

**REPORT TO THE THIRTY-FIRST HAWAII
STATE LEGISLATURE 2021 SESSION**

Executive Office on Aging Annual Report for SFY 2020

**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 Loā Ke Ola"
May Life Be Long*

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

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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) 2020.

In SFY 2020, the EOA received \$15,071,989 from State funds and \$12,915,500 from federal funds for a total of \$27,987,489 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 (KC) and Kupuna Caregivers (KCGP) Programs which offer the following 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. Long-term services and supports reached 8,406 older adults statewide.

In addition, EOA manages the following direct service programs: the Long-Term Care Ombudsman Program (LTCOP) and the LTCOP Volunteer Program, the Hawaii State Health Insurance Assistance Program (SHIP), and the Senior Medicare Patrol (SMP), and programs that support participant direction, such as Participant-Directed and Veterans-Directed Care Programs. EOA continued to undertake, or initiate, special initiatives, such as Hawaii Healthy Aging Partnership (HHAP), 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

In March 2020 legislation to reauthorize the Older Americans Act (OAA) was passed by Congress, as amended through P.L. 116-131. The OAA of 2020 reauthorizes programs for FY2020 through FY2024 and promotes 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 states to designate a SUA to carry out the OAA mission and one or more Area Agencies on Aging to address the needs of older adults and persons with disabilities at the local or regional level. 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 a SUA as described in the OAA. Chapter 349, HRS, also created the Policy Advisory Board on Elder Affairs (PABEA) to advise the EOA Director.

B. Hawaii State Plan on Aging

The Hawaii State Plan on Aging describes how the EOA will use federal and state funds to pursue statewide activities to meet the needs of Hawaii's older adults and persons with disabilities by developing and fostering a coordinated and accessible system of 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 2019-2023 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 (ADRC) system for persons with disabilities, older adults, and their families.

Goal 4: Enable older adults and persons with disabilities to live in their communities through the

availability of and access to high-quality, long-term services and supports (LTSS), including supports for their families and caregivers.

Goal 5: Optimize the health, safety, and independence of Hawaii’s older adults and persons with disabilities.

Part II. State and Federal Funding

In SFY 2020, the total operating budget for the EOA was \$27,987,489. Table 1 shows a breakdown of the source of funding between State (54%) and Federal (46%) monies.

Table 1. EOA’s State and Federal Funding for SFY 2020

| SOURCE | SFY 2020 | PERCENT |
|---------------|---------------------------|----------------|
| State | \$15,071,989 | 54% |
| Federal | \$12,915,500 ¹ | 46% |
| Total | \$27,987,489 | 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. Prior to the COVID-19 period from July 1, 2019 thru March 31, 2020 the total number of contacts received by the ADRCs averaged 3,940 per month for a total of 35,456, and there were 3,183 participants who received an assessment.

During the COVID-19 period the need for information, assistance, and supports increased. From April 1, 2020 through June 30, 2020 the average number of contacts received by the ADRCs was 4,426 per month, a 12.3% increase over the pre-COVID period, for a total of 13,279 contacts.

¹ Federal funding includes COVID Stimulus funding through Families First and the Cares Acts

Participants that were provided an assessment decreased slightly during the COVID-10 period by 8.4% at an average rate of 324 assessments per month which resulted in the completion of 972 assessments. Clearly, the data mentioned above reflects the increased need for information and assistance during the pandemic.

The uncertainty of the COVID pandemic renders planning difficult. Without a clear timeline for when we can expect a return to “normalcy”, it is difficult to predict how contacts, resources, and assessing the needs for long-term services and supports will be impacted. EOA’s next steps for the Hawaii ADRC includes: (1) Retooling the ADRC website for improved outreach and marketing to family caregivers and older adults, including an evaluation analysis of the effectiveness of the updated website, (2) Working with DHS to apply for Medicaid FFP (Federal Financial Participation) claiming which would leverage federal resources at no expense to the State of Hawaii to support services that include the efforts of the ADRC, (3) Revising the brief and core assessments to ensure that the questions asked are relevant to the assessment process, (4) Monitoring and evaluating ADRC processes to ensure the standards for ADRC are upheld by the four ADRC sites so that the users’ experience statewide is standardized and responsive to the needs in the community.

Table 2. Outcomes of Consumer Contacts with the ADRC (SFY 2020)

| Outcomes | Pre-COVID (July 1, 2019 – March 31, 2020) | During COVID (April 30, 2020 – June 30, 2020) |
|--|---|---|
| Monthly Average Number of Contacts Received by the ADRC* | 3,940 | 4,426 |
| Monthly Average Number of Assessments Received | 354 | 324 |

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

B. Kupuna Care Program

The Kupuna Care (KC) Program provides older adults with access to affordable and quality home and community-based services that are person-centered allowing them to age in place with independence and dignity. KC consists of eight core services: adult day care, attendant care, case management, chore, homemaker, personal care, transportation, and home delivered meals. The Kupuna Care Program began in 1999 and is available in all four counties.

To be eligible for the KC program, older adults must be 60 years of age or older, citizens of the United States or a qualified alien, not covered by any comparable government or private home and community-based care program, and not living in an institution. The older adult must have a cognitive impairment such as Alzheimer’s Disease or other disability. In addition, the older adult is unable to independently perform two or more Activities of Daily Living (ADL) such as eating,

dressings, bathing, toileting, transferring in and out of bed or chair, and walking; or performing Instrumental Activities of Daily Living (“IADL”) such as preparing meals, shopping, managing medication, managing money, using the telephone, doing housework, and using available transportation without assistance.

COVID-19 impacted the last quarter (April 1-June 30, 2020) of the KC program. In Table 3 below, the data highlighted in orange shows the decrease in persons served and units of services delivered.

Table 3. Services Provided for FY2020 from July 1, 2019 thru June 30, 2020

| KC Service Summary | Persons Served SFY2019 | Persons Served SFY2020 | Persons Served % Diff. | Units of Service SFY2019 | Units of Service SFY2020 | Units of Service % Diff. |
|---------------------------|-------------------------------|-------------------------------|-------------------------------|---------------------------------|---------------------------------|---------------------------------|
| Personal Care | 827 | 689 | -16.69% | 54,634 | 45,589 | -16.56% |
| Homemaker | 752 | 755 | 0.40% | 23,913 | 23,285 | -2.63% |
| Chore | 82 | 63 | -23.17% | 1,334 | 1,274 | -4.50% |
| Home Delivered Meals | 3,032 | 3,903 | 28.73% | 462,043 | 476,458 | 3.12% |
| Adult Day Care | 339 | 344 | 1.47% | 187,739 | 170,386 | -9.24% |
| Case Management | 5,324 | 3,799 | -28.64% | 30,318 | 28,672 | -5.43% |
| Assisted Transportation | 184 | 159 | -13.59% | 7,577 | 4,959 | -34.55% |
| Transportation | | | | 89,909 | 112,557 | 25.19% |

With COVID-19 older adults were more vulnerable and isolated. Quarantine led to food insecurities, hesitation for participants & families to accept services in the home for fear of exposure to COVID-19, and service providers having to adjust to a new way of supporting the Network. In addition, even after the quarantine was lifted, the uncertainty of the pandemic and the lack of a vaccine affected how older adults went about their daily lives. Many self-chose to quarantine and not accept services and supports. The needs are still evident, but older adults and their family are choosing not to seek support because of the pandemic.

Kupuna Care services that increased in the fourth quarter because of COVID-19 included case management and home delivered meals. Adult day care, personal care, homemaker, chore, and transportation services were impacted and saw decreases in numbers served and units of services during the last quarter of the fiscal year. COVID-19 disrupted the aging network’s ability to deliver senior services and supports, especially the traditional model of supports such as Kupuna

Care.

Service providers were also impacted by COVID-19, particularly as they adjusted their service model to follow CDC guidelines and city and county mandates for social distancing and health and safety measures. EOA surveyed the service providers statewide to find out changes in capacity due to COVID-19 in May 2020 with the following results:

- 98% responded they had a plan to resume services
- 56% will resume at full capacity
- 23% were at 75% capacity
- 15% were at half capacity
- 5% were only at 25% capacity

As the lasting effects of COVID-19 remain in the aging community longer than other populations, the capacity of service providers to serve older adults will continue to be a challenge because only a little over 50% of our providers are able to resume full capacity. Nevertheless, EOA will continue to monitor services and supports of older adults and work with the Area Agencies on Aging to ensure that we are meeting the needs of Hawaii's kupuna.

C. Kupuna Caregivers Program

The Kupuna Caregivers Program (KCGP) began in 2017 to support working caregivers by helping to secure their retirement benefits, assisting businesses to retain qualified workers, and lessening the burden experienced by caregivers. The KCGP is delivered by the Area Agencies on Aging (AAAs) and administered by the EOA. In SFY 2020, the Legislature generously appropriated \$1,500,000 for KCGP. To be eligible for the KCGP, a caregiver must be working thirty (30) hours or more a week and is the primary caregiver for the care recipient who qualifies for the Kupuna Care Program.

In the fall of 2019, at the urging of the Legislature, EOA developed a plan to maximize the number of caregivers served by the program, including additional services to be provided by the KCGP. The objectives and activities were not met because it was derailed by the COVID-19 pandemic. EOA will revisit the plan in 2021.

Prior to COVID-19 (July 1, 2019 – March 31, 2020) EOA reported an 8% increase statewide in the number of registered caregivers from 112 to 121. The number of inquiries for KCGP remained about the same from SFY 2019 to SFY 2020 (1,019 in SFY 2019 and 1,078 in SFY 2020). The cumulative total of unduplicated caregivers served in SFY2019 and SFY2020 was 182 caregivers to 186 care recipients. In SFY2020, KCGP services provided services statewide including Adult Day Care, Assisted Transportation, Homemaker, and Personal Care to 125 care recipients (a 9% increase from 2019).

In 2020, EOA intended to implement our statewide plan by coordinating the efforts of the

Kupuna Network, to maximize the number of caregivers and care recipients served by the program. Unfortunately, this effort was hampered by several external factors. Two of the four Area Agencies on Aging were undergoing a change in administration with new County Executives appointed. Honolulu County faced large turnovers in their frontline and administrative staff, making retaining and recruiting qualified individuals in a timely manner a challenge. Vacancies and budget concerns at EOA further complicated implementation of the maximization plan. Finally, the arrival of the pandemic forced a pivot from the plan to maximize caregivers to an interim strategy to address the immediate needs of food insecurity, social isolation, and the health and safety of our kupuna and their caregivers.

Table 4. Kupuna Caregivers Program: Service Outcomes Due to COVID

| Services Delivered | SFY 2020 Pre-COVID | SFY 2020 COVID |
|---|---------------------------|-----------------------|
| Adult Day Care (hours) | 84,969 | 6,313 |
| Assisted Transportation (number of trips) | 23 | 0 |
| Homemaker (hours) | 205 | 36 |
| Personal Care (hours) | 38 | 0 |

The uncertainty brought on by the pandemic makes committing to next steps difficult. EOA feels that a return to normalcy for older adults is more difficult than other age groups due to the greater vulnerability of this population to contract COVID-19 and recover from COVID-19 if infected. Until a vaccine or other comparable mitigation effort is in place, EOA will continue to see a decrease in “in-home” supports such as homemaker, personal care, and transportation. Providers of services are plagued with capacity issues because of social distancing requirements and health and safety issues. Additionally, many providers have seen their stock of qualified workers decrease due to employment shifts because of the pandemic.

EOA will review its plan to maximize the number of caregivers served and try to balance expectations resulting from the pandemic. A resubmittal of realistic expectations for the KCGP will be reviewed. EOA will propose language changes to HRS 349-18 to support caregivers during COVID and other declared disasters in the future.

D. Title III Older Americans Act Services and Legal Services

In addition to Kupuna Care and Kupuna Caregivers programs, older adults and caregivers may have access to other services and supports through the Older Americans Act (OAA) Title III Services. OAA 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 enable adults to live independent and healthy lives in their homes and communities. Below are the types of services that OAA funds support.

1) ***Title III-B: Supportive Services.*** Title III-B supportive services provide comprehensive and coordinated in-home and community-based long-term care services for older adults, age 60 or older. These services assist older adults by promoting socialization, continued health and independence, addressing functional limitations, and protecting elder rights. Title III-B services include but are not limited to information and referral assistance, adult day care, personal care, homemaker, chore, case management, legal assistance, and mental health services. Title III-B also funds multi-purpose senior centers that coordinate services for older adults such as congregate meals, community education, health screening, exercise and health promotion programs, and transportation. Together these services enable older individuals to maintain the highest level of function, participation, and dignity in the community.

a) **Legal Services:** The purpose of legal assistance is to assist older adults in securing their rights, benefits, and entitlements. The EOA provides Title III-B funds to the four Area Agencies on Aging to offer legal services to older adults statewide. In SFY2020, 1,218 older adults (unduplicated) received 6,028 hours of legal assistance services statewide.

Prior to COVID community outreach and education were conducted statewide to inform older adults and their family caregivers about various legal concerns and on how to access free legal services. These efforts included the following:

- 1) Kauai County - Two (2) community outreach events were held in Kauai County that reached about 146 older adults. Kauai's Annual Elder Law Fair, with over 21 community service providers, distributed information and provided educational presentations on estate planning, scams targeting seniors, Medicare fraud, and fall prevention. Another event, the Kekaha Westside Pantry answered questions from kupuna and distributed legal information.
- 2) Maui County - Four (4) community outreach events were held in Maui County that reached about 171 older adults and four (4) educational presentations were provided to 43 older adults. These educational presentations covered topics that included: advance healthcare directives, Power of Attorney, landlord/tenant issues, and guardianship and adoption concerns for grandparents raising grandchildren.
- 3) Hawaii County – Hawaii County's legal provider visited eleven (11) locations across the island, which included several shelters, senior centers, foodbanks, and the library to provide any legal assistance needed. Hawaii County also participated in two (2) community events, the Akamai Living Health Fair and the Community Cares Resources Fair, to reach out to older adults and their family caregivers and provide information on legal services.

During COVID legal services continued to be offered as providers quickly responded to city and county mandates and CDC guidelines on the critical need for social distancing to

ensure the safety of their clients and staff. Services were adjusted and offered remotely with in-person client meetings offered on an as needed, case by case basis. Legal providers saw an increased need for their clients to use technology to communicate and to review documents. Virtual services posed a challenge for those who do not have a computer or have difficulty navigating technology. Community education and outreach efforts were greatly impacted by the pandemic as large gatherings were no longer permissible and events and educational presentations that were originally scheduled prior to the pandemic had to be cancelled.

Despite the pandemic legal providers partnered with the AAAs and found creative ways to reach out to older adults. For example, in Kauai the legal provider partnered with the Kauai Agency on Elderly Affairs and participated in two (2) drive by food distribution events by providing legal informational brochures and answering questions from participants during the drive-by. In Hawaii County an educational presentation about landlord-tenant housing issues and information on the CARES Act was conducted virtually to participants of the Kuikahi Mediation Center.

In SFY 2021 legal services for older adults will continue to be offered both remotely and in person, on a case by case, as needed basis. With COVID as the “new normal” efforts to reach and provide information to older adults and their family caregivers will be adapted by using virtual technology for video-based training. To better reach older adults without access to a computer and/or internet providers are currently working on developing and fine tuning the following strategies: (1) Communicate with older adults by phone or during limited in-person meetings, (2) Share information with aging services partners, and (3) Distribute printed materials with legal information through Meals on Wheels or with grocery or pharmacy delivery services.

- 2) ***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.

- 3) ***Title III-D: Disease Prevention and Health Promotion Services.*** Title III-D provides 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.

- 4) ***Title III-E: National Family Caregiver Support Program (NFCSP)***. The NFCSP offers a range of services to support family caregivers. Services to caregivers with a care recipient include: 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 2020. Table 4 shows the number of unduplicated persons served, service units delivered, and the unit measure. In the last three months of SFY 2020, service delivery decreased with the onset of COVID-19 and the implementation of mandated social distancing practices.

Table 5. Utilization of Services in SFY 2020

| SERVICES* | PERSONS SERVED (Unduplicated Count) | UNITS OF SERVICE | MEASURE |
|------------------------------------|--|-------------------------|----------------|
| Case Management | 3,799 | 28,672 | Hours |
| Assisted Transportation | 159 | 4,959 | One-way trips |
| Transportation | Not Available | 112,557 | One-way trips |
| Attendant Care | 98 | 3,375 | Hours |
| Personal Care | 689 | 45,589 | Hours |
| Homemaker | 755 | 23,285 | Hours |
| Adult Day Care | 334 | 170,386 | Hours |
| Chore | 63 | 1,274 | Hours |
| Home Delivered Meals | 3,903 | 476,458 | Meals |
| Congregate Meals | 2,834 | 175,953 | Meals |
| Legal Services | 1,218 | 6,028 | Hours |
| Caregiver Services | | | |
| Respite Care | 178 | 26,938 | Hours |
| Counseling/Support Groups/Training | 703 | 4,283 | 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 2020.

A. Other Federal Grant Programs

1. Title VII, Older Americans Act: Long-Term Care Ombudsman Program (LTCOP)

Both federally and state mandated, the LTCOP serves as an advocate for residents of nursing homes, adult residential care homes (ARCH), expanded ARCHs, community care foster family homes (CCFFH) and assisted living facilities. The number of facilities state-wide is approximately 1,729 with 12,876 beds. In SFY2020, the LTCOP staff included: 2 full-time Ombudsman and 4 part-time contracted Ombudsmen.

Prior to COVID the LTCOP responsibilities included:

- Raising awareness of the rights of residents in long-term care facilities through outreach and education with community-based presentations to family members, students, and caregivers. In SFY 2020, the LTCOP provided 9 community education events at the following locations: Maunalani Nursing Facility, Pearl City Public Library, State Health Insurance Assistance Program (SHIP), UH School of Social Work, University of Hawaii Elder Law Program, and St. Francis Healthcare Family Caregiving training series.
- Investigating complaints and opening cases, on behalf of residents/families of long-term care facilities to improve their quality of care and quality of life. In SFY 2020 the LTCOP investigated six (6) complaints. These complaints were at 15 Craigside Assisted Living, Leahi Nursing Facility, adult residential care home (ARCH) on Kauai, and three (3) complaint investigations at Hale Nani Nursing Facility.
- Serving as a resource to administrators and staff of long-term care facilities by providing consultations regarding federal, state, and local regulations that relate to long-term care facilities/settings, which impact the care of residents. Consultations included participating in discharge meetings at Arcadia Assisted Living, training staff at Roselani Place Assisted Living and Maluhia Nursing Facility, and monitoring bankruptcy filing of Legacy Hilo Nursing Facility.
- Providing valuable insight to the Office of Healthcare Assurance (OHCA) regarding the care provided to residents at long-term care facilities during their annual licensing or certification reviews by participating in the nursing home survey with OHCA.
- Training seven volunteer ombudsman representatives with 56 hours of training and shadowing thru on-site visits.

- Engaging with decision makers in the Legislature to ensure the rights of residents in long-term care facilities by: attending monthly meetings for PABEA, Kokua Council, Kupuna Caucus, National Association of the State Long Term Care Ombudsman Program and the Consumer Voice Leadership Council; meeting with legislators and providing testimony regarding SB2337/HB1872 legislation to establish long term care ombudsman positions for the neighbor islands; and speaking to the Kokua Council group and at legislative informational briefings on the protection of long term care residents.

Impacts of COVID-19 on LTCOP:

- Due to COVID-19 the LTCO was not allowed to enter long term care facilities. However, despite the restrictions the LTCOP continued to advocate for and investigate complaints to ensure the safety of kupuna residing in long term care facilities. In place of in-person contact the LTCOP was engaged in the following activities:
- All complaints and cases were investigated through phone and email consultations during the period of March – June 2020. The LTCOP responded to several calls from neighbors concerned for the safety of kupuna residing in particular ARCHs and CCFFHs that are not following social isolation or PPE protocols.
- The LTCO worked with and encouraged OHCA to develop a consistent message regarding visitation, PPEs, etc. to ALL types of LTC facilities. The LTCOP also made sure that ALL LTC facilities received COVID guidelines and updates by working with EOA clerical staff to create an e-mail listing for all ARCHs, which facilitated faster communication, and by providing updates to the ARCH/CCFFH Association leadership and facility social workers on COVID-19 from various national and local sources for dissemination to their membership.
- The LTCO worked closely with media to offer information and consultation including: providing information to *Civil Beat* regarding long-term care facilities, participating as a guest speaker on July 2nd on Hawaii Public Radio’s “*The Conversation*”, and consulting with KHON’s Gina Mangieri regarding generational differences in coping with COVID-19 (risky youth behavior and its impact to kupuna) and the negative effects of lockdown for LTC residents (social isolation and declining mental health).
- During the pandemic the LTCO engaged with legislative decision-makers through the following: virtual presentation to Kokua Council April 27th on *COVID-19 & Protecting Our Kupuna: Infection Control Issues from Ombudsmen Observations*, addressed concerns of legislators regarding “the social isolation of kupuna in LTC facilities” at an informational briefing, and met with former Senator Brickwood Galuteria and Kupuna Power Day staff to assist Board of Elections in strategizing plan to ensure LTC residents are assisted with voter registration.

As COVID-19 continues, the LTCOP has begun preparations for re-entry into facilities pursuant to CMS guidance. EOA worked to develop clear policies and procedures for the State

Ombudsman, contractors and volunteers. The Long-Term Care Ombudsman has been more critical after the complete shutdown of facility-based care since March 2020. The LTCOP must ramp up its efforts to support our residents in institutional settings. We plan to do this by hiring the Oahu LTCO position and implementing a robust volunteer program.

Long-Term Care Ombudsman Volunteer Program

As a volunteer-based program, LTCOP trains and certifies volunteer ombudsmen to focus on residents’ quality of life and quality of care by advocating that their rights be honored and protected. In SFY2020, there were 23 volunteers who provided 914 volunteer hours, valued at \$24,861. Due to the COVID-19 pandemic, visits to long-term care facilities decreased significantly. A plan for future re-entry will be developed to protect the health and safety of residents, volunteers, and staff.

Table 6. Accomplishments for LTCOP Volunteer Program

| Activity | SFY2020 | July 2019 – March 2020 | April 2020 – June 2020 |
|--|---------|------------------------|------------------------|
| # of Volunteers | 23 | 9 | 2 |
| Volunteer Service Hours | 914 | 709 | 205 |
| # of Facility Visits | 527 | 463 | 64 |
| # of Cases Opened | 83 | 79 | 4 |
| # of Cases Closed | 80 | 77 | 3 |
| # of Consultations with family or resident | 400 | 169 | 231 |
| Training and Technical Assistance Hours | 293 | 173 | 120 |
| # of Resident/Family Council Meetings | 26 | 26 | 0 |
| # of Community Outreach Events | 42 | 42 | 0 |
| # of Facility Surveys | 5 | 5 | 0 |
| Legislative Advocacy Hours | 28 | 28 | 0 |

2. *Hawaii State Health Insurance Assistance Program (SHIP)*

Hawaii SHIP is a federally funded volunteer-based program helping Hawaii’s older adults, their families and caregivers, and soon-to-be retirees to make informed, cost-effective decisions about their health plan coverage based on their individual needs and ability to pay. Over 100 locally trained and certified Medicare counselors statewide are available to provide one-on-one information, assistance, and referral services at no cost. Hawaii SHIP services are unbiased with no affiliation to any insurance organization. See table on page 13 for SHIP accomplishments.

Table 7. Accomplishments for Hawaii SHIP

| Activity | SFY2020 | July 2019 – March 2020 | April 2020 – June 2020 |
|--|-------------------|-------------------------------|-------------------------------|
| Beneficiaries Counseled | 2,524 Persons | 2,110 | 414 |
| Medicare Beneficiaries under 65 | 218 Persons | 186 | 32 |
| LEP, Low-Income, Rural Beneficiaries | 1,440 Persons | 1,229 | 211 |
| Enrollment Assistance | 1,632 Persons | 1,377 | 255 |
| Help Line and Website Inquiries | 2,347 Contacts | 1,997 | 350 |
| Persons Reached through Outreach | 23,129 Persons | 22,799 | 330 |
| Digital, Social, and Print Media Reach | 13,929,764 | 12,889,319 | 1,040,445 |

To ensure the health and safety of staff, volunteers, and beneficiaries during the COVID-19 pandemic, in-person counseling and community events were cancelled. Virtual counseling and presentations provided important pandemic-related updates to Medicare, such as: new penalty-free enrollment period for those who could not enroll due to the stay-at-home order or closure of the local Social Security office; special enrollment for those who lost their job-related group health plan; enhanced eligibility for those with End-Stage Renal Disease; and additional benefits to cover testing, hospitalization, and treatment for those inflicted with the coronavirus.

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

The purpose of the federally mandated 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 type of public assistance to help offset medical and prescription drug costs. The MIPPA program, in alignment with the Hawaii State Health Insurance Assistance Program (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 (AAA) and the Aging Disability Resource Centers (ADRC).

Table 8. Accomplishments for MIPPA

| Activity | SFY2020 | July 2019 – March 2020 | April 2020 – June 2020 |
|----------------------------------|---------|------------------------|------------------------|
| Beneficiaries Counseled | 158 | 115 | 43 |
| Persons Reached through Outreach | 2117 | 2117 | 0 |
| Beneficiaries under 65 | 26 | 23 | 3 |
| Rural Beneficiaries | 79 | 52 | 27 |
| Native Hawaiian Beneficiaries | 20 | 16 | 4 |
| English as a Second Language | 11 | 7 | 4 |
| Application Assistance | 27 | 20 | 7 |

To protect the health and safety of staff and volunteers during the COVID-19 pandemic, in-person counseling was not available until safety protocols were in place. One-on-one counseling and group presentations were delivered using virtual tools such as Zoom. MIPPA counselors are specially trained to screen for eligibility and assist low-income beneficiaries who have complex needs such as those with limited-English proficiency and require interpreter services. Counselors helped with comparing medical and prescription drug plans, application, enrollment, and referral to Med-Quest, AAA, or a community resource that provided supports and services for older adults.

4. Senior Medicare Patrol (SMP)

SMP Hawaii is a federally funded volunteer-based program that provides information and assistance to Hawaii’s older adults to protect their personal identity and information, including their Medicare card number. Medicare loses over \$60 million dollars per year from fraudulent billing and scams. SMP teaches beneficiaries to read their medical statements, detect errors, and

report suspicious activity to SMP or local authorities. Statewide prevention and education messaging help to protect everyone by raising awareness of frauds and scams at the local, national, and international level.

In SFY 2020, 56 SMP volunteers provided a total of 6,296 hours of service. See table on page 9 for SMP accomplishments.

Table 9. Accomplishments for SMP

| Activity | SFY2020 | July 2019 – March 2020 | April 2020 – June 2020 |
|----------------------------------|---------|------------------------|------------------------|
| Volunteer Service Hours | 6,296 | 4,640 | 1,655 |
| Beneficiaries Counseled | 203 | 136 | 67 |
| # of Community Outreach Events | 59 | 57 | 2 |
| Persons Reached through Outreach | 9,376 | 9,354 | 22 |

During the COVID-19 pandemic, requests for information and group presentations have increased due to the recent rise in pandemic-related scams, including:

- billing for fake tests, treatments, or vaccines
- fraudulent billing for supplies and equipment, such as N95 masks, gloves, sterilization supplies
- and health insurance solicitation, charity schemes, investment, and financial scams

B. Special Initiatives

1. Hawaii Healthy Aging Partnership

The Hawaii Healthy Aging Partnership (HHAP) is a cooperative endeavor led by the Executive Office on Aging (EOA), the Department of Health Chronic Disease Prevention & Health Promotion Division, and the University of Hawaii at Manoa Center on the Family with the goal to improve the health of Hawaii’s older adults (kupuna) by offering two evidence-based health promotion programs—EnhanceFitness® (EF) and Better Choices Better Health (BCBH).

The EnhanceFitness® Program is an evidenced-based exercise program that combines cardiovascular and balance exercises, strength training, and stretching to prevent functional decline in older adults. Classes are interactive and consist of one-hour sessions conducted three times a week with certified fitness trainers.

The Better Choices, Better Health (BCBH) is an internet-based group workshop that uses content from the Chronic Disease Self-Management Program, which focuses on chronic disease

management, decision making, problem-solving, and action-planning.

In SFY 2020, HHAP received \$550,000 in state funding to sustain its efforts. With the support of partner organizations, HHAP launched its website (<https://hawaiihealthyaging.org/>) to educate and inform the community about the HHAP programs and the benefits of participating in evidence-based health promotion programs, and promote the EF and BCBH classes being offered throughout the state. EF partners—Maui County Office on Aging and Kauai Agency on Elderly Affairs—worked with their respective County Councils to set up Medicare reimbursements. EF was also expanded to include new partners such as the Honolulu YMCA and Waimanalo Health Center. Both organizations utilize their own funding to provide EF on Oahu. For BCBH, partnership building was focused on re-engaging the National Kidney Foundation of Hawaii.

Table 10. Accomplishments for HHAP

| Activity | SFY 2020 |
|--|------------------|
| Pre-COVID (July 1, 2019 – March 31, 2020) | |
| EnhanceFitness Program | 574 Participants |
| Living Well with Chronic Conditions Workshops | 70 Participants |
| COVID period (April 1, 2020 – June 30, 2020) | |
| EF Phone Program (<i>modified version</i>) | 574 Participants |
| EF Gold Star Challenge, Virtual Classes, and TV Airtime of EF Video (<i>modified EF version</i>) | 150 Participants |
| BCBH Phone Workshop (<i>modified version</i>) | 5 Participants |

Before the pandemic, in January 2020, EF conducted two trainings for 11 new instructors to build the program's sustainability. With the use of state funds EF served a total of 574 participants (of those, 75 participants were newly joined). BCBH held seven workshops (three on the Big Island, two on Kauai, and two on Maui), which were attended by 70 people.

During SFY 2020, HHAP faced its most significant challenge yet. When the COVID-19 broke out in Hawaii, HHAP was forced to close all EF sites and cancel BCBH trainings for Master Trainers (trainers who can train BCBH leaders) and in-person BCBH workshops. This drastically reduced HHAP's ability to offer health promotion programs. Between April and May, HHAP partners consulted with the national organizations overseeing the EF and BCBH Programs and learned what components of the program could be modified and how to deliver these evidence-based programs remotely. HHAP collaboratively worked with its partner organizations to adjust the program delivery and design new policies that would allow them to keep kupuna safe and healthy while meeting the needs of Hawaii's communities for health promotion programs.

Unfortunately, Sound Generations, the National EF organization, informed HHAP that remote EF delivery was currently not permissible and instructed HHAP to utilize existing resources. During the pandemic and having to deal with not being able to offer remote delivery of EF, the EF partners on Kauai and Maui made weekly or bi-weekly calls to their former EF participants to check on their health and ease their isolation and loneliness. When the callers identified needs, they connected the kupuna with the ADRC. Callers overall, observed that the number of kupuna who needed help increased due to the long length of staying at home.

While making calls to their EF participants, Maui County Office on Aging realized that the pandemic created social isolation, which triggered cognitive and physical decline and put EF participants at increased risk for falling and worsening health. They received small donations from participants to start the “Gold Star Challenge” to motivate EF participants to stay physically active. In this program, everyone was required to keep track of the days they exercised at home for at least 30 minutes. When they had five days of exercise, they received a gold star. If they accumulated five gold stars or more, they would receive a gift upon returning to their regular EF class. This program ended in June. In addition, the Maui County Office on Aging developed three exercise videos that consisted of EF components. The videos had multiple levels of exercise routines and were aired on AKAKU local TV station since early June and posted on the ADRC website.

Kauai Agency on Elderly Affairs, another EF partner, explored possible approaches to keep their EF participants safe and healthy. They conducted a needs assessment to find out the best approach to keeping seniors moving and active. A virtual exercise class was found to be the most feasible option that could benefit many seniors. They launched six virtual exercise classes for EF participants and people on the program’s waiting list. Each class was offered three times per week.

The BCBH program, on the other hand, was advised by the national Self-Management Resource Center to utilize alternative methods for program delivery. HHAP partners chose to offer BCBH through online, virtual, and phone methods as alternative solutions during the pandemic:

- Online BCBH is a six-week asynchronous program that is offered by Canary Health through its website. Communication between the program and the participants is via threaded discussion boards.
- Phone BCBH is an at-home six-week course that uses a mailed toolkit and includes a leader's weekly follow-up. This alternative solution is suitable for the kupuna who are not technologically savvy.
- Virtual BCBH is very similar to in-person BCBH, except the program uses a cloud-based teleconferencing platform.

To offer Phone BCBH, HHAP partners are required to order hardcopy program materials. Unfortunately, the order took nearly a month to deliver and caused HHAP to run behind

schedule. In mid-June, Hawaii County Office of Aging was the first to pilot the Phone BCBH. Two alternative BCBH classes, one phone and one virtual, were scheduled for July.

During SFY 2020, the HHAP Steering Committee were unable to have a face-to-face annual Strategic Planning meeting. This meeting was rescheduled and is expected to be held virtually at the end of August. The primary funding sources for HHAP utilize federal, state, and county appropriations. The strategic planning meeting will explore variety of options to sustain the HHAP activities financially. HHAP will continue to work on looking for potential funding opportunities, including third-party reimbursement, and expanding partnerships with various organizations, such as medical entities.

2. Community Living Program

The Community Living Program (CLP) is a participant-directed program, which was established in 2013 as an option to the traditional service delivery system. The program is effectively implemented on Maui, Hawaii, and Kauai.

CLP has 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 and will provide care. The care recipient is responsible for explaining the job duties needed to provide the care that is needed, must adhere to a monthly budget, and complete required paperwork on a timely basis. Because the program employs individuals known to the participant, such as a spouse, child or friend, the CLP does not have the same concerns as our traditional service delivery models.

In SFY 2020, a total of 34 qualified individuals were enrolled in the CLP statewide, as compared to 36 participants enrolled in SFY 2019. The COVID-19 pandemic did not impact referrals and enrollments into the program. The reduction in enrollees were the result of attrition.

Because of the flexibility offered by CLP, the idea to expand this service model is promising especially during COVID-19. However, the infrastructure for this program must be sufficient to expand into the City and County of Honolulu. We need to ensure that EOA has a dedicated program manager. In addition, we need to have enough contracted assessors and coaches to provide the services to ensure participants are assessed and enrolled in the program to support them within the home.

3. Veterans-Directed Care Program

The Veterans-Directed Care Program (VDC) 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 2020, a total of 61 veterans were enrolled in the VDC program, as compared to 48 veterans enrolled in SFY 2019. The program continues to grow since its inception in 2015 and the EOA and VA continues to have a strong partnership to support veterans in their homes. Because the program employs individuals known to the participant, such as a spouse, child or friend, the VDC program does not have the same concerns exasperated by COVID-19 as the traditional service delivery model.

As a provider of the VA, we will continue to implement the program as it is beneficial to veterans to age in place rather than being placed in a residential setting especially during COVID-19.

4. No Wrong Door (NWD) Initiative

In 2015, EOA received a three-year grant from the Administration for Community Living (ACL) to develop a “No Wrong Door (NWD) system to break down the silos between state departments and county agencies and streamline the referral process for individuals who need long term services and supports. The idea behind the “No Wrong Door” system is to ensure that no matter what “door” (agency) the individual enters, they will receive an assessment and a warm hand off to the agency/agencies who will be able to help them.

In October 2018, EOA received a no cost extension to September 2019 to complete the activities of the grant. The Hawaii NWD implementation grant: (1) expanded the Aging and Disability Resource Center (ADRC) to incorporate a NWD network that enables older persons and persons with a disability to access all publicly-funded LTSS; (2) developed curriculum and provided training for NWD Network staff in person-centered counseling to meet federal guidance requirements; and (3) developed funding from multiple sources to sustain the NWD Network. Although the NWD grant ended in September 2019, EOA continued to support the NWD Network with agency funding.

EOA continued to conduct bi-monthly meetings via Zoom with the NWD Network agencies to share information about their agencies. Since these bi-monthly meetings are held virtually, EOA was able to continue conducting meetings during the pandemic. The meetings provided a good opportunity to find out what each agency was doing to continue providing services to its clients and identify any challenges it was facing.

The NWD Network agencies used an online referral tool, developed in 2019, to streamline the referrals they made for individuals who entered their "door" and needed assistance from another Door. As newer agencies joined the NWD Network, maintaining the online referral tool with the platform that it was created on became too costly. The referral tool was transferred to the state's

SharePoint platform. EOA contracted with a private web services developer to transfer the online referral tool to SharePoint. However, the NWD Network agencies requested that the online referral tool be HIPAA compliant. EOA sought the assistance of the state's Enterprise Technology Services (ETS) to ensure that the referral tool on the state's SharePoint platform was HIPAA compliant.

With COVID-19 ETS has been busy assisting other state agencies with setting up services and employee worksite remotely. ETS was not able to develop the NWD referral tool onto the State's SharePoint system during this time.

The Administration for Community Living (ACL) who provided EOA with the NWD grant, strongly recommended that states apply for Federal Financial Participation (FFP) funding to continue the NWD Network. FFP will enable EOA to receive reimbursement from the Center for Medicare and Medicaid Services (CMS) for staff time at EOA and the County Area Agencies on Aging, who assist individuals eligible for Medicaid. EOA drafted documents for Med-QUEST (MQD) to submit to the CMS. The documents are being reviewed by the Attorney General's office, and we are waiting for their approval of the Memorandum of Understanding (MOU) between EOA and MQD so the FFP documents can be submitted to CMS.

For SFY2021 EOA will work with ETS to transfer the online referral tool onto the state's SharePoint system and will continue to work with Med-Quest to finalize and submit the paperwork to the Center for Medicare and Medicaid Services (CMS) for federal financial participation.

5. Hawaii Alzheimer's Disease Supportive Services Program Grant

In 2017, the Executive Office on Aging (EOA) received a three-year Alzheimer's Disease Supportive Services Program (ADSSP) grant. The goals of this three-year project for Hawaii are to: 1) build and sustain dementia-capability within the No Wrong Door (NWD) Network and; 2) provide better access to services for persons with dementia and their caregivers.

To accomplish these goals, EOA will: 1) provide training to all staff from NWD Network agencies on dementia basics, cognitive screening, dementia care coordination, and management; 2) implement validated tools at all Doors to better screen and identify persons with memory loss; 3) collaborate with Hawai'i healthcare organizations and residential facilities to improve care transitions for persons with memory loss; and 4) increase timely referrals to community services. In June 2020, EOA was approved for a no cost extension till July 2021 to complete the activities of this grant.

Prior to COVID-19 EOA was able to conduct two in-person dementia capability trainings. One was conducted on Oahu at the Queen's Medical Center and one on Maui. These trainings were open to staff at State, county, and private agencies to learn about dementia, screening tools to administer to identify possible memory problems, and available community resources for

professionals and family caregivers caring for an individual with dementia.

Since the pandemic, dementia capability trainings were modified to be offered on Zoom. Three one-hour presentations were conducted in May. Rather than traveling separately to each of the neighbor islands, offering the trainings virtually provided the opportunity for individuals from all islands to attend all the Zoom presentations.

EOA published “Worried About Your Memory” booklet in 2015. With ADSSP grant funds, the booklet was revised. There was initial concern that printing of the booklets would be delayed with the temporary closure of many businesses due to COVID-19. Since printing was considered an essential service, printing of the “Worried About Your Memory Booklet” was able to be completed. 2500 copies were printed and distributed to the Area Agencies on Aging. With additional funding from the John A. Burns School of Medicine Geriatric Medicine Department, EOA was also able to have the booklet translated into 7 languages (Japanese, Korean, Ilocano, Tagalog, Marshallese, Simplified Chinese and Traditional Chinese). 600 copies of each language were printed and distributed to the Elderly Affairs Division on Oahu, the Hawaii County Office of Aging and the Geriatric Medicine Department at the John A. Burns School of Medicine.

With the intention of creating a dementia resources guide for community agencies EOA distributed an online survey to community agencies to assess their capability to provide services to individuals with dementia. EOA received very few surveys back. It was decided to change the dementia resources guidebook to a "Roadmap for Family Caregivers". This booklet will be modeled after the “Roadmap for Memory Navigators” developed by the University of Hawaii Center on Aging. The Center on Aging and the EOA worked with the graphic artist, who designed “Roadmap for Memory Navigators”, by providing information for the “Roadmap for Family Caregivers”. The Center on Aging was also contracted to update the resources section of the Roadmap.

For the SFY2021 EOA will distribute “Worried About Your Memory” booklets to Maui County Office on Aging and the Kauai Agency on Elderly Affairs. EOA will also work with the graphic artist to finalize the Roadmap for Family Caregivers, then print and distribute booklets to AAAs.

Due to COVID-19, the Savvy Caregiver classes that were originally scheduled for May and June needed to be rescheduled for presentation on Zoom. Since this had not been done before, EOA needs guidance from Dr. Ken Hepburn, the developer of the program, the Administration for Community Living (ACL) who is funding the training and the other states who are presenting Savvy Caregiver classes online. EOA will schedule (1) six-week Savvy Caregiver class via Zoom in August and September and reassess before scheduling another six-week class per the grant requirement.

6. EOA Disability Initiatives

The EOA Disability Specialist (DS) provides information and assistance to elders and persons with disabilities, specifically complex cases referred by the Area Agencies on Aging (AAA) and the EOA clerical staff. In addition, DS provides training, technical assistance, and participates on the Council on Development Disabilities and the Council's Community Supports committee 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.

The table below represents the DS' support to vulnerable populations in FY2020 the DS provided the following to support vulnerable populations:

Table 11. Disability Initiatives Activities

| SFY 2020 | Total | July 2019 – March 2020 | April2020 – June 2020 |
|------------------|-------|---------------------------|--------------------------|
| Persons served | 78 | 70 | 8 |
| Calls received | 44 | 39 | 3 |
| E-mails received | 36 | 29 | 7 |

Based on the data, during the onset of COVID-19 the number of referrals to the disability specialist decreased. The needs of elders and individuals with disabilities shifted focus to food insecurity and social isolation. In addition, the stay at home order may have misled the community into thinking that our office was closed.

As the Title III representative for the EOA, the DS serves as the appointed member to provide input, advocacy and information as it relates to older adults and individuals with disabilities. In FY2020, the DS participated and provided input and guidance on the following:

- Served as the Co-Chair of the Community Supports (CS) Committee of the DD Council, reviewed the DD Council's goals and objectives related to community supports and provided feedback to the Administrator. Reviewed and alerted DD Council on resolutions and bills that could impact individuals with I/DD and provided written feedback and suggestions for language change on these measures
- Participated in 4 meetings of the ABLE (Achieving a Better Life Experience) working group

- Provided follow up information to the Civil Right Commission and Mayor's Committee on Disabilities (Honolulu County is the only one without it being operational)
- Collaborated on a power point presentation on Safe Shopping for seniors and individuals with disabilities
- During COVID-19 the DS collaborated with the DD Council to continue providing guidance and training on (1) working safely, during a pandemic, in congregate settings with individuals with developmental disabilities and the elderly and (2) a statewide, systematic response to COVID-19 and other emergencies.

In SFY 2021, as a member of the DD Council and co-Chair of the committee established to implement the ABLE account in Hawaii, the DS will provide input as to the implementation of the program and be involved in the education and outreach efforts to inform the community about the new program. The EOA and DS will continue its effort to update the language access plan on an annual basis. The DS will collaborate with the Department of Health's Office of Language Access to ensure that EOA's language access plan incorporates the most current information available. Each county Aging and Disability Resource Centers will be provided training on any updates to the language access plan.

APPENDIX A



Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias: 2020 Update

* Note: This report was made available for review and feedback through a 7-day public comment period (November 16-24, 2020).

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Executive Summary

In compliance with Chapter §349-6.5 Hawaii Revised Statutes, the Hawaii Department of Health, Executive Office on Aging (EOA) is mandated to "prepare an update of the state plan on Alzheimer's disease and related dementias no less frequently than once per fiscal biennium". EOA contracted with the University of Hawaii, Center on Aging (COA) to facilitate and prepare this 2020 update of the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias which was originally published in 2013 but has not been updated since then.

Due to the COVID-19 pandemic, the EOA and COA were largely restricted to virtual engagement of its Alzheimer's Disease and Related Dementias (ADRD) taskforce to complete this update (see Appendix A for a list of members). To encourage broad participation across the state, one method COA used was an online "Dementia Experiences Survey" (see Appendix B) during Summer 2020. The survey revealed these top three findings:

1. ADRD care partners need respite and more culturally appropriate long-term service and support (LTSS) options to sustain care of loved ones with dementia;
2. Hawaii needs more dementia-capable providers to identify and support residents living with dementia; and,
3. People living with dementia need more support to prepare for a pandemic, especially those who are living alone.

Despite the challenges shared by ADRD care partners and service providers, COA also heard many stories of reciprocity, hope, joy, and resilience. For example, one care partner shared during the 2020 Dementia Experiences Survey:

"Although my mother-in-law lived for decades [with dementia] and my wife sacrificed her career and earnings and retirement benefits, we would take the journey all over again. The wisdom passed on from my mother-in-law to our extended family members is a legacy treasure. The keiki in our extended family developed a remarkable depth of compassion in being caregivers for years to one of their beloved kupuna." – from a care partner who lived with his mother-in-law with ADRD for more than 25 years (from 1994 to 2019)

This report is an update of the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias plan for the 2021 Legislature. In this report, the goals remained the same but updates are provided for: 1) activities since the plan was first published in 2013; and 2) strategies with input from the ADRD taskforce and larger community (through the Dementia Experiences Survey). This report was made available for review and feedback through a 7-day public comment period from November 16-24, 2020.

Introduction

In 2018, the Hawaii State Legislature added Chapter §349-6.5, Hawaii Revised Statutes (HRS) requiring the Hawaii State Department of Health, Executive Office on Aging (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.” In EOA’s 2019 annual report, a status of the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias was provided, see: <https://health.hawaii.gov/opppd/files/2019/12/EOA-Annual-Legislative-Report-2019.pdf>. In 2020, the ADRD task force and interested stakeholders convened to provide an update of the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias which has not been updated since it was first published in 2013. Further necessitating this update, federal requirements and funding opportunities require states demonstrate and progress dementia capability, through person-centered, coordinated services for persons with ADRD and their care partners.

With this update demonstrating larger projections of Hawaii residents living with ADRD into the future than originally indicated, EOA has responded to the need to scale the capacity of Hawaii’s current health and LTSS systems. Since 2013, EOA and many ADRD community advocates have worked to demonstrate this burgeoning need while advocating for resources to support the growing demand. An ADRD Services Coordinator position was established in statute within the EOA (Chapter §349-3.2 HRS), and funding for the position was appropriated in EOA's budget but the position is in limbo due to a technical error that EOA will resolve in the 2021 Legislative session. While this position will undoubtedly propel implementation of the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias, more support is needed. For example, there is no dementia-specific position within the Hawaii Department of Health, Chronic Disease Prevention and Health Promotion Division (CDPHPD), despite some efforts to demonstrate its need. The role of CDPHPD is to promote wellness and improve the quality and years of life for Hawaii’s people through effective prevention, detection and management of chronic diseases; recognizing dementia as a chronic disease is essential to developing systems to support dementia into the future.

Purpose and Methodology

The purpose of this document is to update the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias, originally published in 2013. EOA contracted with COA to facilitate and prepare this update. The goals in the Hawaii 2025 State Plan are unchanged; COA solicited broad community feedback to update the state plan’s strategies. These strategy updates reflect Hawaii’s current ADRD landscape and future opportunities, and was gathered from the following three main sources:

- Feedback from the ADRD working group, which was reconvened for this update during three meetings (a kick-off meeting in March 2020, and additional virtual meetings in October 2020).
- An online “Dementia Experiences Survey” (Summer 2020) gathered statewide feedback from (n=141) ADRD care partners, service providers, and advocates.
- COA also sought additional feedback from key Hawaii’s ADRD community leaders, such as the Alzheimer’s Association- Aloha Chapter.

To guide the data updates, EOA and COA partnered with the Telecommunications and Social Informatics Research Program/Pacific Health Informatics and Data Center (TASI/PHIDC) group at the University of Hawaii. The TASI/ PHIDC group analyzed Hawaii-specific Medicare data for disease prevalence and healthcare services utilization, and health care costs accumulated over the course of ADRD. The growth of the state’s dementia population was forecast using Department of Business, Economic Development, and Tourism’s (DBEDT) Hawaii population models.

The following graphs and tables in the *Latest ADRD Data and Statistics* section include Medicare Fee for Service (FFS) beneficiaries from 2010-2014 in Hawaii who were aged 65 and older (younger persons comprised a small, non-representative sample and were not included) with at least 3 years of continuous coverage. In total, the sample included roughly 60,000 individuals without ADRD every year from 2010-2014, and approximately 9,000 individuals with ADRD every year (approximately 13%), for a total sample of 70,000 beneficiaries per year from 2010-2014.

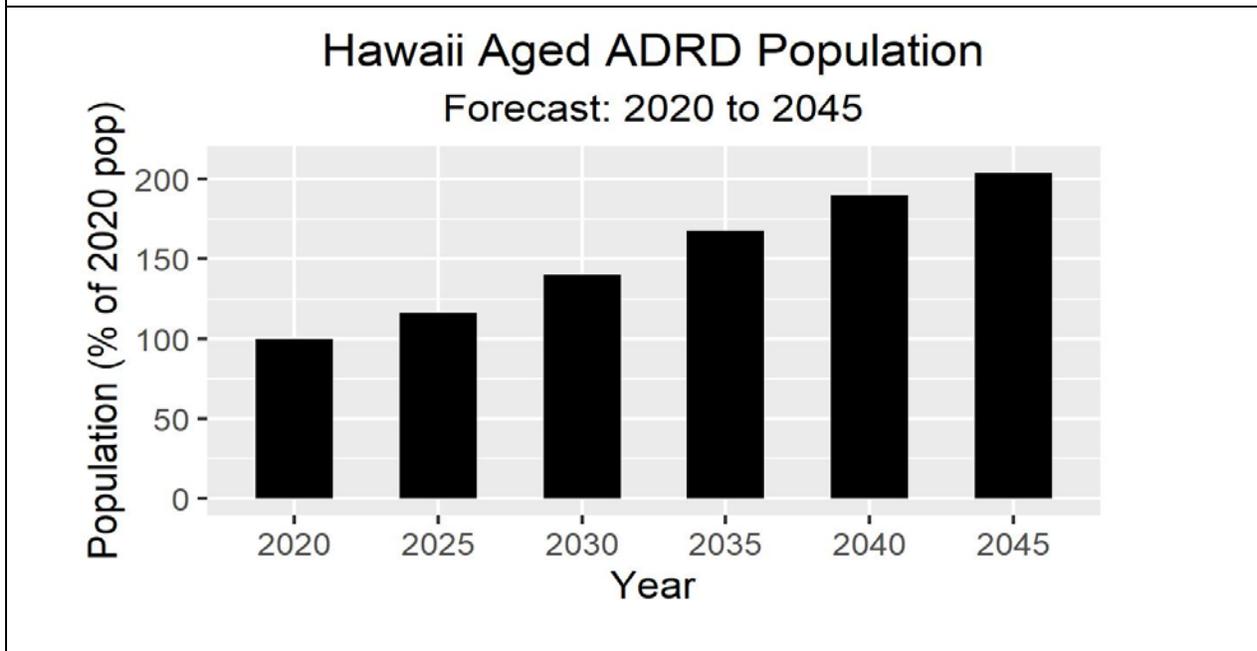
Limitations exist when working with this data set, however, and two items are noted. 1) ADRD rates by county or island are not possible due to privacy restrictions; and 2) limited data sets prevent reliability of ADRD rates by race/ethnicity, so disaggregated race rates are unavailable currently.

Latest ADRD Data and Statistics

According to the Alzheimer’s Association’s 2020 Facts and Figures report, Hawaii is now home to approximately 29,000 individuals with Alzheimer’s disease, with an expected increase to 35,000 by 2025.¹ More than 66,000 care partners buffer that economic impact, acquiring 75,000,000 hours in unpaid care which quantifies to \$944,000,000 value in unpaid care.¹

Table 1 indicates that the ADRD population in Hawaii will double between 2020 to 2045. The graph, based on Medicare FFS data and the DBEDT data, indicates that the growth in the ADRD population will reach 100% by 2045.

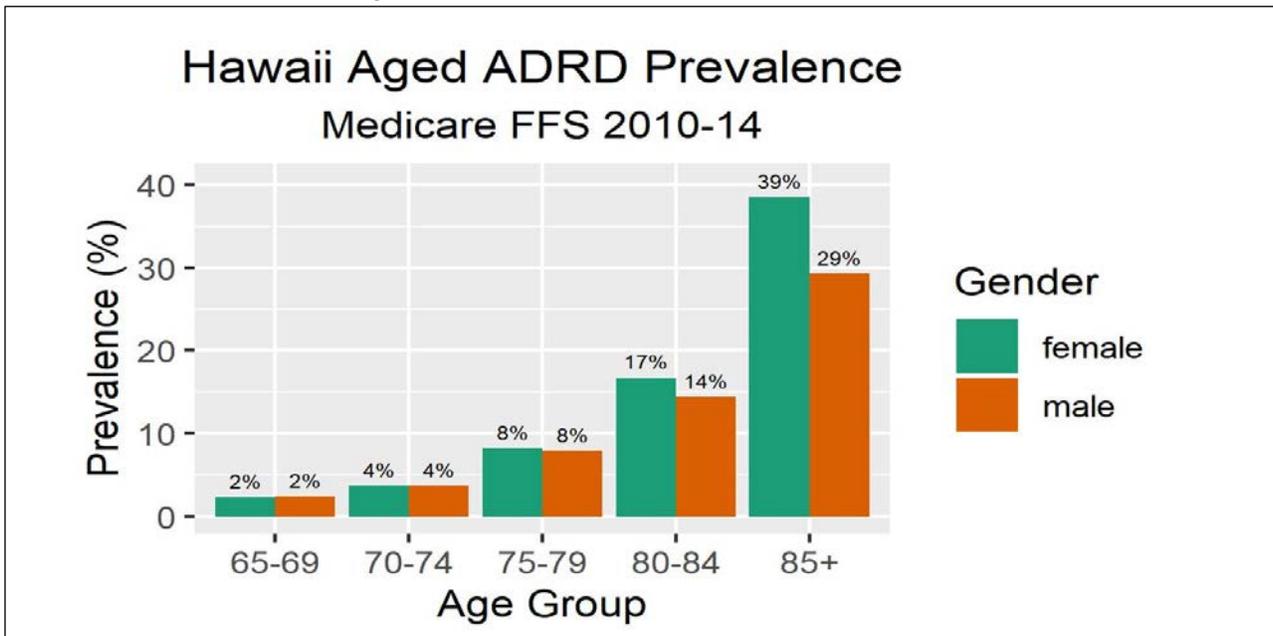
Table 1: ADRD Population Growth



Graph produced by UH TASI in Oct 2020

Table 2 indicates that ADRD prevalence is higher among females in Hawaii and this difference increases with age. Among the 85+ population, 39% of females and 29% of males have ADRD.

Table 2. ADRD Prevalence by Gender



Graph produced by UH TASI in Oct 2020

Table 3 shows that Medicare service utilization is substantially higher among the ADRD population. Using age-adjusted ratios, beneficiaries with ADRD utilized 8 times more hospice days, 7.5 times more skilled nursing facility days, and 4.3 times more acute inpatient days per year. Beneficiaries with ADRD also had 5.3 times more home health visits, 3.8 times more emergency room visits that became inpatient stays, 2.4 times more emergency room visits that became outpatient stays, and 2.2 times more outpatient hospital visits per year. The table also indicates that Medicare costs are higher per year among the ADRD population. In total, Medicare costs are nearly \$10,000 higher in the ADRD population in comparison to the non-ADRD population. The highest cost differences were in acute inpatient hospital costs (\$4,070), skilled nursing facility costs (\$2,198), and hospice care (\$1,206).

Table 3. Medicare service utilization among ADRD and non-ADRD population

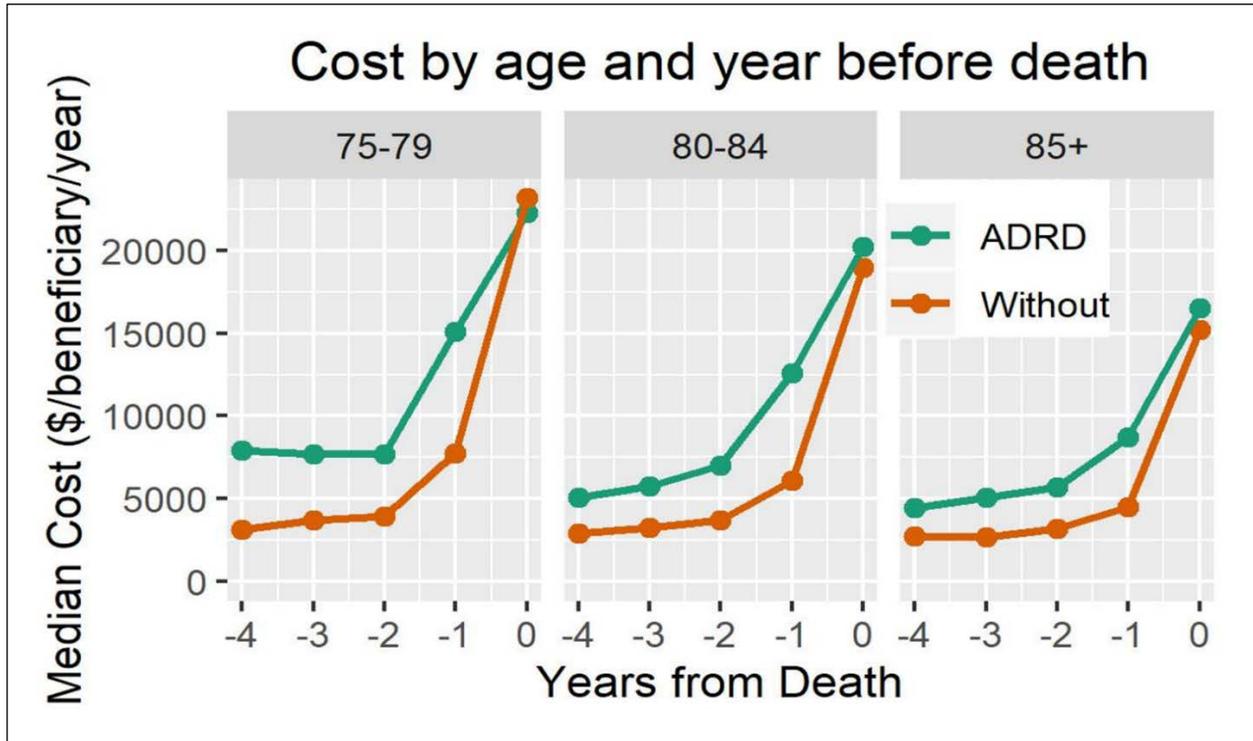
| DAYS / Beneficiary / Year, average | Study Population | | | Age-adjusted | Metric |
|--------------------------------------|------------------|---------|-------|--------------|-------------------------|
| | ADRD | Without | Ratio | Ratio | |
| Hospice | 7.6 | 0.6 | 13.1 | 8.0 | Covered Days/bene/year |
| Skilled Nursing Facility | 5.2 | 0.6 | 9.0 | 7.5 | Covered Days/bene/year |
| Acute Inpatient Hospital | 3.3 | 0.9 | 3.8 | 4.3 | Covered Days/bene/year |
| Other Inpatient | 0.3 | 0.1 | 4.2 | 5.0 | Covered Days/bene/year |
| | | | | | |
| VISITS / Beneficiary / Year, average | ADRD | Without | Ratio | Ratio | Metric |
| Home Health | 1.9 | 0.3 | 5.9 | 5.3 | Visits / bene / year |
| Emergency Room -> Inpatient | 0.4 | 0.1 | 3.8 | 3.8 | ER Visits / bene / year |
| Emergency Room -> Outpatient | 0.6 | 0.3 | 2.2 | 2.4 | ER Visits / bene / year |
| Hospital Outpatient | 8.1 | 4.8 | 1.7 | 2.2 | Visits / bene / year |

| COST / Beneficiary / Year, average | Study Population | | | Metric |
|------------------------------------|------------------|----------|------------|------------------|
| | ADRD | Without | Difference | |
| Total Medicare Payment | \$ 16,521 | \$ 6,851 | \$ 9,669 | \$ / bene / year |
| Acute Inpatient Hospital | \$ 6,308 | \$ 2,238 | \$ 4,070 | \$ / bene / year |
| Skilled Nursing Facility | \$ 2,487 | \$ 289 | \$ 2,198 | \$ / bene / year |
| Hospice | \$ 1,307 | \$ 102 | \$ 1,206 | \$ / bene / year |
| Drug, Part D | \$ 1,370 | \$ 805 | \$ 565 | \$ / bene / year |
| Evaluation and Management | \$ 793 | \$ 288 | \$ 504 | \$ / bene / year |
| Skilled Nursing Facility | \$ 432 | \$ 42 | \$ 390 | \$ / bene / year |
| Home Health | \$ 455 | \$ 77 | \$ 378 | \$ / bene / year |
| Hospital Outpatient | \$ 1,499 | \$ 1,185 | \$ 314 | \$ / bene / year |

Table produced by UH TASI in October 2020

Table 4 indicates that ADRD's costs accumulate over the course of the disease, with the highest costs incurred in the last year of life. ADRD sustains greater costs (ranging from \$2000 to \$4000) in the years prior to death with the gap closing in the last year of life.

Table 4. Costs of ADRD in the years prior to death



Graph produced by UH TASI in October 2020

From the lens of increasing prevalence of ADRD as well as high service utilization and high costs associated with the disease, the next section provides updates on ADRD state plan implementation activities since 2013 and revised strategies highlighting next steps toward creating statewide dementia capability.

Recommendations

Goal 1: Prevent and effectively treat Alzheimer’s Disease by 2025

Hawaii will seek to expand and support local research efforts, as well as keep Hawaii healthcare professionals and the public informed on the most current dementia research on effective prevention and treatment of dementia, both nationally and worldwide. Hawaii’s diverse cultural and ethnic environment can be a laboratory for studies unique to Hawaii, which could contribute to the growing worldwide body of research.

Progress in Hawaii Since 2013

Federal legislation has demonstrated a commitment to Alzheimer’s disease research and services. The enactment of the National Alzheimer’s Project Act (NAPA) propelled Congress to

increase Alzheimer's and dementia research funding more than six-fold, including two landmark allocations in 2019: 1) \$350 million for Alzheimer's and dementia research funding at NIH; and 2) \$10 million to implement the BOLD Infrastructure for Alzheimer's Act (P.L. 115-406). Both allocations acknowledge and intends to address Alzheimer's as a widespread public health crisis.

In pursuit of improved treatments and a cure, Hawaii has advanced clinical research in dementia. Hawaii's participation is vital to advancing research with Asian American and Pacific Islanders (AAPI), as the state and nation's AAPI communities are expected to grow into the future. One example was Hawaii Pacific Neuroscience's (HPN) establishment of Hawaii's first Genematch program. This genetic database registry is being implemented as part of the global Alzheimer's Prevention Initiative sponsored by [NIH/NIA Genematch Alzheimer's Prevention Registry](#). In addition, HPN's Alzheimer's Research Unit & Memory Disorders Center enabled an [HPN patient to become the 8th person in the world](#) to receive the first in human study to potentially prevent Alzheimer's using Anti-Tau Humanized Monoclonal Antibody IV Infusion.

ALZHEIMER'S DISEASE GENETIC TESTING IN HAWAII

Hawaii Pacific Neuroscience (HPN) 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.

Research conducted by the John A. Burns School of Medicine, Department of Geriatric Medicine has examined dementia risk factors and since 2013 and has demonstrated that impaired renal function has been linked to cognitive impairment. The Honolulu Heart Program is a prospective study that began in 1965 with 8006 Japanese American men aged 45 to 68 years. The Honolulu Asia Aging Study began 20 years later, with cognitive assessment by the Cognitive Abilities Screening Instrument (CASI) administered to 3734 men. Findings indicated that mid-life proteinuria was an independent predictor for late-life dementia and cognitive decline over 8 years.²

Updated Strategies

1. Develop a Hawaii dementia research network that identifies and connects researchers conducting biomedical and social and behavioral research in dementia. The network will encourage and recruit diverse participants in research and support and translate evidence-based research into practice.
2. Convene a bi-annual dementia care and research symposium to foster scientific collaboration, share research findings, and set research priorities.

3. Build relationships with national organizations and mainland universities in order to conduct multi-site studies to increase federal funding opportunities and expand the impact of research findings.
4. Disseminate the latest research evidence to all stakeholders and the larger community through educational events, online sources, and the media.

NATIONAL RESOURCE

Collaborative Approach for Asian Americans and Pacific Islanders (AAPI) Research and Education (CARE) Registry:

- A national registry being developed to create a very large repository of AAPI research participants, with a focus on ADRD. These individuals can then be contacted in the future about research participation.
- The goal is to ensure adequate representation of AAPI in research studies.
- Registration in English, Cantonese, Mandarin, Korean, and Vietnamese
- <https://careregistry.ucsf.edu/about-care-registry>

Goal 2: Enhance care quality and efficiency

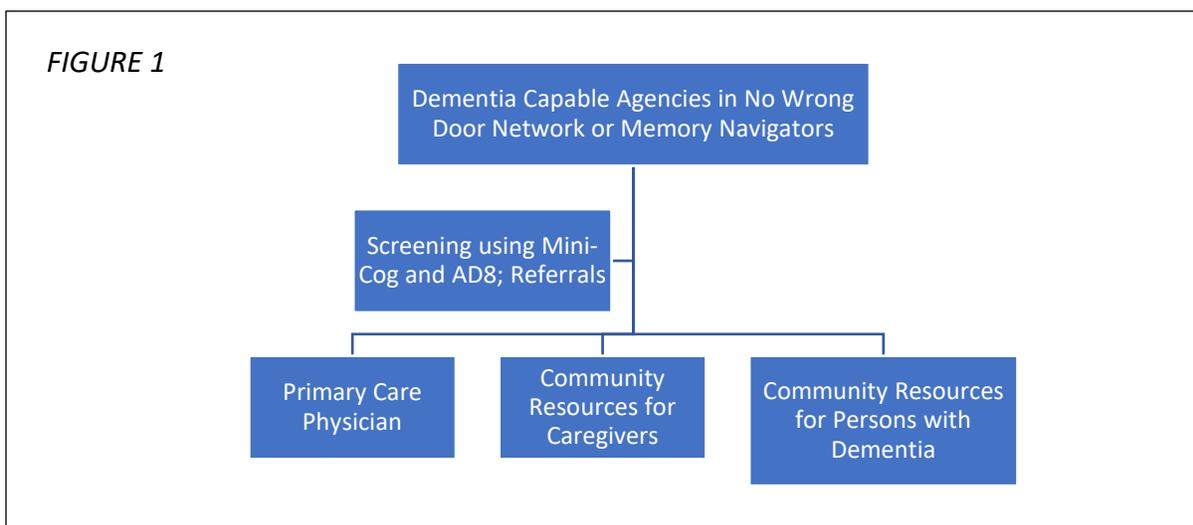
In order for Hawaii to achieve the vision of the best quality of life for those touched by dementia, it is imperative to achieve the highest quality of culturally competent care possible and a state infrastructure sensitive to the needs of people with ADRD and their care partners. Quality care begins with “dementia capable” services. Consumers and their families need to have appropriate services and care to maximize quality of life, delivered in a coordinated way from early and accurate diagnosis to the end of life.

Progress in Hawaii Since 2013

Statewide efforts have strengthened quality and efficiency of care and support for persons with ADRD. Hawaii’s statewide Aging and Disability Resource Center (ADRC) has a goal of streamlining and coordinating long-term services and supports (LTSS) for kupuna and persons with disabilities. The implementation of the ADRC was underway at the ADRD state plan’s original publication in 2013 and is now fully implemented by the four county Area Agencies on Aging (AAAs).

Beyond EOA and the county AAAs, EOA led a larger system change initiative to improve coordination of LTSS across state agencies. Through a cooperative agreement with Administration for Community Living (ACL) the EOA implemented a "No Wrong Door" (NWD) system. The NWD system provides a statewide coordinated system of information and streamlined access for all persons needing LTSS. For dementia LTSS, individuals and care

partners can access support through any “Door” at one of the following agencies: the four county AAAs operating the 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 Veterans' 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). Staff at these agencies have been trained to do memory screenings (i.e., Mini-Cog and AD8) and have adopted dementia-capable protocols to refer families to their primary care physician for further cognitive assessment and dementia capable providers of LTSS in their community (see Figure 1).



Other community initiatives have also expanded care quality and efficiency. In 2018, The Queen’s Medical Center-Punchbowl was the first hospital in Hawaii (fifth in the nation) to be accredited as providing the highest level of care to the geriatric population as a Level 1 Geriatric Emergency Department by the American College of Emergency Physicians (ACEP) while the Queen’s Medical Center-West Oahu received a Level 2 designation and both Molokai General Hospital and North Hawaii Community Hospital received Level 3 accreditations.

In addition, there is a growing recognition of the need to grow Hawaii’s dementia capable workforce, evidenced by the John A. Burns School of Medicine’s (JABSOM) Geriatric Workforce Enhancement Program (GWEP). GWEP received additional funding in 2019 from the Health Resources and Services Administration (HRSA) to 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 in creating age-friendly health systems.

Finally, the Healthcare Association of Hawaii (with American Health Care Association and National Center for Assisted Living) is offering members CARES® online dementia care training

and the Alzheimer's Association essentialALZ® certification program for individuals. This is the only online training option recognized by CMS. CARES® Dementia Basics & Advanced Care™ Online Training Program is one of only three programs nationally recommended by the Centers for Medicare & Medicaid Services (CMS) to meet its national nursing aide training requirements (part of Section 6121 of the Affordable Care Act mandates for enhanced nursing aide training). The CARES Program™ is an online dementia care training program.

Updated Strategies:

1. Launch initiatives in partnership with primary care providers to promote best practices in brain health and chronic disease management across the lifespan.
2. Build a health care workforce, including professionals, paraprofessionals, and allied health care partners with the skills to provide high quality care for people with ADRD.
3. Identify and provide ongoing dementia training on topics that will support quality care to care home operators, long-term care providers health care providers including, but not limited to nurse practitioners, EMS and other first responders, providers in homeless shelters, and care coordinators at health plans.
4. Discuss standardizing and mandating dementia training for first responders and city and county transportation providers, including bus drivers and HandiVan drivers.
5. Align with existing educational efforts to avoid duplication. For example, the Geriatric Workforce Enhancement Project (GWEP) is currently working on expanding Project ECHO (Extension for Community Healthcare Outcomes) to long-term care settings.
6. Incentivize, foster, and develop Hawaii's geriatric workforce by reaching students at earlier stages.
 - 6a. Modify high school curriculums to include mandatory or elective health-related and aging courses.
 - 6b. Integrate dementia education within higher education including, but not limited to medical, nursing, social work, pharmacy, and public health programs. Curriculum to include dementia capability, care navigation, and interdisciplinary care coordination.
7. Implement policy changes that require dementia education for provider continuing education and recertification. Allow for multiple methods of delivery including virtual and self-directed training.
8. Ensure timely and accurate diagnosis by training all primary care physicians and nurse practitioners in memory and dementia screening and access to referral resources.

9. Train on best practice and evidence-based screening tools available- i.e., Mini-Cog, AD8, National Task Group for Intellectual Disabilities and Dementia Practices screen tool for intellectual and developmental disabilities population. Ensure cultural sensitivity of screening tools for Native Hawaiian/Pacific Islanders.
10. Identify high-quality dementia care guidelines and measures across care settings
 - 10a. Select the best existing and evolving dementia care guidelines and measures being used locally and nationally to adapt to the spectrum of Hawaii service providers and care settings, including primary care physicians, the direct care workforce, Hawaii's aging and public health workforce, and care partners.
 - 10b. Examine cost-savings models of dementia care and explore feasibility for application in Hawaii's care settings.
11. Ensure that people with ADRD experience coordinated care and transitions between health care settings and between acute and long-term care systems.
 - 11a. Examine evidence-based care transitions models to reduce unnecessary hospital readmissions and emergency room use by people with ADRD.
 - 11b. Explore options for care planning/coordination across a range of medical professionals, insurance companies, and hospital systems. These options should support better outcomes for all and can be scaled into the future.
12. Build capacity to address an increasing number of behavioral crises that occur in patients with dementia. Create a special workgroup to find ways to identify barriers, enhance training, and expand capacity of geriatric psychiatric and crisis services statewide.
13. Standardize electronic medical records across care settings to streamline referrals and ensure efficient system tracking after diagnosis to include follow up, data collection, and continuous monitoring.
14. Streamline and standardize ADRD discharge information from acute care settings. Discharge packets to include resources on dementia capable providers, legal planning (including pro bono resources for ADRD families, completion of guardianship and capacity assessment, advance care planning), caregiver support, and respite programs.

15. Advance and expand coordinated and integrated health and long-term services and supports for individuals living with ADRD by expanding interdisciplinary models, similar to the memory clinic model at Kokua Kalihi Valley, to different settings.
16. Improve quality of care for populations in Hawaii who are disproportionately affected by ADRD, including but not limited to individuals with: Down Syndrome and traumatic brain injury, as well as improve access to care for those with early onset dementia, homeless and those living in poverty with dementia, residents of rural areas with limited access to providers and specialists, and those from different ethnic groups, with a particular focus on Native Hawaiians and Compacts of Free Association (COFA) residents.

LOCAL RESOURCE

The evidence-based Geriatric Resources for Assessment and Care of Elders (GRACE) model of primary care is available through Aloha Care, offering home-based geriatric assessment and care management as part of an interdisciplinary team for individuals who have geriatric conditions, including ADRD.

Goal 3: Expand supports for people with Alzheimer’s disease and their families

Quality, professional healthcare for people with dementia should be balanced with community supports necessary to help caregivers and families coping with the disease. Upon diagnosis, there should be easy and affordable access to a multitude of services and trainings, including respite, legal and financial counseling, advance care planning, and safety measures.

Progress in Hawaii Since 2013

The longstanding leadership of the Alzheimer's Association in Hawaii’s communities continues, with the Aloha Chapter expanding their supports for people with Alzheimer’s disease and their families by developing a new caregiver support group on Molokai, with the hope of providing more dementia related supports. Through a partnership with the Hawaii County ADRC, The Aloha Chapter also developed a Memory Café Hui at the Hilo ADRC, which has pivoted to a virtual cafe in 2020 due to the COVID-19 pandemic.

Resources restricted EOA’s execution of the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias, but a series of grants awarded to Hawaii by the federal Administration for Community Living (ACL) provided critical resources for implementation. In 2015, the University of Hawaii Center on Aging (COA) was awarded a dementia grant from ACL to create the Hawaii Alzheimer’s Disease Initiatives (HADI). The grant took steps toward dementia capability by providing training to health professionals, paraprofessionals, and family caregivers. Through COA’s cooperative agreements with ACL, a memory clinic model developed at Kokua Kalihi Valley (KKV), a federally- qualified health center (FQHC), is being replicated within three other

FQHCs and within one senior center (Lanakila Multi-Purpose Senior Center). HADI developed a memory care navigator model, based on national best practice, that was implemented by the Public Health Nurses and Project Dana volunteers. The memory care navigator model promotes early screening and identification, education, and connection to community resources. The federal grant also implemented the evidence-based Savvy Caregiver program in Hawaii, a psychosocial program designed to improve the practical skills of dementia caregivers. Hawaii's Savvy Caregiver program is championed by two trainers- Dr. Lucas Morgan, clinical psychologist, and Dr. Poki`i Balaz, advanced practice registered nurse.

In 2017, EOA received a 3-year federal ACL grant to train state agencies in the No Wrong Door Network to ensure that staff are dementia capable, meaning that they are able to administer cognitive screening tools and make appropriate community referrals to memory care services. In coordination with HADI, this grant also streamlined referrals from state agencies to community memory care resources, including memory clinics, memory care navigators, the Savvy Caregiver program, and the Alzheimer's Association- Aloha Chapter. Funding also enabled the continuation and expansion of Savvy Caregiver program to other parts of the state. This funding also enabled EOA to improve transitions of care of patients with dementia from hospital to home through pilot projects at Straub and Pali Momi hospitals. Another key objective of the grant was to empower families with the knowledge to navigate the long-term care system and connect to valuable memory care resources. Finally, the grant created a Memory Care Roadmap for Family Caregivers with both local and national dementia resources (see Appendix C).

In 2019, Catholic Charities Hawaii (CCH) received federal funding from the ACL to create the Hawaii Circle of Care for Dementia. One grant objective is to implement the evidence-based REACH program, an educational program to improve knowledge and skills of dementia caregivers. Another objective is to pilot outreach and engagement strategies to culturally diverse faith-based communities through the Dementia Friends program. The grant also intends to reduce the silos between aging and disability systems through targeted education to people with intellectual and developmental disabilities (I/DD), who are disproportionately affected by ADRD. CCH is improving ADRD screening for people with I/DD by providing training to use the National Task Group (NTG) Early Detection Screen for Dementia (NTG-EDSD).

These 3 federal grants have enabled Hawaii to pilot and evaluate evidence-based and best practice programs and approaches. Training provided to health care professionals and family caregivers address critical needs, particularly in the areas of awareness and knowledge of ADRD.

Lastly, in 2019, Senator Brian Schatz cosponsored the [Younger-Onset Alzheimer's Disease Act of 2019](#) (H.R. 1903/S. 901) to create supports for people living with ADRD who are under the age of 60 years and do not have access to services 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. ADRD is not just a disease of old age, younger onset dementia is devastating because the individual is diagnosed in their 30s, 40s, and even 50s. State policy changes are likely needed to effectively support those with younger onset dementia.

Updated Strategies

1. Ensure that Hawaii care partners and families receive culturally sensitive education, training and support materials.
 - 1a. Culturally sensitive materials and trainings will be identified and expanded, then distributed throughout the community. This should include health information technology found through online links and referrals, available not only from home computers but in community settings.
2. Examine the COVID-19 pandemic's impact on how community-based, services and supports are provided. A dementia care provider shared in the 2020 Dementia Experiences Survey:
"The senior center I am the head of has closed, so we have had to offer online classes to seniors. However, many of them do not have computers or smart phones to access such programming. We are making phone calls to every senior center member and mailing birthday cards to keep their spirits high and to assist them to fulfill their basic needs and connect them with community services. It is a time that the human spirit shines brightly with the kindness, appreciation, and thoughtfulness shown by seniors and their families, the community and our staff."
3. Empower Hawaii's family caregivers and families to continue to provide care while maintaining their own health and well-being.
 - 3a. Utilize peer mentors or coaches, more access to care partner support groups, affordable transportation options especially in rural areas, and available and affordable respite services inside and outside the home.
 - 3b. Collaborate with employers and the business community to offer flexible employee benefits and policies to employees who are balancing work and caregiving.
4. Assist individuals and families in planning for future care, legal, and financial needs, while considering the cost and impact of dementia.
 - 4a. Hold annual summits that will feature national presenters on all the options for LTSS: private, public, and innovative, like participant-directed services programs.
 - 4b. Create a resource list of financial professionals, organizations, and providers that can offer pro bono or affordable services for families impacted by ADRD.

- 4c. Develop resources for capacity assessments and guardianship support for persons with ADRD, especially during the COVID-19 pandemic.
5. Maintain the dignity, safety and rights of people with ADRD and their care partners.
- 5a. Increase collaboration between health and legal service providers, for example, Legal Aid Society, the Alzheimer's Association Aloha Chapter, ADRCs, first responders, financial institutions, Adult Protective Services, law enforcement, Hawaii State Bar Association, Hawaii's Long-Term Care Ombudsman program, county prosecutors, and the Office of the Public Guardian.
- 5b. Collaborate with community partners to provide ongoing training and support for capacity assessments, advance care planning, Physician Orders for Life-Sustaining Treatment (POLST), Durable Power of Attorney for Healthcare, fiduciaries, mediation and family counseling, and guardianship and conservatorship proceedings in the Hawaii court system.
- 5c. Advocate for and support local and national policy efforts that strengthen the dignity, safety, and rights of people with ADRD and their care partners. For example, H.R.6813, Promoting Alzheimer's Awareness to Prevent Elder Abuse Act, passed the House of Representatives in October 2020. If enacted, this bill requires the Department of Justice (DOJ) to update best practices and other training materials specifically addressing victims and witnesses who have ADRD. These resources will be used to progress the dementia capability of law enforcement, judicial officials, and others whose work may bring them in contact with elder abuse.
- 5d. Develop stronger collaborations between Hawaii's Aging Network and Adult Protective Services. Institute statutory changes needed to uphold the dignity, safety and rights of people with ADRD and their care partners.
6. Improve safety for people with ADRD and their care partners.
- 6a. Target persons who live alone with dementia and educate them on fall prevention, as well as offering home safety assessments, and how to monitor those that wander from home.
- 6b. Ensure clear Federal Emergency Management Agency (FEMA) guidelines for evacuating and sheltering people with dementia and their care partners.
- 6c. Develop Hawaii's crisis capacity for care partners who are burnt out or ill, or when the person with dementia is having severe behavioral issues. Presently, there is little or no crisis intervention or safe and affordable emergency respite options in the state for these situations.

6d. Expand programs like Project Lifesaver, a project of the Hawaii Fire Department on Hawaii Island, statewide. The project’s mission is to provide timely response to save lives and reduce potential injury for adults and children who may wander due to Alzheimer’s, autism, and other related cognitive conditions.

6e. Develop artificial intelligence, remote monitoring, and other technology to help persons with dementia age in place.

6f. Create Silver Alert system in Hawaii, a program that sends out an alert to help find older adults who are missing.

6g. Address issues of loneliness and social isolation, particularly during the COVID-19 pandemic. One caregiver respondent to the Dementia Experiences Survey, indicated that:

“It has helped and hurt. The senior free daily/ weekly meals have been a huge blessing for my father! But he really misses going out and hanging out at McDonald’s with a book. He feels lonely, he tells me, and would like someone to chat with.”

ADVOCACY SPOTLIGHT

While no federal legislation coordinates the search of missing persons with ADRD, many states, including Hawaii, are exploring “Silver Alert” Systems. During the 2020 legislative session, Hawaii Senate Bill 3123 continued that effort, and although not enacted, advocates intend to continue their efforts during the 2021 Hawaii legislative session

Goal 4: Enhance public awareness and engagement

The public will be well-educated about brain health and dementia, risk factors, recognition of early signs of dementia, and behavioral issues – and are able to maintain good health practices and appropriately access resources when necessary. Public awareness of ADRD is one of the most recommended goals of all state, national, and global plans. The fear and stigma associated with dementia are compounded by a lack of knowledge and public education about the disease, its stages, the treatments, how to support caregivers, and where to get services.

Progress in Hawaii Since 2013

Hawaii has made substantial progress in improving public awareness about ADRD. First, the Alzheimer’s Association- Aloha Chapter’s ongoing mission is to raise awareness on the importance of early detection so that families can prepare and make long-term care and end-of-life decisions. A commercial aired by the Alzheimer’s Association, Aloha Chapter through

KHON from January - March 2019 resulted in a 72% increase in program contacts and a 57% increase in the number of physician referrals.

Second, the Alzheimer's Association also held a statewide series of community forums in 2018, which revealed updated insights into the unique challenges facing Hawaii's rural care partners and persons with dementia. In particular, the following were key lessons learned: 1) transportation continues to be a significant barrier in 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.

Third, with federal ACL funding provided to the COA, EOA, and CCH, there have been extensive efforts to promote dementia awareness and education in the state. The trainings targeted Hawaii's health care providers, including primary care providers, other allied health professionals, paraprofessionals, state agencies that are part of the No Wrong Door Network, and family caregivers statewide. The core concepts covered by the training included: 1) basic dementia capability, specifically distinctions between normal aging and dementia, treatments, and communication strategies; 2) the use of the AD8 Dementia Screening Interview (AD8) and Mini-Cog screening tools to promote early detection; and 3) special topics including non-pharmacological strategies to manage behavioral challenges, end-of-life care, and dementia with intellectual and developmental disability populations. To accomplish this, the federal ACL grantees in Hawaii coordinated in-person and virtual trainings in partnership with the John A. Burns School of Medicine, Department of Psychiatry and Department of Geriatric Medicine's Geriatric Workforce Enhancement Program; Positive Approaches to Care certified trainers; Kokua Mau, a Hawaii non-profit organization which focuses on advance care planning, hospice, and palliative care; and the National Task Group on Intellectual Disabilities and Dementia Practices.

Another effort connects Hawaii to a global initiative to reduce stigma around dementia. Dementia Friends Hawaii, part of Dementia Friends USA and connected to Dementia Friends programs in other parts of the world, is a public engagement initiative that aims to provide education and build dementia-friendly communities. The program is a partnership between Age-Friendly Honolulu and the 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 has been targeting different sectors in the community, including libraries, financial sectors, senior groups, churches and schools. Manoa Cottages in Kaimuki and Manoa have trained their staff in the Dementia Friends curriculum. Thus far, Dementia Friends Hawaii has trained nearly 1400

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.

Finally, community organizations continue to champion aging and dementia education. Positive Approach to Care (PAC) trainings have been offered statewide and led by Dorothy Colby, certified trainer and Director of Community Engagement at Hale Kuike. PAC is a nationally recognized training developed by an occupational therapist and delivered via in-person, group sessions by a local certified trainer. The content focused on making positive connections, helping caregivers see more than just loss, addressing challenging behaviors, assisting with feeding and dining tasks, and preparing for the end of life. The focus is on providing family caregivers with the practical knowledge needed to keep their loved one with dementia at home and maintain their quality of life. Another valuable training series, Dealing with Dementia, has been offered by Hale Hau`oli Hawai`i with support from the Rosalynn Carter Institute of Caregiving. The training series focused on understanding dementia, addressing problem behaviors, and managing stress. Hale Hau`oli Hawai`i followed up with another series of workshops called “Dementia in the Family”, which covered caregiving, legal, and stress management issues. Lastly, Generations Magazine’s Aging in Place conferences are visible and well-attended events that include dementia presentations.

LOCAL RESOURCE

Many people living in Hawaii do not speak English as their primary language, thus, public awareness and engagement efforts must consider the diverse language needs of the state. For example, EOA translated “Worried About Your Memory” into Ilocano, Japanese, Korean, Marshallese, Simplified and Traditional Chinese and Tagalog:
<https://hawaiidrc.org/site/459/hadssp.aspx>

Updated Strategies

1. Think broadly about partnerships to assist in disseminating ADRD public awareness including:

| | |
|---|--|
| <ul style="list-style-type: none"> • Younger care partners (including child caregivers and millennial caregivers) • Former caregivers • Medical professionals, broadly defined (including, but not limited to Primary Care Physicians (PCPs), allied health professionals, pharmacists, formal caregivers) | <ul style="list-style-type: none"> • Office of Language Access • Schools/ students (including but not limited to health sciences, business, law, architecture, and engineering programs) • Transportation providers including, but not limited to The Bus, Handi Van, taxis, Uber, Lyft, non-emergency medical transportation providers |
|---|--|

- Senior and respite companion programs
- Federally Qualified Health Centers
- Organizations and providers of persons with disabilities
- Financial institutions
- Bar Association
- Department of Parks and Recreation Senior Clubs
- Community organizations serving Native Hawaiian and Pacific Islander groups

- Grocery stores
- Emergency providers including, but not limited to law enforcement, fire fighters, first responders
- Faith-based community
- Resident managers and property managers

SPOTLIGHT: Human interest stories are a valuable awareness strategy. View this impactful story about Dr. Poki`i Balaz and her father at: <https://www.khon2.com/kupuna-life/kupuna-life-a-caregiver-for-the-ages/>



2. Employ creative methods and strategies to increase effectiveness and impact of dementia education.

2a. Increase culturally appropriate ADRD outreach.

2b. Share human interest stories broadly on web, TV, radio, print, and podcasts and utilize local celebrities with large followings.

2c. Create an intergenerational marketing campaign that is inclusive of all generations and identifies the impact of the disease on the entire family.

- 2d. Generate awareness among younger generations through digital games or apps as well as engagement of health science students as volunteers.
 - 2e. Target PCPs to normalize conversations about memory concerns and conduct regular cognitive screening.
 - 2f. Connect brain health messages to prevention of other diseases (e.g., connection between heart and brain health).
- 3. Build capacity for public education campaigns by identifying additional funding mechanisms, including private sector and corporate support.
 - 4. Identify critical ADRD messages to support families with ADRD at all phases of the disease, including: a) brain health; b) warning signs; c) early detection and diagnosis; d) steps after diagnosis; e) community resources and long-term planning; and f) special issues including living alone with ADRD and addressing stigma.

LOCAL SPOTLIGHT

Public awareness of support needed for care partners is paramount to a growing population of people living with ADRD. Encouraging care partners to prioritize their own health and well-being can be a challenge. A resource developed by the Alzheimer's Association, Aloha Chapter, helps increase awareness among care partners and provide encouragement to accept help through support groups: <https://youtu.be/JdUNAMgCFjw>

Goal 5: Improve data to track progress

Hawaii needs to identify measurable indicators to track progress in reaching its goals and objectives. Additionally, Hawaii should develop a system for collecting the data and monitoring the implementation of its action plan. Consistent sources of data can contribute to continuous monitoring, quality improvement, and guide programmatic and policy decisions.

Progress in Hawaii Since 2013

Steps have been taken to standardize and better understand the needs of persons with ADRD. First, an ADRD Data Advisory Team was established in 2019. EOA and COA partnered with the Telecommunications and Social Informatics Research Program/Pacific Health Informatics and Data Center (TASI/PHIDC) group at the University of Hawaii. The TASI/ PHIDC group analyzed the Hawaii-specific All-Payer Claims Database, which includes Medicare data for disease prevalence, healthcare services utilization, and costs.

Second, standardized dementia screening has been added to the ADRC in-home assessment tool. In particular, ADRC staff utilize the validated Mini-Cog and AD8 with clients who express memory concerns. The in-home assessment data, with the expanded dementia screening, can provide a larger picture of the demographic characteristics, health and social needs, and services provided to clients with memory loss.

Third, federal funding has enabled EOA to purchase the cognitive decline module of the Behavioral Risk Factor Surveillance System (BRFSS). This Centers for Disease Control's national survey collects state-level data on health-related risk behaviors, chronic health conditions, and use of preventive services. Results from the 2020 BRFSS survey in Hawaii, including the cognitive decline and caregiver modules, will be available in 2021.

Updated Strategies

1. Identify opportunities for improved data collection and analysis on ADRD in Hawaii.
 - 1a. Collaborate with agencies and organizations that have an interest in developing a better surveillance system for dementia.
 - 1b. Pursue continuous funding for data collection and analysis, including the administration of the cognitive decline and caregiver modules in the BRFSS survey.
 - 1c. Continue collaboration with UH TASI and their All-Payer Claims Database to continue to analyze service utilization and costs by comparing the ADRD population and the non-ADRD population. Utilize updated data as available (updated Medicare, Medicaid, dual eligible data).
 - 1d. Expand partnerships to collect data from persons with dementia and their care partners and encourage participation from those underrepresented in research (for example, Native Hawaiians and other Pacific Islanders). Sources include but are not limited to: Physician offices (e.g. primary care physicians, audiologists), community health clinics (e.g. federally qualified health centers), churches, and community forums (e.g. AARP events).
 - 1e. Identify additional data sources to better understand the needs and issues of persons with ADRD, including: ADRD within Hawaii's Medicaid population, family caregiver costs, out-of-pocket ADRD expenses, quality of care/ life for the patient and care partners, and stress and well-being of ADRD families.
2. Use data effectively for continuous quality improvement and to inform providers, program development, and policy
3. Use data and evaluation to monitor progress on the implementation of the state plan and set new goals to further Hawaii's dementia capability.

Concluding Thoughts

While all strategies are important, the feedback received throughout this update suggests stronger intersections are necessary between public awareness needs and all goals within the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias. Strengthening the quality of and access to dementia capable LTSS by 2025 is paramount, however, denial and shame restrict many with early cognitive impairment from sharing cognitive concerns with providers. Even among ADRD providers, worry of one's own brain health was evident, suggesting that we need to continue increasing public awareness to challenge broad dementia stigma in our state.

"Lately words do not come out as easily... [I'm] forgetting the right words to use or say. [I] get distracted easily and so forget what I was gonna do or what I went to the kitchen for," going on to share that she is worried about forgetting appointments and meetings.

-Powerful Tools for Family Caregivers support group facilitator worrying about her own memory

Stigmatizing attitudes of ADRD as a mental health diagnosis and cultural myths that normalize cognitive impairment will be difficult to overcome. Challenging this paradigm, however, EOA intends to continue statewide leadership and collaboration, inviting all systems that serve people living with ADRD and their caregivers to participate in making Hawaii more dementia-capable and making our communities more dementia friendly. EOA is also supporting and empowering families to better navigate and access support services, as evidenced by the Memory Care Roadmap for the Family Caregiver (See Appendix C).

Next Steps

This report is an update for the 2021 Legislature, highlighting ADRD as a critical public health emergency and challenge for Hawaii's families. The next step is to conduct a full update of the state plan. In October 2020, EOA received a 3-year dementia planning grant from the Centers for Disease Control (CDC), as part of its "BOLD Public Health Programs to Address Alzheimer's Disease and Related Dementias" funding opportunity. The purpose of the opportunity is to align Hawaii's state plan with the CDC Healthy Brain Initiative Roadmap. Over the next several months, the EOA will contract with an ADRD coordinator using grant funds to begin grant planning activities. At the same time, during the 2021 Legislative session, EOA will advocate for full-time 1.0 FTE funding for the Alzheimer's Disease coordinator position and if approved, will hire a full-time ADRD coordinator.

With CDC funding, the ADRD coordinator will engage a diverse group of stakeholders to expand the Hawaii ADRD State Plan in order to:

- **Ensure inclusion and expand the use of effective interventions** by the Aging and Disability Resource Center (ADRC) sites and LTSS service providers.
- **Increase the number of sources of data** and ensure consistent reporting in order to ensure continuous quality improvement and the use of data to guide program and policy decisions
- **Improve knowledge** by healthcare professionals about the best available evidence on dementia, caregiving for persons with dementia, and available tools and supports.
- **Increase messaging and create tailored messages** targeted to different AAPI communities on the important role of caregivers.

Mahalo to stakeholders who have contributed to this state plan update. In the next several months, the EOA will re-engage stakeholders and expand stakeholder involvement to begin implementation of the CDC grant.

References

1. Alzheimer's Association. Alzheimer's Disease Facts and Figures. Retrieved 10/28/20 from <https://www.alz.org/media/documents/hawaii-alzheimers-facts-figures-2018.pdf>
2. Alzheimer Dis Assoc Disord. 2015 Jan 24. [Epub ahead of print] PMID: 25626635

Appendix A. List of ADRD Taskforce Members

| NAME | ORGANIZATION |
|------------------------|--|
| Aida Wen, MD | University of Hawaii, JABSOM |
| Andrew Yeh, Ph.D. | University of Hawaii, Telecommunications and Social Informatics Research Program / Pacific Health Informatics and Data Center (TASI/PHIDC) |
| Dr. Brett Lu | University of Hawaii, JABSOM |
| Calvin Hara | Retired, Manoa Cottage |
| Christy Nishita, Ph.D. | Consultant, University of Hawaii, Center on Aging |
| Caroline Cadirao | Executive Office on Aging |
| Cristina Valenzuela | Executive Office on Aging |
| Dawn Meaney | Plaza Assisted Living |
| Debbie Shimizu | Executive Office on Aging |
| Diane Terada | Catholic Charities Hawaii |
| Dorothy Colby | Hale Kuike |
| Felicia Marquez-Wong | Retired, St Francis Hospice |
| Gary Simon | AARP Hawaii |
| Heather Chun | Consultant, University of Hawaii, Center on Aging |
| Ian Ross | Alzheimer's Association, Aloha Chapter |
| Ivy Castellanos | Alzheimer's Association, Aloha Chapter |
| Janie Tomihara | Retired, Department of Health, Public Health Nursing |
| Jody Mishan | Catholic Charities Hawaii |
| Kamal Masaki, MD | University of Hawaii, JABSOM |
| Katelyn Shirai | University of Hawaii, Student |
| Kathy Wyatt | Hale Hau'oli Adult Day Care |
| Kevin Kawamoto | University of Hawaii |
| Kore Liow, MD | Hawaii Pacific Neuroscience |
| Ku'unani Demante | Caregiver's Heart Hawaii |
| LJ Duenas | Alzheimer's Association, Aloha Chapter |
| Linda Axtell-Thompson | Policy Advisory Board on Elder Affairs (PABEA) |
| Lori Tsurada | Adult Protective Services |
| Lucas Morgan, Ph.D. | I Ola Lahui |
| Lyn Moku | Catholic Charities Hawaii |
| Mary Gadam | Retired, Department of Health, Public Health Nursing |
| Paige Heckathorn Choy | Healthcare Association of Hawaii |
| Poki'i Balaz, APRN | Lunalilo Home, Kokua Kalihi Valley |
| Ray Rice | Adult Protective Services |
| Ritabelle Fernandes | Kalihi Palama Health Center |
| Sean Okamoto | University of Hawaii, Telecommunications and Social Informatics Research Program / Pacific Health Informatics and Data Center (TASI/PHIDC) |
| Tricia Medeiros | Plaza Assisted Living |



Dementia Experiences in Hawaii

Hawaii first developed a **State Plan on Alzheimer's Disease and Related Dementias (ADRD)** in 2013. Five goals were identified: 1) Prevent and effectively treat dementia; 2) Enhance care quality; 3) Increase available support services in the community; 4) Enhance public awareness about dementia; 5) Improve data to track progress.

A lot has changed over the last seven years. To better prepare and identify opportunities to help persons with dementia and their caregivers, the Executive Office on Aging and UH Center on Aging would like to hear your thoughts and experiences with ADRD in order to update the plan.

Whether you are someone with dementia, a family member, a provider, or advocate, we would like to know how dementia has impacted you! Please complete this brief survey. Please feel free to share this survey with others as well.

Please complete by August 31, 2020.

1. First and Last Name (Optional)

2. E-mail address (Optional)

3. How has Alzheimer's Disease or related dementias affected your life or your work?

Appendix B- Dementia Experiences Survey

4. What are you MOST concerned about (as someone with dementia, caring for someone with dementia, or a professional)?

5. What is the ONE CHANGE you would like to see in Hawaii in the future? (Dementia-related, of course!)

6. If you are a person with memory loss or a caregiver, what kind of help or support is most valuable to you (e.g., respite care, neighbor checking in)?

7. How has COVID-19 impacted you (as a person with dementia, caregiver, etc)?

8. (Optional) Tell us an uplifting personal story about your experience with dementia! Interested in sharing a photo with us (e.g., caregiving or other good work you do)? Please email to uhcoa@hawaii.edu

Thank you for sharing your feedback! Later this summer, UH Center on Aging will put together findings from this survey and input from our stakeholders to draft an update of the "Alzheimer's Disease and Related Dementias State Plan". We will then ask for community review and feedback on the updated plan before finalizing. If you have any questions, please e-mail cnishita@hawaii.edu

Appendix B. Dementia Experiences Survey- Highlights
May to August 2020

Total Survey Responses from Persons with ADRD, Caregivers, and Professionals (n = 141)

Highlights and Quotes:

1. Feedback from those living with ADRD

- Concern about future disability
 - “My aging mind is still okay but it is becoming more challenging to engage in complex mental tasks and I’m concerned about possible future disability.”
 - Concerned about: “Being able to make competent decisions and managing to be self-sufficient in running my affairs”
- Concern about daily tasks
 - “Lately words do not come out as easily. . .in other words, forgetting the right words to use or say. Get distracted easily and so forget what I was gonna do or what I went to the kitchen for.”
 - Concerned about: “medication and keeping appointments”
 - “Family education, for the young as well, to understand why grandma/grandpa acts the way they do. Not to be afraid being around people with dementia.”
 - “Isolated and lack of activities for this active senior, stress and frustration on a high level.”
- Interest in supporting others with ADRD
 - From Powerful Tools for Family Caregivers program facilitator sharing positive aspects of the program: “...having participants know that they are NOT alone. Sharing of stories and experiences builds the confidence that they can do it!”

2. COVID-19 Impacts

On person with ADRD

- Increased anxiety and confusion
- Lacking understanding on proper mask wearing and need for increased sanitation
- Social isolation/ lack of stimulation
 - For those living at home
 - “It has helped and hurt. The senior free daily/ weekly meals have been a huge blessing for my father! But he really misses going out and hanging out at McDonald’s with a book. He feels lonely, he tells me, and would like someone to chat with.”
 - “So far, I have not been impacted by COVID-19 and I'm trying to be very careful to avoid this disease.”
 - For those living in long-term care facilities
 - “Restricted Visiting policy at facilities and care homes on lockdown.”

Appendix B. Dementia Experiences Survey- Highlights

May to August 2020

- "...a good friend was not able to visit her mother dementia. And although her mother was already frail, not visiting her mother added to her mother not eating and failure to thrive."
- "My family is not allowed to see my grandma [with dementia] who lives in a care home. We take her out every weekend for lunches but are unable to. We will miss her birthday, but technology will allow us to see her, just not hug her."
- "I have not been able to visit my loved one in a care home."
- "I was deemed essential at the onset of the COVID-19 epidemic, so I've been at work every day throughout. I was prohibited from seeing my father in his nursing home because of the pandemic, and he died there alone, 2 months ago."
- Increased hospitalizations
 - "My clients have had fewer outings, less contact with immediate family. My clients have fewer outlets to reduce their pre-existing mental health conditions and have had multiple hospitalizations due to lack of coping skills available to them." Case manager (who also has experienced ADRD with grandparents earlier in life)

On Caregivers

- Caregivers feeling their own social isolation, decreased mental health, and increased anxiety and doubt in ability to provide adequate care
 - "My Mom hasn't been out of our house since March 20. Her day care is closed. She used to attend twice a week. I've only been out twice, once to take a blood test and once to go to the bank. Both times I was able to go out because a cousin came in to watch Mom."
 - "My sister in the Mainland tries to help. She does a FaceTime session with Mom each day for 1-2 hours, so I can get some rest. They sing, talk and count. My sister tries to get Mom to do some kind of craft, like tying bows with ribbon. Mom doesn't always cooperate, but my sister keeps trying. It's a real help."
 - "My mother's Adult Day Health Care Program is closed and has been since March. I've had to keep my mother at her home and provide 24/7 care with the help of caregivers along with continuing to work full time at my current job."
 - "Meals on Wheels. This was stopped due to COVID pandemic and is sorely missed."
 - "Limited accessibility to health care and groceries are major issues that everyone are dealing with during the COVID-19 pandemic. I believe that caregivers are most affected as they have to deal with both their loved ones and self."

Appendix B. Dementia Experiences Survey- Highlights
May to August 2020

- “In order to keep my parent safe, family caregivers must keep themselves fairly isolated as well. Lack of stimulation for parent whose only outing is to go on rides w/o getting out of the car. Have had many Dr. appts. cancelled. Will see how well the telehealth works.”
- “Allowed me and my sister to work from home, making it easier for other caregivers to have us here. It will be difficult for everyone, when we have to work from our offices.”
- “I am reluctant to see elders in my family in their homes for fear of exposing them to COVID-19. But, distancing myself from my family elders has an emotional price for me.”

On Professionals:

- Professionals faced numerous challenges in providing care and facing closures of worksites.
 - “I can only service half my clients, as to stay 6 feet apart! Daily!” – Malama Adult Day Care service provider
 - “Our adult day center had to close for 3 1/2 months during COVID-19 and laid off 27 employees (re-opened July 1, 2020) Our caregivers had to care for their loved ones with dementia, etc. during this time 24/7 without any form of respite. We were in contact with our caregivers during this time and while they managed, they could hardly wait until we opened again. We have seen some diminished conditions of some of our participants as they returned to the center.”
 - “As a nursing home social worker, COVID -19 has added more job stress and anxiety over keeping the virus away and my clients safe. Also having to go to work every day, hoping not to get the virus or unknowingly being a carrier.”
 - Virtual engagement has made it challenging to assess functional changes
 - “Remote assessments, relying on caregivers to be honest communicators for seniors needs, when they may have an agenda or lack of awareness or understanding about disease or person needs.”
 - “We have more people in the hospital, whose families could not keep them in the home (they would just leave, because they do not understand COVID-19 and staying home. We also have had no services for patients and families.” – hospital social worker
 - “We have had to decide who could come back to the Center and who could not. Those that would not sit in their 6ft. space and wants to touch everything and everyone. Those that drool (bodily fluids). Most dementia people will not keep their masks on. Constant cleaning where they've touched.” – Adult Day Care specializing in memory care
 - “Limited home visits and facilities not accepting new clients as residents. COVID-19 testing protocols for admission vary.”

Appendix B. Dementia Experiences Survey- Highlights
May to August 2020

- “As a member of the ADRC team, we focused on helping people not to feel isolated. Had some success connecting people with Dementia and their caregivers to support groups via video communication.”
- “COVID-19 has limited our ability to provide direct Public Health Nursing services.”
- “COVID-19 has slowed ability to support persons with dementia and their family caregivers, because of the restriction on PHN home visiting. Caregivers have been left with little support, in absence of the adult day care, which closed due to COVID 19 March 23-June 1, 2020. Many assigned in-home staff caregivers had to stay home with school-age children when schools closed, diluting the already strained homebased agency caregiver pool. People kept coming out of the hospital needing home services, or declining in function during the COVID-19 shutdown months, but our capacity to assist them has been limited, and elders living in unsafe conditions have proliferated. "early dementia can live alone with adequate support services". In absence of adequate service providers, able to visit homes regularly, early dementia patients have been at risk.” – Public Health Nurse, West Hawaii
- “We have seen an increase in the amount of referrals to do "Welfare Checks" on vulnerable seniors with medical issues and dementia that either are staying at home to avoid COVID-19 or who are making poor decisions r/t dementia and going out to seek services. Unfortunately, with COVID-19, we could not do a lot for these clients and there were very few resources to help these clients.”
- “The senior center I am the head of has closed, so we have had to offer online classes to seniors. However, many of them do not have computers or smart phones to access such programming. We are making phone calls to every senior center member and mailing birthday cards to keep their spirits high and to assist them to fulfill their basic needs and connect them with community services. It is a time that the human spirit shines brightly with the kindness, appreciation, and thoughtfulness shown by seniors and their families, the community and our staff.”
- “Severely complicated face-to-face interactions which result in heightened anxiety on the part of those with dementia conditions.”

3. Uplifting Stories and ADRD Experiences

From Caregivers:

- “It definitely gives my life a sense of purpose. It has led me to focus more on the present moment and enjoy it. It has also led me to focus more urgently on the spiritual than the temporal, realizing how fragile and changeable our life circumstances are. This makes me a more stable person.”

Appendix B. Dementia Experiences Survey- Highlights
May to August 2020

- “When the one you give care to, looks you square in your eyes, recites your name, and tells you how much they love you and appreciate all you do for them (which is giving them the care they need, with love, respect, understanding, and patience).”
- “My father's change in personality with Alzheimer's had a special silver lining to the cloud.....despite all the horrid and strange and odd and scary and sad, mad and bad behavioral changes, he also became much more expressive, open and sharing of his feelings and love for me. My father was raised in a strict catholic New England family where there was no showing of affection. His hugs were more of a distant “pat pat” on the back. I could count on 2 fingers how often he had told me he loved me through the 55 years before his Alzheimer's set in. As his Alzheimer's progressed, he became more and more affectionate, to the point that when I would enter the room, he's jump up out of his chair, raise his arms up in the air and say "oooooh, you're here, you're here!" and then put out his arms for a big hug. And when I'd tell him I loved him, he'd finally tell me he loved me too.”
- “A good friend and former parish nurse, set up a rotation with six people who each came by to take my Mom on an outing each week, based on what they liked doing. One would take her to a lunch and matinee. Another to the art museum, another on a drive to Kailua to see the beauty of the mountains, ocean, trees. When it was hard to take Mom out, some chose to visit her at our home. One read her Winnie the Pooh stories, another brought lunch and they watched the Three Tenors DVD multiple times. It was quite precious. She couldn't recall later what she'd done but in the present, she was elated.”
- “Since my partner can't remember to worry he wakes up happy and care free and he always tells me how great life is.”
- “Given that my grandmother took care of me, it was not just an exhausting experience, but the most rewarding experience ever being able to care for her. It made me see things differently, humbled me.”
- “My grandma was lucky enough to have a strong support system of 4 caring children. Seeing all the family members come together to help care and take her on outings was special to see because we lacked that connection and closeness when grandpa died in 2011. It was a silver lining that her [dementia] brought the family together. Even though she is now in a care home, after living with family for 10+ years, we are closer and initiate more family gatherings besides holidays (Card night). Of course, COVID-19 put a stop to that, but we are looking forward to when a vaccine is created.”
- “Alzheimer's Association has been a life savor in numerous situations!!”
- “I was caregiver for my Mom. Growing up we were a dog family and Mom hated cats! Every time my best girlfriend's cat would have kittens, she would beg my Mom to let me have one. When Mom came to live with me, her dementia allowed her to forget that she hated cats and she absolutely loved to watch my cat play and loved it when he would curl up on her lap.”

Appendix B. Dementia Experiences Survey- Highlights
May to August 2020

- “A strange and wonderful thing happened to my [sister] who had had a left- brain stroke affecting speech. She began getting lost in her daily routine forgetting what to do. She was put on Alzheimer’s meds, [which improved] her speech that was affected by the stroke, amazingly improving [her] enunciation and sentence structure.”
- “The last thirteen years of my mother's life were the best years of our relationship. She lived in a foster home for ten years before passing. She had excellent care and was treated as a family member (the entire family called her "mother.") My visits with her were spent driving all over the island; going to restaurants; eating anything she wanted to eat; and talking for hours while she listened and smiled. I set and combed her hair; gave her manicures and massages; held her hands; and kissed her all over her face when I left to go home. The grandkids would visit her, sharing their coloring books with her and arguing over who the toys belonged to. We had tea parties; wore birthday tiaras and laughed so hard we cried. For the first time in her life she had no worries and that was a good thing. She was always smiling and seemed genuinely happy. We didn't think about AD as time went on. We just enjoyed the time together and were left with wonderful memories.”
- “The staff at the home kept telling me what bad shape my mother's memory was in. It was discouraging. Then last February, as I sat with her and the staff was adjusting the TV, mom & I were having a chat about shows, my Mom made her comments in Spanish and the staff immediately became attentive! "I didn't know you could speak Spanish" ..worker said. I replied yes my mom taught herself Spanish years ago to help at work and funny huh she remembers how to comment to you in another language. It showed me you can't rule an old person out by their outer appearance. I hoped it showed staff too not to assume things. Mom died in May at 102.5 years old.”
- “Mom was 96 when she passed away. Gratefully, despite the decline from the disease, she maintained a sweet and calm disposition, often expressing her gratitude for everyone's care and help. She was able to engage in (relatively lucid) conversation and could sing along with songs from early days. HAPPY BIRTHDAY song was a favorite and sung often at Hale Malamalama and one day after the group sing-a-long, one of the staff randomly wished Mom happy birthday. From what I understand, Mom thought about it, then asked the staffer if it really was June 20 (her birthday.) It wasn't! Think staff were surprised that that had bubbled up from her long term memory. We are very grateful that dementia never robbed us of Mom's personality or clouded her memory so much that she lost her connection to us, especially to Dad. Until the end, Mom knew him by name, knew he was her husband and would express disbelief when reminded that she'd been married to the same man for 70 years. Know that this brings Dad some comfort everyday.”
- “I am amazed at my mother's approach to her situation. Note it is complicated by a back injury that has he wheelchair bound. She rarely complains, she is appreciative of

Appendix B. Dementia Experiences Survey- Highlights
May to August 2020

all that we do and I am amazed by her resiliency. An amazing woman, mother, grandmother and great- grandmother. Love you mom!!”

- “Although my mother-in-law lived for decades with ADRD and my wife sacrificed her career and earnings and retirement benefits, we would take the journey all over again. The wisdom passed on from my mother-in-law to our extended family members is a legacy treasure. The keiki in our extended family developed a remarkable depth of compassion in being caregivers for years to one of their beloved kupuna.” – from a caregiver who lived with his mother-in-law with ADRD for more than 25 years (from 1994 to 2019). His, “wife quit her career in 1994 to provide around the clock support to her mom, who died in our home in 2019.”

From Professionals:

- “Two gentlemen who were moderate to late Alzheimer's that knew each other but never socialized together, were put with a caregiver who took them riding weekly. They both talked nonstop the whole entire time like best friends, and yet would not have said more than hello previously. I have seen pairing that would never have imagined that were perfect together at this time in their journey. Never can assume anything and everything is possible just don't give up!”
- “We take Miniature Horses to Long Term Care facilities to visit with their residents...It is the highlight of their week.”
- “We are caregivers. we take care of dementia clients all day every day. We find the most rewarding times are during those moments of clarity when they come through with an appropriate statement like ‘thank you for being so kind to me’ or ‘thank you for taking care of me’ or ‘did you know this is my favorite song’ or ‘you have a beautiful voice’.” - Adult Day Care specializing in memory care
- “As fellow caregiver, I feel uplifted when I can help caregiver in the thick of it take a breath and appreciate the experience and time they are having with their loved one. Help them recognize that time with their loved one is limited commodity and enjoy all it while it lasts. Helping them recognize and re-frame caregiving as opportunity to create memories for themselves and experiences for their loved one that they can look back with joy and fondness and pride.”
- “There are seniors who let me know of their concerns with their growing inability to remember things, but they are proactive and want to seek out activities that help exercise their brain. The warmth and sweetness of these older adults even with what is happening to them is evident and endears all they interact with. I love and care about them.” – self identified as the head of a local senior center.

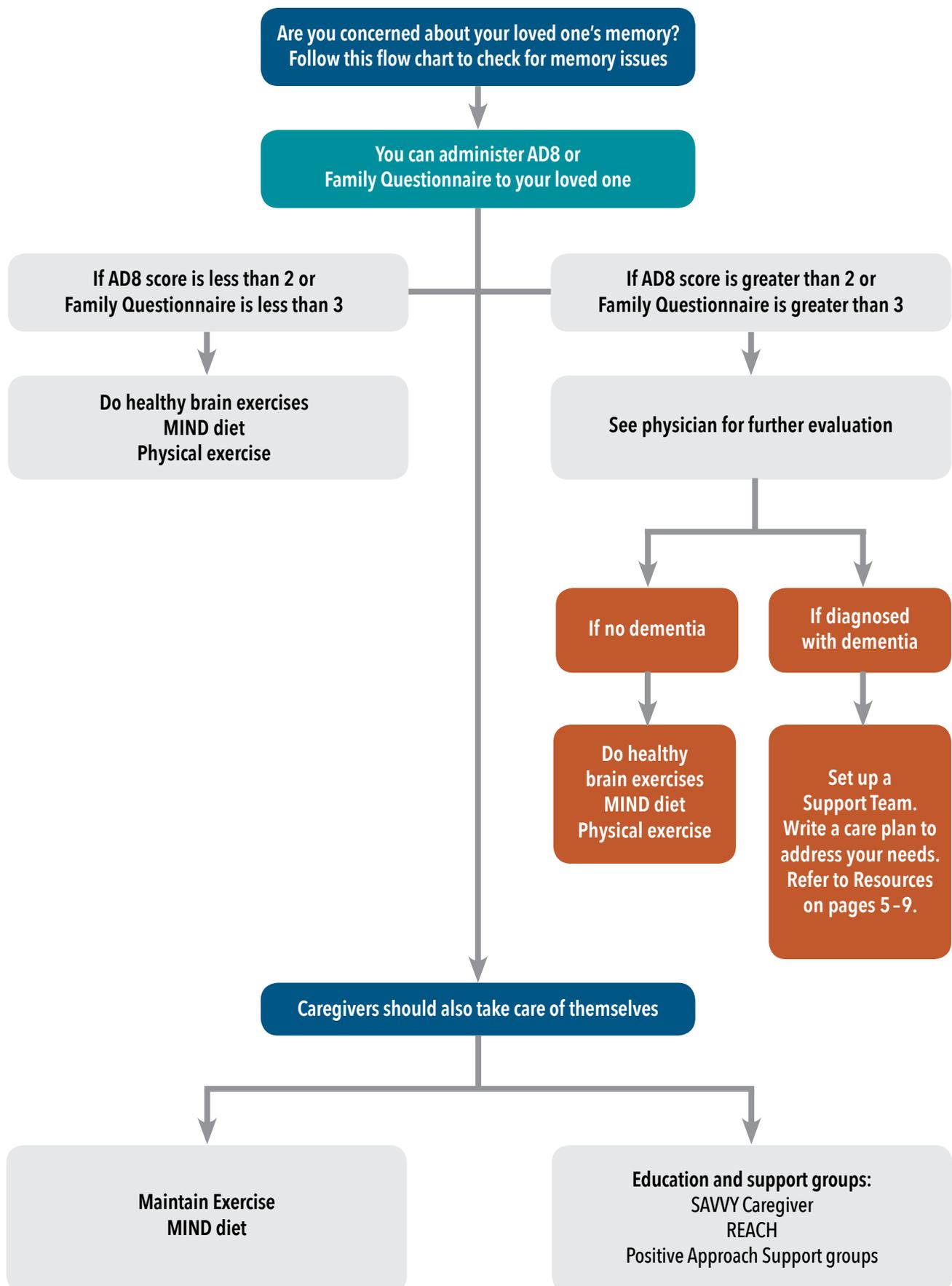


Memory Care Roadmap for Family Caregivers

A Guide for Families Caring for Their Loved One with Dementia

Roadmap for Family Caregivers

COGNITIVE SCREENING FLOW CHART



Roadmap for Family Caregivers

DEMENTIA SCREENING TOOLS

AD8 Dementia Screening Interview

| Remember, "Yes, a change" indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems. | YES, A change | NO, No change | N/A, Don't know |
|--|------------------|------------------|--------------------|
| 1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking) | | | |
| 2. Less interest in hobbies/activities | | | |
| 3. Repeats the same things over and over (questions, stories, or statements) | | | |
| 4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control) | | | |
| 5. Forgets correct month or year | | | |
| 6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills) | | | |
| 7. Trouble remembering appointments | | | |
| 8. Daily problems with thinking and/or memory | | | |
| TOTAL AD8 SCORE | | | |

Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, *Neurology* 2005;65:559-564.
Copyright 2005. The AD8 is a copyrighted instrument of the Alzheimer's Disease Research Center, Washington University, St. Louis, Missouri. All Rights Reserved.

The AD8 Administration and Scoring Guidelines

- A spontaneous self-correction is allowed for all responses without counting as an error.
- The questions are given to the respondent on a clipboard for self-administration or can be read aloud to the respondent either in person or over the phone. It is preferable to administer the AD8 to an informant, if available. If an informant is not available, the AD8 may be administered to the patient.
- When administered to an informant, specifically ask the respondent to rate change in the patient.
- When administered to the patient, specifically ask the patient to rate changes in his/her ability for each of the items, **without** attributing causality.
- If read aloud to the respondent, it is important for the clinician to carefully read the phrase as worded and give emphasis to note changes due to cognitive problems (not physical problems).
- There should be a one second delay between individual items.
- No timeframe for change is required.
- The final score is a sum of the number items marked "Yes, A change".

Scoring criteria = Scores in the impaired range (see below) indicate a need for further assessment. Scores in the "normal" range suggest that a dementing disorder is unlikely, but a very early disease process cannot be ruled out. More advanced assessment may be warranted in cases where other objective evidence of impairment exists.

- 0 - 1: Normal cognition
- 2 or greater: Cognitive impairment is likely to be present

Family Questionnaire

In your opinion does _____ have problems with any of the following?

Please circle the answer.

| | | | | |
|---|------------|-----------|------------|----------------|
| 1. Repeating or asking the same thing over and over? | Not at all | Sometimes | Frequently | Does not apply |
| 2. Remembering appointments, family occasions, holidays? | Not at all | Sometimes | Frequently | Does not apply |
| 3. Writing checks, paying bills, balancing the checkbook? | Not at all | Sometimes | Frequently | Does not apply |
| 4. Deciding what groceries or clothes to buy? | Not at all | Sometimes | Frequently | Does not apply |
| 5. Taking medications according to instructions? | Not at all | Sometimes | Frequently | Does not apply |

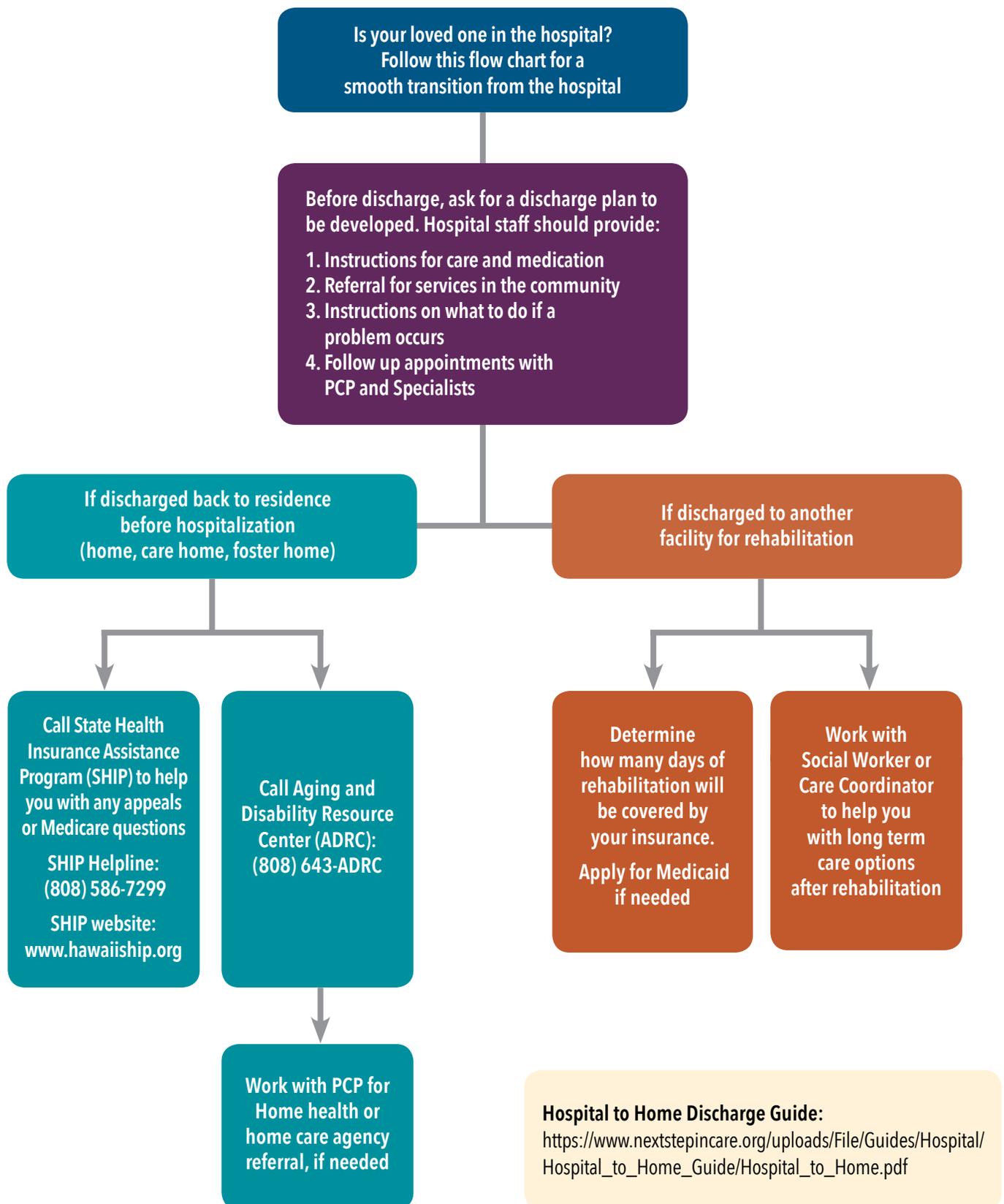
Relationship to patient _____ (spouse, son, daughter, sister, grandchild, friend, etc.)

Scoring: Not at all=0, Sometimes=1, Frequently=2. Sum to get total score. A score of 3 or more should prompt the consideration of a more detailed evaluation

*Adapted from the Care Management Advisory Group of the Chronic Care Networks For Alzheimer's Disease Initiative. Full version from: (<https://www.alz.org/documents/national/CCN-AD03.pdf>)

Roadmap for Family Caregivers

HOSPITAL DISCHARGE FLOW CHART



Roadmap for Family Caregivers

GUIDE TO CHOOSING CARE OPTION

A Caregiver's Guide in Choosing a Care Option

Introduction

Caregiving can be stressful and overwhelming for many families. Sometimes seeking outside help can be lifesaver for a caregiver. The extra assistance can help prevent caregiver's burnout while providing the kind of care that may be beneficial to the person with dementia. When searching for the appropriate service, caregivers may want help from a professional advocate to navigate our long-term care system which can be complex and confusing for many. Caregivers can contact the local county Area Agency on Aging (AAA) that is available in each county. They provide free information and referrals to the public. It is also the designated Aging and Disability Resource Center (ADRC), the one stop shop for information and resources for seniors, people with disabilities and family caregivers. The public may call the statewide number 643-ADRC (2372) or visit their website – www.HawaiiADRC.org to be connected to their local AAA/ADRC. The AAA/ADRC staff will assess the caller's needs and help identify the different options available in the community.

Options for In-home care

In-home care can help people continue to live independently or with family. Services range from weekly household chores to extensive overnight care. There are two types of in-home care:

1. **Home health care** - Home health care is required if your loved one has extensive medical needs (tube-feeding, medication administration, wound dressing change). A licensed staff (registered nurse or licensed practical nurse) is required to perform skilled nursing care. The fees for Licensed nurses range from \$30-50/hour.
2. **Home care** - Home care helps with personal care (bathing, grooming), meal preparation, light housekeeping, companionship, etc. Most individuals can be assisted by a home care aide or certified nurse aide whose rates range from \$20-25/hour. Many home care agencies have a minimum requirement of 2-4 hour of services and charges a one-time assessment fee. The agency will develop a plan of care based on the client and family's needs.

Home Care guide: https://www.nextstepincare.org/uploads/File/Guides/Home_Care/Guide/Home_Care.pdf

Options for Out-of-home Care

There is a wide range of home and community-based programs for individuals with dementia. Some services offer care during the day, while others can provide 24-hour coverage in the person's home, and/or full-time residence. Some families use a combination of in-home care and out-of-home care such as adult day care to provide the extra assistance needed especially if they are working caregivers with jobs. These are some out-of-home care options:

- Adult Day Care Center
- Adult Day Health Center
(for those who need more assistance during the day)
- Adult Residential Care Homes
- Foster Family Care Homes
- Assisted Living facilities with memory support units
- Nursing Homes

These facilities are designed to help individuals who are in varying stages of dementia. People can participate in a day care program for many years before gradually requiring more medical attention that can be provided by an adult day health center which has licensed nurses. Residential facilities assist individuals who can no longer reside safely in their own homes. Some assisted living and nursing homes offer temporary respite beds for caregivers who need a short break or a vacation. Nursing homes provide extensive medical supervision and extra help for individuals who need more care. Nursing homes are the most expensive long-term care service.

Tips for Selecting a Long-Term Care Provider or Facility trained to provide care for persons with Dementia

- ✓ Ask if the agency/organization provides services or supports to persons with memory loss or dementia
 - If yes, find out if they have any restrictions or limitations in serving those in advanced or late state dementia or with individuals with challenging behaviors related to dementia such as wandering or aggressive behaviors.
 - Ask if the staff has received dementia-specific training
- ✓ Ask about security measures to prevent wandering offsite, and search protocol for elopement
- ✓ Families have the option to ask for another caregiver if not compatible with the dementia client. Sometimes, people interact better with different types of personalities

Roadmap for Family Caregivers

DEMENTIA RESOURCES

Visit the Aging and Disability Resource Center (<https://www.hawaiiadrc.org>) for additional resources and information.

Note: Inclusion of an agency/organization in this Roadmap does not imply endorsement by HADSSP

Help with Diagnosis and Behavior Management

Refer to Specialist as Needed

- Neurologist (dementia focus, if possible) <https://www.hawaiiadrc.org/site/459/hadssp.aspx>
- Geriatric Psychiatrist, <https://www.hawaiiadrc.org/site/459/hadssp.aspx>
- Geriatrician (A doctor who specializes in treating conditions that affect older adults), <https://www.hawaiiadrc.org/site/459/hadssp.aspx>
- Information on stages & behaviors, <https://www.alz.org/care/alzheimers-dementia-stages-behaviors.asp>

Link to Caregivers Support Groups

Hawaii (Big Island)

- Alzheimer's Association Support Group, (800) 272- 3900, www.alz.org/crf
- Big Island Stroke Club, 1190 Waianuenue Avenue, Hilo Medical Center (The Learning Center), Hilo 96720, (808) 932-3045

Kauai

- Alzheimer's Association Support Group, (800) 272- 3900, www.alz.org/crf

Maui

- Alzheimer's Association Support Group, (800) 272- 3900, www.alz.org/crf
- Powerful Tools for Caregivers (UH Manoa Extension), 310 Ka'ahumanu Ave., Bldg. 214, Kahului 96732, (808) 244-3242 x226

Oahu

- Alzheimer's Association Support Group, (800) 272- 3900, www.alz.org/crf
- Castle Caregiver Support Group, (808) 263-5400
- Hale Hauoli Hawaii-Caregiver Support Group, 98-1247 Kaahumanu St., Suite 207, Aiea 96701, (808) 292-4665, www.halehauolihawaii.org
- Kokua Kalihi Valley Caregiver Support, 1846 Gulick Ave., Honolulu 96819, (808) 791-4900, www.kkv.net
- Caregivers Foundation Support Group, Various Locations, (808) 625-3782, www.thecaregiverfoundation.org
- Project Dana, Caring for the Caregiver Support Group, 902 University Ave., Honolulu 96826, (808) 945-3736, www.projectdana.org
- VA Caregivers Support Group, 459 Patterson Rd., Honolulu 96819, (808) 433-7646
- Windward Seniors Day Care-CG Support Group, 77 N. Kainalu Dr., Kailua 96734, (808) 261-4947, www.windwardseniordaycarecenter.org/resources.html

Link to Community Resources

- Contact the Alzheimer's Association – Aloha Chapter 24/7 Helpline at 1-800-272-3900 or www.alz.org/hawaii
- Contact Hawaii Aging and Disability Resource Center (ADRC)* statewide at 643-ADRC (2372) TTY line: 643-0889. Or, go to www.HawaiiADRC.org and click on "Professionals & Service Providers"
- Alzheimer's and Dementia Caregiver Center, www.alz.org/care/
- TrialMatch®, www.alz.org/trialmatch
- Life After Diagnosis, www.alz.org/alzheimers_disease_life_after_diagnosis.asp
- Taking Action Workbook, www.actonalz.org/pdf/Taking-Action.pdf
- NIH Caring for a Person with Alzheimer's Disease, <https://www.nia.nih.gov/alzheimers>

Counseling, Education, Support & Planning

*The Hawaii Aging and Disability Resource Center (ADRC) helps older adults, individuals with disabilities, and family caregivers find options for long term supports and services available to them in the State of Hawaii.

Roadmap for Family Caregivers

DEMENTIA RESOURCES - Continued

Counseling, Education, Support & Planning (cont'd)

Link to Community Resources (cont'd)

- Contact Case Management Services, By County/Statewide, 643-ADRC (2372), www.HawaiiADRC.org
- Contact Home Care/In Home Assistance, By County/Statewide, 643-ADRC (2372), www.HawaiiADRC.org
- Contact Adult Day Services, By County/Statewide, 643-ADRC (2372), www.HawaiiADRC.org
- Contact Respite Services, By County/Statewide, 643-ADRC (2372), www.HawaiiADRC.org
- Check if Home Care agency, Adult Day Services or Long Term Care Facility is licensed, <https://health.hawaii.gov/ohca/state-licensing-section/>

Link to Education Resources

- Online Education Programs - Presented by the Alzheimer's Association-Hawaii, 1-800-272-3900, www.alz.org/hawaii/
- Online Program Descriptions - Presented by the Alzheimer's Association-Hawaii, 1-800-272-3900, www.alz.org/hawaii/

Stimulation/Activity/ Maximizing Function

- Living Well Workbook, www.actonalz.org/pdf/Living-Well.pdf
- Adult Day Services, By County/Statewide, 643-ADRC (2372), www.HawaiiADRC.org
- Sensory aids (hearing aids, pocket talker, glasses, etc.), www.HawaiiADRC.org or 643-ADRC (2372)
- NIH's Caring for a Person with Alzheimer's Disease, <https://www.nia.nih.gov/alzheimers>
- Exercise for Frail and Disabled Elders, By County/Statewide, 643-ADRC (2372), www.HawaiiADRC.org
- Audient - Affordable Hearing Aids, 1-866-956-5400, www.audientalliance.net
- Hearing Aid Helpline, 1-800-521-5247, www.ihsinfo.org
- Seniors EyeCare Program, www.eyecareamerica.org
- Assistive Technology Resource Center Hawaii, 200 N. Vineyard Blvd, Honolulu 96817, (808) 532-7110, <https://www.atrc.org>

Medication Therapy and Management

- Family oversight or health care professional monitoring
- Identify all medications, including over-the-counter medications, vitamins and herbal remedies
- Educate patient and care partner on medication management aids (pill organizers, dispensers, alarms)
- Use a tool like "Tracking Your Medication Worksheet" and share the list with the healthcare team <https://www.nia.nih.gov/health/tracking-your-medications-worksheet>
- Medicine, Age, and Your Brain, <https://www.nia.nih.gov/sites/default/files/d7/MedAgeBrain-FactSheet.pdf>
- Medicare Part D, <https://www.medicare.gov/drug-coverage-part-d>
- Hawaii SHIP-Eligibility and help choosing a health plan, <https://hawaiiiship.org> (808) 586-7299, 1-888-875-9229
- Med-QUEST Division (Medicaid), Eligibility Branch Offices - County, <https://medquest.hawaii.gov/en/resources/med-quest-offices.html>

Cultural Resources & Language Services

- Screening diverse populations, <https://actonalz.org/screening-diverse-populations>
- HADI culturally competent resources, www.hawaii.edu/aging/coa-projects-all/hadi-project/hadi-resources/
- For materials in different languages, go to Alzheimer's Association (www.alz.org), scroll down to the bottom of the page and click on "Select Language".
- Bilingual Access Line (24-Hours) - Helping Hands Hawaii, 2100 N. Nimitz Hwy, Honolulu 96819, (808) 526-9724, www.helpinghandshawaii.org

Roadmap for Family Caregivers

DEMENTIA RESOURCES - Continued

Safety

Note: Individuals with dementia are vulnerable adults and may be at a higher risk for elder abuse and exploitation.

Driving

- Refer to driving rehab specialist/occupational therapist for clinical and/or in-vehicle evaluation
- Understanding Dementia and Driving, <https://www.thehartford.com/resources/mature-market-excellence/dementia-driving>
- At the Crossroads Guidebook, https://s0.hfdstatic.com/sites/the_hartford/files/cmme-crossroads.pdf
- Dementia and Driving Resource Center, www.alz.org/care/alzheimers-dementia-and-driving.asp
- Fitness to Drive Screening Tool, <https://www.aarp.org/auto/driver-safety/info-2013/fitness-to-drive-screening-tool.html?migration=rdrct>
- Rehab Hospital Driving Evaluation and Training Program, 226 N. Kuakini St., Honolulu 96817 (808) 566-3762, www.rehabhospital.org

Fall Prevention

- Preventing Falls Among Older Adults, <https://health.hawaii.gov/injuryprevention/home/preventing-falls/information/>
- Refer to an occupational therapist and/or physical therapist to address fall risk, sensory/mobility aids and home modifications
- Project Dana Fall Prevention Program, 902 University Ave., Honolulu 96826, (808) 945-3736, www.projectdana.org
- Connect America (Medical Alert System), 98-030-Hekaha St. #4 Aiea 96701, (808) 721-1201, www.connectamerica.com

Wandering

- MedicAlert® and Alzheimer's Association 24/7 Wandering Support, <https://www.alz.org/help-support/caregiving/safety/medicalert-with-24-7-wandering-support>
- Six out of 10 People With Alzheimer's Will Wander, <https://www.alz.org/help-support/caregiving/stages-behaviors/wandering>
- Wandering and Getting Lost, www.alz.org/care/alzheimers-dementia-wandering.asp

Legal/Financial

- Encourage patient, as appropriate, to include designating an agent and an alternate agent in a durable power of attorney for health care decisions and to designate an agent or alternative agent in a durable power of attorney for legal and financial matters.
 - UH Elder Law Program Health Care Decision Making, www.hawaii.edu/uhelp/elderlaw.htm
 - "Deciding What Matters and What to Do", www.hawaii.edu/uhelp/handbook.htm
- Refer to elder law attorney as needed
 - Hawaii State Bar Association Lawyer Referral & Information Service, www.hawaiilawyerreferral.com
 - University of Hawaii Elder Law Program, www.hawaii.edu/uhelp/
 - Legal Aid Society of Hawaii, www.legalaidhawaii.org
- Consumer Credit Counseling Services of Hawaii, www.cccsofhawaii.org/
- Guardianship Pro-se Packet, Steps to establish guardianship of an incapacitated person, <https://www.courts.state.hi.us/docs/1FP/ProSelncap.pdf>
- Mediation Services - Mediation Center of the Pacific, 245 N. Kukui St. Ste 206, Honolulu 96817, (808) 521-6767, www.mediatehawaii.org
- Affordable Lawyers Project, (808) 527-8027

Preventing Elder Abuse, Neglect and Fraud

- Monitor for Elder Abuse, Neglect and Fraud. If suspected, contact Adult Protective Services, www.humanservices.hawaii.gov/ssd/home/adult-services/
- Elder Abuse Justice Unit, Office of the Prosecuting Attorney, Honolulu, (808) 768-6452, <https://honoluluprosecutor.org/elder-abuse-justice-unit/>; Hawaii County, (808) 934-3461; Maui County, (808) 270-7777; Kauai County, (808) 241-1888

Roadmap for Family Caregivers

DEMENTIA RESOURCES - Continued

Safety (cont'd)

Preventing Elder Abuse, Neglect and Fraud (cont'd)

- Hawaii's Fraud Prevention & Resource Guide, www.cca.hawaii.gov/blog/news-release-hawaiis-fraud-prevention-resource-guide-gets-an-update/
- Information about Medicare/Medicaid Fraud, Contact Senior Medicare patrol (SMP), 1-800-296-9422, www.smphawaii.org
- Federal Hotline on Medicare, Medicaid or health care fraud- Inspector General's Office, 1-800-447-8477
- Office of Health Care Assurance, Hawaii Department of Health, <https://health.hawaii.gov/ohca/state-licensing-section/>
- Care Home Complaints, 601 Kamokila Blvd. #361, Kapolei, 96707, (808) 692-7400, <https://health.hawaii.gov/ohca/state-licensing-section/>
- Hospital and Nursing Home Complaints, 601 Kamokila Blvd. #395, Kapolei, 96707, (808) 692-7420, <https://health.hawaii.gov/ohca/state-licensing-section/>
- Long-Term Care Ombudsman, (808) 586-7268, for complaints by or on behalf of residents in long-term care facilities

Advance Care Planning

Hawaii Advance Care Planning and POLST Forms:

- Refer to advance care planning facilitator within system, if available
- Encourage, as appropriate, execution of advance health care directive and POLST forms
- Refer to Your Conversation Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia, <https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf>
- University of Hawaii Elder Law Program, 2515 Dole St. #201 Honolulu 96822, (808) 956-6544, www.hawaii.edu/uhelp
- Kokua Mau - Hawaii Hospice & Palliative Care Organization, (808) 585-9977, www.kokuamau.org



Roadmap for Family Caregivers

DEMENTIA RESOURCES - Continued

Other Dementia Resources

- Hawaii Alzheimer's Disease Initiative (HADI), www.hawaii.edu/aging/hadi
- Dementia Friends Hawaii, www.agefriendlyhonolulu.com/dementia-friends/
- Dementia Friends USA, <https://dementiafriendsusa.org>
- Dementia Friends Japan, <https://www.alz.co.uk/dementia-friendly-communities/japan>

Hawaii COVID-19 Resources

- Covid-19 Tips for Caregivers, 1-800-272-3900, www.alz.org/hawaii/
- Hawaii Aging and Disability Resource Center COVID-19643-ADRC (2372), www.Hawaiiadrc.org
- Kokua Mau: A Movement to Improve Care, <https://kokuamau.org/covid-19-resources/>
- Healthcare Association of Hawaii Covid-19 Resource Page, 707 Richards St #PH2, Honolulu 96813 (808) 521-8961, www.hah.org
- Hawaii Public Health Institute, 850 Richards St #210, Honolulu 96813, (808) 591-6508, www.hiphi.org/covid19/

National COVID-19 Resources and Links

- National Alzheimer's and Dementia Resource Center (NADRC), <http://nadrc.acl.gov>
- The National Alzheimer's Project Act Home Page, <https://aspe.hhs.gov/national-alzheimers-project-act>
- University of California San Francisco COVID-19 Memory and Aging Center, <https://memory.ucsf.edu/covid>
- Administration for Community Living (ACL), <https://acl.gov/COVID-19>
- Centers for Disease Control and Prevention (CDC) Covid-19 page, <https://www.cdc.gov>
- National Alliance for Caregiving Covid-19 Resources For Families, <https://www.caregiving.org/resources/covid-19-resources-for-families/>
- Caregiving In The U.S. 2020 Report, <https://www.caregiving.org/caregiving-in-the-us-2020/>
- Mindset Centre For Living With Dementia, www.mindsetmemory.com
- Reducing the Stigma of Dementia: The Conversation on How to Talk About Dementia Appropriately, <https://www.dementia.org.au/sites/default/files/resources/dementia-language-guidelines.pdf>

International COVID-19 Resources and Links

- Alzheimer's Disease International, The Global Voice on Dementia, <https://www.alz.co.uk/news/adi-releases-position-paper-on-covid-19-and-dementia>
- Dementia Alliance International COVID-19 Resource Page, <https://www.dementiaallianceinternational.org/covid-19-resources/>

COVID-19 and Dementia Resources

** If the business is not listed in the Department of Health, check for their business registration in the Hawaii Department of Commerce and Consumer Affairs (DCCA). You can also see if any complaints were filed against the company or individual: <https://cca.hawaii.gov/>

Roadmap for Family Caregivers

HELPFUL TIPS

| NORMAL AGING | SERIOUS MEMORY PROBLEM (like Alzheimer's) |
|--|---|
| Making a bad decision once in a while | Making poor judgments and decisions a lot of the time |
| Missing a monthly payment | Problems taking care of monthly bills |
| Forgetting which day it is but remembering it later | Losing track of the date or time of the year |
| Sometimes forgetting which word to use | Trouble having a conversation |
| Misplacing things from time to time and retracing steps to find them | Misplacing things and losing the ability to retrace steps |

NIH National Institute on Aging (<https://www.nia.nih.gov/health/do-memory-problems-always-mean-alzheimers-disease>)

Some do's and don'ts for effective communication with persons with dementia

| DO | DON'T |
|----|-------|
|----|-------|

- Do use their first name to get their attention
- Do speak in a normal tone of voice at a normal volume
- Do your best to eliminate any distractions such as a TV or radio
- Do give short, one sentence explanations
- Speak slowly and clearly
- Allow plenty of time for comprehension
- Agree with them or distract them to a different subject or activity
- Accept the blame when something's wrong (even if it's a fantasy)
- Do encourage reminiscing if it is enjoyable to the person
- Respond to the feelings rather than the words
- Be patient, cheerful, and reassuring
- Go with the flow

- Don't interrupt
- Don't reason
- Don't argue
- Don't confront
- Don't question recent memory
- Don't insist, try again later
- Don't criticize or correct
- Don't take it personally



Roadmap for Family Caregivers

MCI & STAGES OF ALZHEIMER'S DISEASE

Symptoms and Duration: Alzheimer's symptoms vary. The information below provides a general idea of how abilities change during the course of the disease. Not everyone will experience the same symptoms nor progress at the same rate. Find additional information on the stages of Alzheimer's at: <https://www.alz.org/alzheimers-dementia/stages>

Mild Cognitive Impairment (MCI)

<https://www.mayoclinic.org/diseases-conditions/mild-cognitive-impairment/symptoms-causes/syc-20354578>

- Mild forgetfulness
- Increasingly overwhelmed by making decisions, planning steps to accomplish a task or interpreting instructions
- Mild difficulty finding way in unfamiliar environments
- Mild impulsivity and/or difficulty with judgment
- Family and friends notice some or all of these symptoms
- IADLs* only mildly compromised; ADLs* are intact

Alzheimer's Disease Early Stage

2-4 years in duration

- Increased short-term memory loss
- Difficulty keeping track of appointments
- Trouble with time/sequence relationships
- More mental energy needed to process information
- Trouble multi-tasking
- May write reminders, but lose them
- Mild mood and/or personality changes
- Increased preference for familiar things
- IADLs more clearly impaired; ADLs slightly impaired

Alzheimer's Disease Middle Stage

2-10 years in duration

- Significant short-term memory loss; long-term memory begins to decline
- Fluctuating disorientation
- Diminished insight
- Changes in appearance
- Learning new things becomes very difficult
- Restricted interest in activities
- Declining recognition of acquaintances, relatives
- Mood and behavioral changes
- Alterations in sleep and appetite
- Wandering
- Loss of bladder control
- IADLs and ADLs broadly impaired

Alzheimer's Disease Late Stage

1-3 years in duration

- Severe disorientation to time and place
- No short-term memory
- Long-term memory fragments
- Loss of speech
- Difficulty walking
- Loss of bladder/bowel control
- No longer recognizes family members
- Inability to survive without total care

*IADLs (Instrumental Activities of Daily Living) are activities that allow people to live independently such as shopping, preparing food, housekeeping, managing finances

*ADLs (Activities of Daily Living) are activities for self-care such as feeding, toileting, dressing, bathing

Roadmap for Family Caregivers

MIND DIET

Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet

The MIND diet is a combination of the Mediterranean and Dietary Approaches to Stop Hypertension (DASH) diets. It aims to reduce the risk of developing dementia and improve brain health. Please consult with your physician first.

The MIND Diet - 9 Foods to Eat

| FOOD | QUANTITY & SERVINGS | EXAMPLES & TIPS |
|-------------------------------|--|--|
| Green Leafy Vegetables | At least 1 serving/day *One serving = 1 cup raw or ½ cup cooked | Spinach, kale, collards, Swiss chard, mustard greens, turnip greens, dandelion greens, arugula, endive, grape leaves, romaine lettuce |
| Most Other Vegetables | At least 1 serving/day *One serving = ½ cup | *A salad + at least 1 other veggie everyday Asparagus, broccoli, brussels sprouts, cabbage, carrots, cauliflower, eggplant, green beans, mushrooms, onions, okra, snow peas, squash, bell peppers, sweet potatoes, tomatoes/tomato sauce |
| Nuts | 5 oz. total/week *One serving = 1 oz. | Peanuts, almonds, walnuts, cashews, pistachios, or Nut butter |
| Berries | At least 5 servings/week *One serving = ½ cup | Blueberries, strawberries, raspberries, blackberries |
| Beans/Legumes | At least 3 servings/week *One serving = ½ cup | Black, pinto, cannellini, garbanzo, kidney, lima, red/white, navy, lentils, tofu, edamame, hummus, soy yogurt |
| Whole Grains | 3 servings/day, every day *One serving = ½ cup or 1 slice | Dark or whole grain bread, brown rice, whole grain pasta, wild rice, quinoa, barley, bulgur, farro, oats, whole grain cereal |
| Fish | At least 1 serving/week *One serving = 3 to 5 oz. | *Not Fried Salmon, tuna, tilapia, cod, mahi mahi, halibut |
| Poultry | At least 2 servings/week *One serving = 3 to 5 oz. | *White meat & Skinless Chicken or turkey breast |
| Extra Virgin Olive Oil | 2 TB/day *One serving = 2 TB | Use EVOO as primary oil Look for Unrefined EVOO |

The MIND Diet - 5 Foods to Avoid

| FOOD | QUANTITY & SERVINGS | EXAMPLES & TIPS |
|--------------------------------------|---|---|
| Red Meat & Processed Meat | No more than 3 servings/week *One serving = 3 to 5 oz. | Beef, lamb, pork, ham, burger, hot dogs, sausages, bacon, roast beef, salami |
| Butter & Stick Margarine | Less than 1 pat (tsp)/day | *Use EVOO instead *Smart Balance, Earth Balance |
| Regular Cheese | No more than 2 oz./week | Full fat cheeses |
| Pastries & Other Sweets | No more than 4 treats/week | Biscuit/roll, pop tarts, cake, snack cakes/Twinkies, Danish/sweet rolls/pastry, donuts, cookies, brownies, pie, candy bars, other candy, ice cream, pudding, milkshakes |
| Fried Foods & Fast Foods | No more than 1 meal/week | Fast food or Fast casual restaurants Any fried foods including fried potato chips |

Adapted: Morris, MC et al. MIND diet associated with reduced incidence of Alzheimer's disease. *Alzheimer's & Dementia*; 2015. Lindseth, G. et al., *Neurobehavioral Effects of Consuming Dietary Fatty Acids*. Biol Res Nurs 2016 Jul 13.

10 WAYS TO LOVE YOUR BRAIN



START NOW. It's never too late or too early to incorporate healthy habits.



BREAK A SWEAT

Engage in regular cardiovascular exercise that elevates heart rate and increases blood flow. Studies have found that physical activity reduces risk of cognitive decline.



HIT THE BOOKS

Formal education will help reduce risk of cognitive decline and dementia. Take a class at a local college, community center or online.



BUTT OUT

Smoking increases risk of cognitive decline. Quitting smoking can reduce risk to levels comparable to those who have not smoked.



FOLLOW YOUR HEART

Risk factors for cardiovascular disease and stroke – obesity, high blood pressure and diabetes – negatively impact your cognitive health.



STUMP YOURSELF

Challenge your mind. Build a piece of furniture. Play games of strategy, like bridge.

Growing evidence indicates that people can reduce their risk of cognitive decline by adopting key lifestyle habits. When possible, combine these habits to achieve maximum benefit for the brain and body.

HEADS UP!

Brain injury can raise risk of cognitive decline and dementia. Wear a seat belt and use a helmet when playing contact sports or riding a bike.



BUDDY UP

Staying socially engaged may support brain health. Find ways to be part of your local community or share activities with friends and family.



TAKE CARE OF YOUR MENTAL HEALTH

Some studies link depression with cognitive decline, so seek treatment if you have depression, anxiety or stress.



CATCH SOME ZZZ'S

Not getting enough sleep may result in problems with memory and thinking.



FUEL UP RIGHT

Eat a balanced diet that is higher in vegetables and fruit to help reduce the risk of cognitive decline.



https://www.alz.org/help-support/brain_health/10_ways_to_love_your_brain

alzheimer's  association®

THE BRAINS BEHIND SAVING YOURS®



To care for those who once cared for us is one of the highest honors.

- Tia Walker

Mahalo for all you do



Nondiscrimination in Services: We provide access to our activities without regard to race, color, national origin, language, age, sex (including gender identity or expression), sexual orientation, religion, or disability. Contact the Executive office on Aging at 250 South Hotel Street, Suite 406, Honolulu, Hawaii 96813 or call (808) 586-0100 or our Affirmative Action Office at P.O. Box 3378, Honolulu, HI 96801, or call (808)586-4614 within 180 days of the problem.

This publication contains information and general advice. It should not be used as a substitute for personalized advice from a qualified professional. The Alzheimer's Association and Hawaii Executive Office on Aging, Hawaii Department of Health does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time.

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