strengthen the dementia capability of state agencies and improve linkages to community supports, including those developed by the UH Center on Aging and Catholic Charities Hawaii through their federal grants. See Table 2 for a listing of the innovative programs developed since 2017.

Table 2. List of Innovative Pilot Programs/Services Since State ADRD Plan was			
Developed			
Interdisciplinary Memory Clinic	An interdisciplinary team provides care to patient and caregiver, 1x per month, held at 4 federally qualified health centers statewide		

Memory Care Navigation	Provided by Public Health Nurses; provides
	education, support, and connection to other
	resources
Savvy Caregiver	Six-week, evidence-based program for
	dementia caregivers
Dealing With Dementia	Four-hour workshop discussion and review
	of comprehensive resource guidebook
Resources for Enhancing Alzheimer's	Evidence-based program, providing one-on-
Caregivers Health (REACH)	one support to dementia caregivers in the
	home, teaching them practical caregiving
	skills
Positive Approaches to Care	Training to empower caregivers to provide
	skills for positive interactions with persons
	with dementia.
GRACE Project	Service coordination for persons with
	dementia that also addresses social
	determinants of health (for example, non-
	medical needs such as citizenship
	applications)

Additionally, over the past two years, the Alzheimer's Association, Aloha Chapter, expanded their supports for people with ADRD and their families by developing a new caregiver support group on Molokai, an isolated, rural island lacking in supports for ADRD caregivers, with the hope of providing more ADRD related supports.

Goal 4. Enhance public awareness and engagement

Strategy 1. Educate and engage the public about ADRD.

Over the past two years, there have been several efforts by the Alzheimer's Association, Dementia Friends, and the Plaza Assisted Living, to increase public awareness around the importance of early detection and diagnosis of ADRD. In 2017, the Alzheimer's Association-Aloha Chapter launched a public awareness campaign to raise awareness on the importance of early detection so that families can prepare and make long-term care and end-of-life decisions. The campaign was comprehensive in nature and consisted of general community presentations, caregiver classes, TV commercials, radio commercials, print ads, social media ads, etc. As a result of the "Early Detection" Public Awareness commercial by KHON, which aired from January - March 2019, the Alzheimer's Association, Aloha Chapter experienced a 72% increase in program contacts and a 57% increase in the number of physician referrals.

With a targeted focus on increasing ADRD awareness in communities facing health inequities, the Alzheimer's Association, Aloha Chapter has focused on engaging and reaching geographically hard- to- reach community members. In 2018, the Alzheimer's Association, Aloha Chapter held community forums statewide in rural communities to gather insights and perspectives from family caregivers and persons with dementia:

- Hawaii Island: North Kohala Community Forum held on July 27, 2018 (35 participants)
- Oahu: Hau'ula Community Forum held on November 9, 2018 (31 participants)
- Kauai: Lihue Community Forum held on November 13, 2018 (19 participants)
- Maui: Kahului Community Forum held on December 5, 2018 (18 participants)

From these forums, the Alzheimer's Association, Aloha Chapter learned the following: 1) transportation tended to be a significant barrier in more rural communities; 2) neighbor island communities were very interested in web-based education and telehealth (for their providers); and 3) after a 45-minute education on program on the basics of Alzheimer's and dementia, most participants were not confident in their understanding of the disease.

Another intervention called Dementia Friends Hawaii and part of Dementia Friends USA, is a public engagement initiative that aims to provide education and reduce stigma around dementia. The program is a partnership between Age-Friendly Honolulu and UH Center on Aging's Hawaii Alzheimer's Disease Initiative. As part of the Dementia Friends curriculum, attendees pledge to become a "Dementia Friend" and pledge to "take action" within their family or community. Dementia Friends Hawaii targeted different sectors in the community, including libraries, financial sectors, senior groups, churches and schools. Manoa Cottage in Kaimuki and Manoa Cottage in Manoa have trained their staff in the Dementia Friends curriculum. Thus far, Dementia Friends Hawaii has trained 530 persons and has recently expanded to Kauai and is embraced by the Mayor and county directors. With funding from the National Asian Pacific Center on Aging (NAPCA), Dementia Friends Hawaii also collaborated to translate and pilot Dementia Friends with Chinese and Samoan churches on Oahu.

The Plaza Assisted Living sponsored the Hali'a Memory Care Conference in 2018 and 2019. These conferences included national and international experts in the field of Alzheimer's disease and other forms of dementia to discuss research and approaches to dementia care. Approximately 400 conference attendees were both care partners and those within the professional community.

Goal 5. Improve data to track progress

Strategy 1. Identify opportunities for improved data collection and analysis on ADRD in

Hawaii.

Strategy 2. Monitor progress on the Hawaii State Plan on ADRD.

The Behavioral Risk Factor Surveillance Survey (BRFSS) is a national health-related, telephone survey. In 2015, EOA purchased the administration of the cognitive module, a supplemental set of questions that measures subjective cognitive decline and its associated effects on function and daily living. Questions measure the BRFSS respondents' perceptions about any confusion or memory loss that is happening more often or is getting worse. In 2020, EOA intends to purchase the full module to learn more about the percentage of Hawaii adults that experience cognitive decline and its impact on daily function.

Efforts are also underway to update data on persons living with dementia in Hawaii. A partnership with the Hawaii Health Data Center (HHDC) All-Payer Claims Database (APCD) will provide data on demographics, utilization, and Medicare Fee for Service costs relating to dementia.

Standardized screening questions (Mini cog and AD8) used by the ADRC have provided EOA with data to better understand persons with ADRD who are delivered LTSS statewide. For example, EOA learned that the 85.2% majority of individuals with ADRD who are served by the ADRC are homebound.

Finally, dementia advocates throughout Hawaii have asked the Legislature to establish a position at the EOA to monitor progress and support the implementation of the State Plan on ADRD. In 2019, Act 127 appropriated funds to EOA for an ADRD Coordinator position. Unfortunately, due to a technicality in the language in Act 127, the position could not be established, and the funds have been used to contract a provider to update the State Plan on ADRD and draft the EOA's 2019 annual ADRD report to the Legislature. EOA requested the language correction as part of the Governor's Legislative package. EOA remains hopeful that it will be able to establish and fill its ADRD Coordinator position in 2020. The ADRD Coordinator will be critical in working with and monitoring the efforts of community partners and stakeholders to address the goals of the State Plan on ADRD.

Next Steps

In 2020, the EOA will convene dementia allies, advocates, and professionals to form workgroups to regularly update the goals and strategies of the ADRD State Plan and prepare a report for the 2021 legislative session.