Evaluation of TCARE Pilot Program

Colette Browne, DrPH, Professor
Myron B. Thompson School of Social Work
University of Hawai`i
Christy Nishita, PhD, Interim Director
Center on Aging
University of Hawai`i
Heather Chun, MSW, Researcher
Center on Aging University of Hawai`i

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An evaluation by the University of Hawai`i to explore the feasibility of implementing the evidence-based TCARE program statewide and improve the quality of services provided to caregivers in Hawai`i.

EXECUTIVE SUMMARY

The ensuing report describes findings and provides recommendations from the Hawai'i Tailored Caregiver Assessment and Referral (TCARE) pilot project. Supported by a grant from the Administration on Community Living (ACL), and initiated through a contract between the Hawai'i Department of Health, Executive Office on Aging (EOA) and the University of Hawai'i, Center on Aging and Myron B. Thompson School of Social Work (UH), hereafter referred to as the UH Team, a feasibility evaluation of the TCARE program was conducted.

TCARE is a standardized care management process designed to help efficiently target resources and services (both formal and informal) available within a community to effectively and appropriately address caregivers' needs. Aligning with the strategic direction of the State – while capitalizing on the UH's investigations of culturally appropriate and person-centered care management programs for caregivers – TCARE was identified by EOA as an evidence-based program that would enable a standardized approach to caregiver assessment and referral throughout the statewide Aging and Disability Resource Center (ADRC).

The University of Hawai'i team completed a comprehensive evaluation of the TCARE pilot project in partnership with the pilot site, the Maui Area Agency on Aging (AAA), the Maui County Office on Aging (MCOA). **The focus of this evaluation was on the feasibility of implementing TCARE statewide.** Quantitatively, the TCARE processes, specifically the timeliness and mechanics, were evaluated. To begin to better understand the characteristics of our state's caregivers, participant data was also analyzed. The Team also utilized qualitative methods to determine the feasibility of TCARE's statewide integration within the ADRC. Key informant interviews with AAA County Directors, EOA, and other states who have adopted TCARE were conducted. UH also completed participant interviews and a focus group with MCOA staff on their experiences in the TCARE pilot project. Lastly, ongoing dialogue with Tailored Care Enterprises, LLC. further informed this project's evaluation.

<u>Recommendations based on the results of this evaluation:</u>

The adoption of the TCARE model statewide offers the potential for improving care and support to older adults and families. The evaluation finds TCARE to be feasible, but statewide integration through the ADRC will require a large investment of State resources. The limited availability of affordable LTCSS remains a serious problem to the adoption of any long-term care system that aims to improve assessment and coordination of care. As such, we consider

and discuss the cost and sustainability of statewide implementation in a later section of this report. Table 1 below is a summary of the report's recommendations:

	Recommendations
Feasibility of ADRC Integration	• **Ensure TCARE included within ADRC expansion** • **Implement TCARE screener through I&R staff**
Operations and Sustainability	• **Utilize train-the-trainer approach for sustainability and provide continuing support** • **Integrate TCARE into Harmony and create a crosswalk of resources** • **Ongoing evaluations to strengthen caregiver support**
Need for Cultural Tailoring	• **Develop a culturally tailored TCARE protocol**

I. INTRODUCTION AND BACKGROUND

Without proactive planning, our rapidly aging state will face extreme economic and social challenges. Systems change initiatives are underway, both locally and nationally, to develop infrastructures capable of supporting those who are aging and their caregivers. Nationally, federal systems – for example, the Administration on Aging (AoA), a department under the Administration for Community Living (ACL) which administers Older American's Act—are evolving to meet these escalating needs. Trends in funding are incentivizing state programming that has been demonstrated through rigorous evaluation to be evidence-based and effective. Enabling informed decision making that allows for individual preferences, or person-centered planning, is also being embedded within federal initiatives that strengthen long-term services and supports (LTSS) for older adults throughout the United States.

One federal initiative is the development of Aging and Disability Resource Centers (ADRCs). Aligned with the rest of the nation, Hawai'i is in the process of developing and implementing a statewide ADRC. The Area Agency on Aging (AAA) in each county is the operating entity for the ADRC in Hawaii. The vision of Hawai'i's ADRC is "to serve residents of all incomes and ages in every community in Hawai'i as the highly visible and trusted source of information on the full range of long-term support options and as the single point of entry for access to public long-term support programs and benefits." As a strategic priority issue of the State Unit on Aging (SUA) – the Executive Office on Aging (EOA), ADRC funding and support is being administered through EOA to the AAAs as efforts continue to fully develop ADRCs within each county. Evidence-based programming and person-centered processes are at the core of Hawai'i's ADRCs, strengthening service approaches and ensuring efficient spending of public funding for services that are demonstrated to have proven outcomes.

One of the major accomplishments of Hawai'i's ADRC has been the adoption of a standardized intake and assessment tool for care recipients. The implementation of this tool is still underway in two counties and the natural progression of the State's efforts to standardize person-centered assessment processes with care recipients is to expand to caregivers. As a strategic direction outlined within EOA's Strategic Plan, assessment, projection of needs, and the development of sufficient family caregiver supports over the next decade will be imperative. There has been a growing recognition of the significant contribution caregivers make to care for older adults within our communities, with Hawai'i's caregivers providing 144 million hours of care in 2013, an economic value of $2.1 billion[1].

At the conception of this project, numerous conversations and efforts to explore evidence-based caregiver interventions occurred, with a strong interest in strengthening the infrastructure of LTSS for caregivers throughout Hawai'i. Aligning with these strategic directions – while capitalizing on the UH's investigations of culturally appropriate, person-centered, and evidence-based care management programs for caregivers – Tailored Caregiver Assessment and Referral (TCARE) was identified by EOA as an evidence-based program that would enable a standardized approach to caregiver assessment and referral throughout the statewide ADRC. Prior to this project, there was no uniformity of caregiver assessment tools between the AAAs. In addition, the caregiver assessments used by the AAAs were not person-centered, were constructed to collect the data needed for federal and state reporting, and largely focused on demographics.

Between 2011 and 2013, collaborations between EOA and the University of Hawai'i led to several planning meetings, discussions with TCARE founders and researchers, and grant writing efforts to enable the application and evaluation of TCARE within Hawai'i's unique population. Made possible by an ADRC grant that EOA received from ACL in 2013, a contract between EOA and the University of Hawai'i – Center on Aging and Myron B. Thompson School of Social Work was initiated. The contract between EOA and the University of Hawai'i facilitated a partnership between 2014 and 2015 to train ADRC staff on the TCARE protocol, conduct a TCARE pilot project, and to complete the proceeding feasibility evaluation.

Program Description: Tailored Caregiver Assessment and Referral (TCARE Program)

The Tailored Caregiver Assessment and Referral (TCARE) protocol is a standardized care management process designed to help efficiently target resources and services available within a community – both formal and informal – to effectively and appropriately address caregivers' needs. After rigorous review of program data, TCARE was acclaimed by ACL as an evidence-based care management program. Validated through 25 years of research on family caregiving, TCARE is grounded in the *Caregiver Identity Theory*.[2] The *Caregiver Identity Theory* describes caregiving as a systemic process of identity change, for example, changing from the original role of daughter to caregiver. The identity change is recognized as a significant factor influencing the type and severity of stress the family caregiver is enduring.

Theoretical Grounding. The *Caregiver Identity Theory* highlights three insights that describe the variations among caregivers. First, stress is multidimensional and caregivers perceive stress differently from one another. Second, the type and quantity of caregiving tasks vary greatly, as does the duration of time in which they occur, the costs they incur, and the benefits the

caregiver perceives. Lastly, there is great variation in service utilization among caregivers, with caregivers only utilizing services they want or need.

The theory explains why caregiving interventions are not uniformly beneficial for all caregivers. For example, a son who is a new caregiver to his mother with dementia may be struggling with feeling that his mother should be doing more to care for herself, as she's always done, not understanding the progression of the disease. Rather than looking solely at publicly funded caregiver LTSS, such as respite, an evidence-based assessment will produce individualized recommendations for care planning. Through computer software that uses a decision algorithm to provide a profile of the caregiver and suggestions for a service plan, TCARE care managers' work with a caregiver to develop a person-centered care plan. In this example, the TCARE protocol will highlight the identity discrepancy this caregiver is facing. Knowing that the caregiver is struggling with identity discrepancy, or his perception that he should be assuming the role of a son more than as his mother's caregiver, the care manager will be better equipped to suggest strategies to help this caregiver cope with his new and evolving role. The care manager may suggest to the caregiver that he consider education on dementia to help him learn about the disease and strategies to help him care for his mother, assisting him in identifying educational classes in the community while working collaboratively on his care plan. A support group may be suggested to help him cope with his transition from the role of a son to a caregiver for his mother. Informal supports, such as other family members, may additionally be considered to help shoulder the responsibilities of caring for his mom.

TCARE Processes. Care managers and caregivers work together on the core elements of care management through a **six-step TCARE process**: (1) Conducting an assessment; (2) interpreting the assessment; (3) identifying appropriate goals, strategies, and services; (4) consulting with the caregiver; (5) developing person-centered care plans; and, (6) conducting follow-up and evaluating progress. The TCARE processes maximize benefits for families throughout their caregiving journey while appropriately allocating resources. The availability of a standardized care management protocol, such as TCARE, is desired at a time where public funding for LTSS is unable to meet the demand of a rapidly aging demographic and their caregivers. Interventions that support a **systematic assessment of the needs and strengths of caregivers equip care managers with a more efficient way to target public funding.** TCARE trains care managers (also referred to throughout this report as TCARE assessors) to explore support options available in the community or the caregiver's informal networks, such as in the example above, that extend beyond the care manager's typical set of services for which they have the most knowledge.

II. PILOT PROJECT

This evaluation project explored the feasibility of implementing TCARE statewide, thereby improving the quality of services provided to caregivers in Hawai`i.

Partners, Collaborators, and Roles

- **The Executive Office on Aging (EOA).** In October 2014, the Department of Health, Executive Office on Aging (EOA), with funds from the Administration on Community Living (ACL), awarded a contract to the University of Hawai`i Center on Aging (COA) and the Myron B. Thompson School of Social Work (MBTSSW) to evaluate the TCARE pilot project in Hawai`i. Throughout the project, EOA administered and maintained the contract with the University of Hawaii, maintaining regular, ongoing, and timely communication. Additionally, EOA provided feedback as key informant during the project's evaluation.

- **The University of Hawai'i Team.** Composed of faculty from COA and MBTSSW, the UH Team was responsible for overseeing the implementation and evaluation of the TCARE pilot project with the Maui County Office on Aging (MCOA), Hawai`i's TCARE pilot site. Ongoing project support to maintain close and regular support was provided to the eight TCARE care managers and leadership at the MCOA. For the project's evaluation protocol, UH focused on the fidelity of TCARE implementation, feasibility of the TCARE model for statewide replication, and if necessary, recommending changes and adaptations to the TCARE model, with particular attention to multicultural and rural populations.

- **Maui County Office on Aging (MCOA).** MCOA, one of Hawaii's four AAAs, was the site for the TCARE pilot project. MCOA's leadership in ADRC development and implementation is noteworthy, and as the first AAA in Hawaii to have their ADRC fully functioning, it was a natural fit for the piloting of TCARE. In December 2014, eight care managers became TCARE certified through MCOA; six of these care managers participated in the pilot project. During the pilot project, UH remained in close contact with MCOA for the TCARE evaluation. In July 2015, care managers provided feedback to UH on the pilot project during a focus group, and the MCOA County Executive was interviewed as a key informant.

- **Tailored Care Enterprises, LLC.** In September 2014, Tailored Care Enterprises, LLC provided an in-person training to care managers with MCOA and staff at EOA. After the in-person training, Tailored Care Enterprises, LLC provided additional webinar trainings to complete Hawaii's training, led a TCARE screener training, and certified eleven care managers in December 2014. Of the eleven certified, seven care managers participated in the TCARE pilot project. Throughout the pilot project, Tailored Care Enterprises, LLC maintained regular and ongoing communication and technical assistance with UH, EOA, and MCOA. They also provided data to UH for the evaluation of the pilot project.

Project Timeline

The pilot project launched on February 2, 2015 and new participants included within the first phase of the project's evaluation were accepted through May 8, 2015. Moving forward, care managers completed 3-month TCARE follow-ups with each caregiver during the second phase of the project, with the pilot concluding on August 7, 2015. Concurrently, during the 3- month TCARE follow-up period, UH collected participant data, conducted additional qualitative evaluations, and analyzed the project's findings. Finally, UH completed the proceeding final report for submission to EOA, in accordance with their contract and in advance of EOA's final grant report to ACL.

TCARE Pilot Protocol

UH and MCOA care managers had several planning meetings and discussions to inform the protocol that would guide the implementation of the Hawaii TCARE pilot project. In an effort to recruit a diverse sample, the pilot project targeted both caregivers who were new to MCOA and those who had been working with MCOA previously. With approval from the University of Hawaii Institutional Review Board (IRB), UH developed and provided training to MCOA on the informed consent for caregivers participating in the Hawaii TCARE pilot project. Prior to participation, care managers were instructed to utilize the script developed by UH to introduce the project to caregivers, requesting each caregiver's written consent to participate. After collection, UH requested MCOA care managers to upload caregiver consent forms into the statewide secure Social Assistance Management System (SAMS) database.

At the launch of the project, each care manager was asked to complete the TCARE protocol with a minimum of five caregivers. During the first phase of the project – between February 2, 2015 and May 8, 2015 – care managers were expected to complete the following four TCARE components with each caregiver: TCARE assessment form, TCARE assessment summary worksheet, TCARE care consultation worksheet, and TCARE care plan. To complete all four components, care managers typically required one conversation with each caregiver by phone

and two follow-up in-home visits, although the number of discussions varied by caregiver. The four components were to be completed within 3 weeks, which is the timeframe prescribed by Tailored Care Enterprises, LLC.

Adhering to the protocol outlined by Tailored Care Enterprises, LLC, the Hawaii TCARE pilot project administered a 3-month TCARE follow-up with each caregiver. As part of the process, a short TCARE screener (developed by Tailored Care Enterprises) would be used and based on scores, a full in-home assessment would be administered. The TCARE follow-up was intended to monitor the caregiver's progress and determined whether or not the existing care plan was still appropriate or needed modifications. When warranted, updates to caregiver care plans were made together with caregivers and their care managers. All 3-month follow-ups were required to be completed by August 7, 2015 to be included within the pilot project's evaluation.

Support Provided by UH

Regular and ongoing communications were conducted between UH, EOA, MCOA, and all stakeholders in the TCARE pilot project. At a minimum, bi-weekly communications with the pilot project site (MCOA) occurred through conference calls during staff meetings, emails, and travel to Maui. UH provided individual technical assistance to MCOA staff and leadership weekly, on average, and occurring more often when needed. The chart in Appendix B details the major support activities conducted by UH throughout the Hawaii TCARE pilot project.

III. EVALUATION METHODS

The Administration on Community Living (ACL) has designated TCARE as an evidence-based care management protocol for caregivers of older adults. In a randomized controlled trial, positive caregiver outcomes have already been demonstrated. The purpose of this pilot project, therefore, was not to evaluate the effectiveness of the TCARE intervention, rather, the aim was to explore TCARE's feasibility in Hawai`i and second, monitor the fidelity of Hawai`i's pilot. To ensure a high quality evaluation, the UH Team utilized both quantitative and qualitative methods.

Quantitative Methods

First, as EOA's intention was to explore the viability of integrating TCARE within the state's ADRCs, the TCARE processes were analyzed beginning with quantitative methods. The amount of time between the in-home assessment and care plan, as well as the number and types of service recommendations were examined. Further observations looked at whether or not the mechanics of TCARE were consistent with the protocol defined by Tailored Care Enterprises, LLC. To better understand the characteristics of the pilot's participants, caregiver characteristics were also analyzed.

UH was given administrative access to TCAREe (the online software care managers use to complete the TCARE processes). All quantitative data for the pilot project were collected through TCAREe by UH and tracked in an excel database. Collectively, UH analyzed the data and produce the findings included within this report.

Qualitative Methods

UH analyzed the feedback shared by key players of the pilot project (AAA Executives, EOA, TCARE assessors, and caregivers), as well as from other states that have adopted TCARE, gathering additional information that could inform the future of the TCARE program in Hawai'i. UH collected and analyzed data using standard, accepted qualitative methods.

Key Informant Interview Methods

- **AAA Executives-** Understanding the perspectives of the AAA Executives/Directors who oversee the county-based ADRC operations was imperative to gauging their interest and concerns for statewide TCARE adoption. An AAA Executive questionnaire was developed by UH. Each of the four county Executives were then approached and asked to participate in a one-on-one key informant interview. Two out of the four AAA Executives participated; Honolulu County and Maui County's

Executives were interviewed. The interviews were conducted in June 2015 and each interview lasted approximately one hour.

- **Interview with EOA-** As the State Unit on Aging (SUA) responsible for administering funding and planning for the state's Aging Network, EOA will have a vital role in the sustainability of TCARE as the pilot project concludes. Following the conversations with AAA Executives, UH developed a questionnaire for EOA to explore areas of concern expressed by the AAA Executives as well as TCARE sustainability options. The interview was conducted in June 2015 and lasted one hour.

- **Interviews with Michigan, Minnesota, and Washington-** UH looked at other states for examples of best practices in the implementation of TCARE. Tailored Care Enterprises, LLC recommended Michigan, Minnesota, and Washington as well-established TCARE systems with strong leadership systems. Telephone interviews were conducted in July 2015 and lasted one hour each.

Caregiver Interview Methods

In July 2015, a sample of caregiver participants were interviewed by telephone about their experiences in the program. UH attempted to contact all caregivers with a signed informed consent and in total, eight (8) caregivers consented to an interview. When the researcher contacted participants, she used a script developed by UH which identified that the interview was voluntary, that the conversation would be recorded (and the recording disposed of after analysis), and that all information provided would remain anonymous. The researcher asked twelve (12) questions about the participant's experiences in the TCARE program.

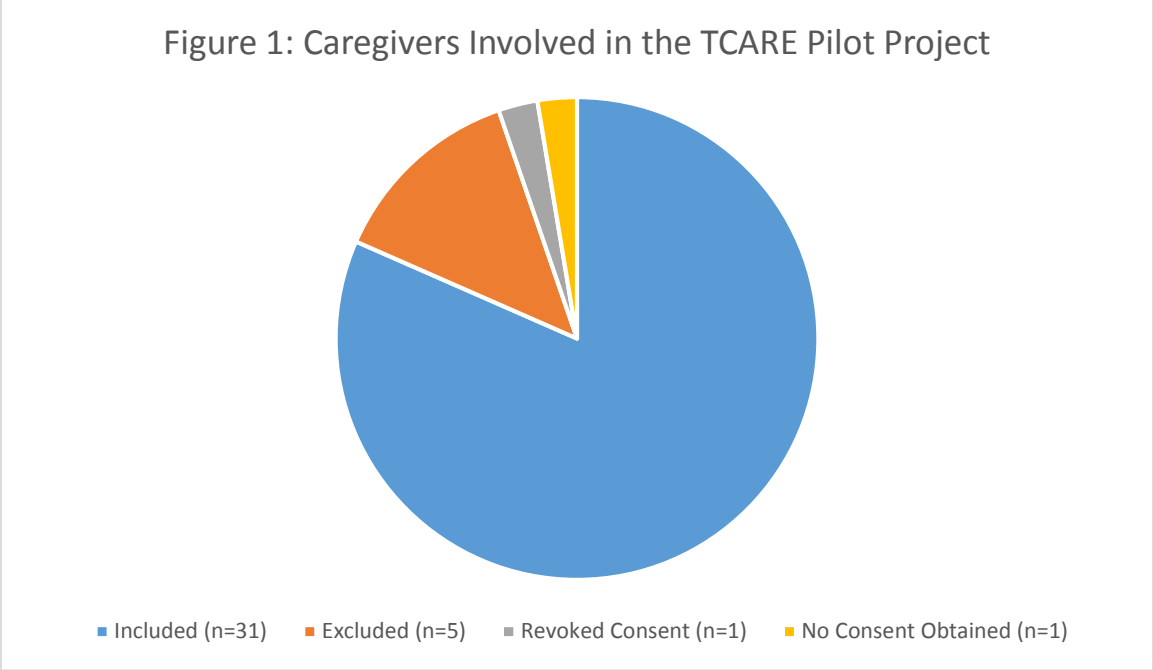
Focus Group Methods with MCOA Care Managers

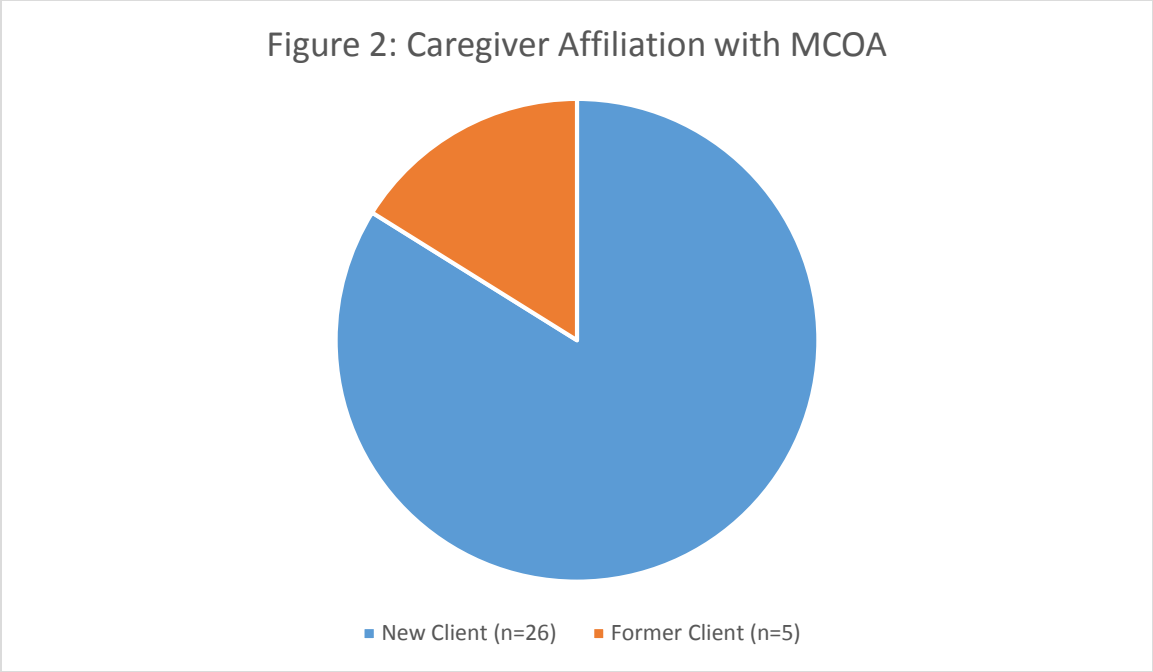
On July 1, 2015, UH researchers conducted a focus group with Maui County Office on Aging (MCOA) staff to better understand experiences implementing TCARE, discuss recommended changes, including cultural translation. The researchers chose a focus group format to allow MCOA care managers to provide both structure and unstructured comments about their experiences working with older adults and families using TCARE over the past 6 months. Researchers asked questions specific to cultural translation, as well as questions on implementation and administrative issues. All comments were recorded manually by one of the researchers, and data were reviewed by both researchers for accuracy and comprehensiveness. Data analysis followed commonly used qualitative research method analysis strategies.

IV. EVALUATION RESULTS

Caregiver Participants

Thirty-eight caregivers were approached to participate in the TCARE pilot project (see Figure 1). Of that sample, 31 participants consented and were included within the project's evaluation (n=31). Five participants were excluded from the project's evaluation (as they did not complete the four TCARE processes during the first phase of the pilot), 1 participant did not provide informed consent, and 1 participant withdrew their informed consent during the pilot project; these eight participants were not included within the evaluation of Hawai'i's TCARE pilot project. Of the 31 participants included within the pilot project, 26 were caregivers previously affiliated with MCOA and 5 caregivers were new to the organization (see Figure 2).





Caregiver Demographics

Caregiver gender, age, ethnicity, and employment status were collected and included within this evaluation's findings (see Table 1).

Table 1: Caregiver Demographics N=31	
Caregiver Gender	Males = 10 (32%) Females = 21 (68%)
Caregiver Age	Mean = 61.7 years Range = 42 years – 83 years
Caregiver Ethnicity	White = 10 (32%) Hispanic/ Latino = 2 (7%) African American = 1 (3%) Asian = 14 (45%) Native Hawaiian/ Pacific Islander = 3 (10%) Portuguese = 1 (3%)
Caregiver Employment	Full Time = 9 (29%) Part Time = 5 (16%) Fully Retired = 11 (36%) Unemployed = 6 (19%)

Caregiver Assessment Findings

The following caregiver assessment findings were collected during phase 1 of the pilot project (see Table 2).

Table 2: Caregiver Assessment Findings N=31	
Care Recipient with Dementia	Yes = 25 (81%) No = 6 (19%)
Relationship Burden	Low = 23 (74%) Medium = 5 (16%) High = 3 (10%)
Objective Burden	Low = 14 (45%) Medium = 10 (32%) High = 7 (23%)
Stress Burden	Low = 17 (55%) Medium = 11 (35%) High = 3 (10%)
Depression	Low = 16 (52%) Medium = 10 (32%) High = 5 (16%)
Identity Discrepancy	Low = 7 (23%) Medium = 15 (48%) High = 9 (29%)
Uplifts	Low = 6 (20%) Medium = 10 (32%) High = 15 (48%)
Intention to Place	Yes = 5 (16%) No = 26 (84%)
Weekly Total Hours of Care	Mean = 44.7 Range = 4 – 128
Caregiver self-reported health	Poor = 5 (16%) Fair = 6 (20%) Good = 15 (48%) Very Good = 5 (16%)
Caregiver Income	Less $10k = 3 (10%) $10k – 15k = 3 (10%)

	$15k – 25k = 5 (16%) $25k – 35k = 3 (10%) $35k – 50k = 8 (25%) $50k – 75k = 6 (19%) More $75k = 3 (10%)
Care Recipient Unmet ADL	Low = 5 (16%) Medium = 15 (48%) High = 11 (36%)
Care Recipient Unmet IADL	Low = 2 (6%) Medium = 11 (36%) High = 18 (58%)
Care Recipient Living Arrangements	Alone = 5 (16%) With Another Relative = 2 (7%) With Caregiver = 23 (74%) Nursing Home = 1 (3%)

Three Month Follow-up with Caregivers

The TCARE protocol indicates that as a follow-up, care managers administer the short TCARE screener with caregivers. This follow-up period was set at 3 months. Scores from the screener determine whether a full assessment and support plan revision is needed. However, MCOA care managers elected to utilize the full in-home assessment as the follow-up instrument. This full assessment was completed with 27 out of the 31 caregivers. In other words, the TCARE protocol indicates that the screener is used to determine whether a full assessment and support plan revision is needed. However, in Hawaii's pilot, scores from the full assessment was used to determine whether a support plan revision was needed. For example:

1) If a caregiver's burden scores and identity discrepancy scores were low, *and* if the caregiver did not have an intention to place their care recipient in an institutional setting, a support plan revision was not needed.

2) If caregivers demonstrated high burden scores and identity discrepancy scores *and* did have an intention to place, then another support plan (or revision) was needed.

Of the 27 participants who completed the full assessment, scores from 4 out of the 27 full assessments actually did not meet the criteria to trigger an in-person meeting to revise the support plan. Twenty three participants did meet the criteria to trigger a support plan revision. This may mean that the caregiver's situation stayed the same or even worsened. However, it is

more likely that the window of time (3 months) is too short; it takes time to link caregivers to services.

Of the 23 participants that did meet the criteria to trigger a support plan revision, only 11 support plan revisions were completed. Care managers reported that they were unable to complete all the support plans for a variety of reasons, such as having to travel to another island to meet with the caregiver, caregiver appointment cancelations, and other work that delayed their ability to complete the processes within the required timeframe.

Findings from Caregiver Interviews

Two themes emerged from the telephone interviews with a sample of caregivers.

1. *Increased accessibility and awareness of a Caregiver Network*

   Seven caregivers identified that working with their care manager on TCARE helped them become more aware of services that were available to them in the community. One caregiver shared that the adult daycare her husband had been attending prior to her participation in TCARE is now providing her husband with bathing services. This caregiver went on to say, "The adult day care has been more open with us and I feel that we are partners now; I guess the system is really working."

   Extending beyond their increased accessibility and awareness of services in the community, all participants shared that they have developed strong rapport with their care manager. Caregivers acknowledged their comfort in contacting their care manager in the future if needing additional assistance, which further extends their network of support.

2. *Significance of Caregiver's Role*

   The TCARE program's singular, person-centered focus on a caregiver is unique. For many who participated in this pilot project, this is the first program they've participated in that has placed the emphasis on the caregiver as the center of assessment and support planning. Caregiver participation is vital to the TCARE processes. One participant exclaimed, "[TCARE] gave me an opportunity to put in my thoughts on what is important as a caregiver." Moreover, caregivers acknowledged that the TCARE program was one of personal discovery, validation, and gratitude. One participant summarized her participation in the program by stating, "The questionnaire at the end [of assessment] was so helpful; an eye opener. It made me realize that I'm pretty lucky to be the caregiver of my husband." Lastly, another participant admitted, "She specifically mentioned what I'm doing okay; that's really important because caregivers are just doing the best they can."

Summary and Discussion of Caregiver Findings

Qualitative findings indicate an *increased awareness of services and supports* in the community as a result of their participation in the TCARE pilot project. Overwhelmingly, caregivers felt that the TCARE processes strengthened their rapport with their care manager, which largely contributed to their opinions and experiences in the program. Not only did the program foster a stronger relationship with their care manager, but it also validated the caregiver's responsibility to their care recipient, the uplifts in their life, and objectively detailed their challenges.

It is difficult for evaluators to indicate whether the TCARE model improved caregiver support in this pilot project. First, care managers had difficulty completing the follow-up assessment and support plan with caregivers. However, administering the short TCARE screener over the phone may be more feasible for care managers. The majority of caregivers (23 out of 27) *did need additional support* at the 3-month time period. Only 4 did not need additional assessment and support, based on their scores on burden, identify discrepancy, and "intention to place" questions. This finding may indicate that the caregiver situation did not change, or even got worse. However, this finding can be interpreted differently, that it takes time for care managers and caregivers to connect with services. The 3-month timeframe is likely too short. Future evaluations will need a larger sample size, and a longer follow-up period to note changes in caregiver outcomes.

For some, the primary *challenge* was a language barrier. Echoed by care managers throughout the project, the University of Hawai'i researchers also experienced difficulty communicating with caregivers when interviewed during the evaluation. Often times, caregivers required questions to be repeated and rephrased several times to ensure they were able to understand what was being asked of them. In addition, some caregivers were not able to distinguish TCARE from other support services they are receiving from MCOA (e.g. the Community Living Program).

Key Informant Interviews

Findings from Interviews with Maui and Honolulu AAA Executives. Conversations with Hawai'i's AAA directors provided evaluators with a more comprehensive assessment on the feasibility of TCARE's statewide implementation. Strongly motivating the information shared by each AAA director was their respective county's ADRCs, which are at very different stages of implementation and development. Findings from these key informant interviews are summarized into three major themes – (1) developing buy-in, (2) ADRC expansion, and (3) programmatic resources – which are discussed below.

1. Developing Buy-In

Similar to the standardization of a statewide assessment for older adults, integrating a statewide evidence-based assessment and care management program – such as TCARE – will require a paradigm shift among staff and administrators alike. During a time where Hawai'i's systems change initiative requires each AAA to dedicate their resources to developing an ADRC, the AAA directors interviewed shared that it will be important to demonstrate the value of the TCARE program to gain support. More specifically, it will be essential to convey how TCARE makes the ADRC processes more efficient and services more accessible to caregivers.

Developing buy-in will also require additional training on TCARE. As the pilot site for this project, the Maui County Office on Aging is the only AAA to have received TCARE training to date. As such, Maui's AAA County Executive was well versed on TCARE prior to the key informant interview. Honolulu's AAA County Executive, however, received no training on TCARE prior to the key informant interview and therefore required some background information on the program prior to the discussion. Although Honolulu's County Executive had little information on TCARE prior to the interview, she felt that the program may be feasible for her County's ADRC moving forward. Caregiver LTSS were noted by each of the AAA County Executives as lacking in their respective counties, lending to the support for an evidence-based caregiver program such as TCARE.

2. ADRC Expansion: Consolidated Statewide Data System

As the single point of entry for access to public long-term support programs, the efficiency of Hawai'i's ADRCs is paramount. Both AAA County Executives identified the efficiency of TCARE as imperative to the feasibility of the program's statewide integration. Additionally, each AAA County Executive highlighted the vast resources that have been dedicated to the development of the current statewide client data system, Harmony Information System, during the ADRC system's change initiative. Investing in a new statewide data system for caregivers, through the TCAREe system, may not be prioritized as an efficient use of the limited ADRC resources moving forward. If the ADRC expansion will adopt these standardized statewide assessment tools for caregivers, the AAA County Executives discussed their interest in integrating the TCARE assessment tools within Harmony Information Systems. Consolidating all the ADRC assessment tools within one statewide data system is perceived to be more feasible and efficient. As one AAA County Executive noted, "There are a lot of great pilot and standalone projects. We need to make thoughtful decisions on how everything fits together."

3. Programmatic Resources

Not surprisingly, much of these discussions were focused on the ADRC resources that would be available and necessary to implement and sustain a statewide TCARE program. To determine whether or not their respective ADRC would be able to implement the TCARE program, the AAA County Executives would need to consider the costs of training and sustaining TCARE assessors, the availability of ongoing technical assistance, AAA access to TCARE data, and the resources available to aid the implementation and sustainability of their TCARE programs. AAA County Executives raised questions about EOA's intentions moving forward, and more specifically, whether or not funding would be available to the AAAs if TCARE were embedded within their contracts in the future.

Lastly, in considering how to maximize AAA resources, Maui's AAA County Executive discussed the potential for TCARE to be a tool to aid AAAs in prioritizing public funding for caregivers in the future. She noted, "I would like to make it so that anyone who receives family caregiver services is assessed through TCARE first." By doing so, Maui's AAA County Executive believes that TCARE will enable AAAs to identify at-risk caregivers (those with medium to high levels of burden or those who are considering placing their care recipient in a long-term care facility) and target limited public services to those most in need.

Interview with EOA Staff

In addition, UH interviewed EOA to further explore the feasibility of TCARE's statewide integration. Findings from this key informant interview are summarized into three major themes – (1) programmatic resources, (2) reconceptualization of caregiver LTSS, and, (3) caregiver LTSS prioritization – which are discussed below.

1. Programmatic Resources

EOA acknowledged that developing sustainable resources for TCARE integration will require innovation and some consideration on how funding streams may be allocated to the AAAs in the future. Resources from the Older American's Act – for example, administrative funds from Title III or the National Family Caregiver Support Program – may present opportunities for EOA to consider redirecting funds to aid TCARE sustainability. ADRC implementation funds may afford some assistance in the initial integration of TCARE into the statewide ADRC; however, EOA noted that this was not a sustainable source of funding. Legislative funding through the state's Kupuna Care Program may also open an opportunity for future resources; however, with a lack of administrative rules for the Kupuna Care Program currently, EOA cautioned that extending this funding to TCARE may be difficult. Based on the interest of the AAA County Executives, and in addition to the additional funding for its development, EOA acknowledged

that consolidating the TCARE assessment tools into Harmony Information Systems would require additional conversation with Tailored Care Enterprise, LLC.

To maximize the value of TCARE to AAAs, EOA discussed the need for further resources to develop a consolidated statewide ADRC resource database and a robust crosswalk of caregiver LTSS. EOA noted that this necessitates staffing at the state level, however, it may require innovative approaches to fulfilling this function (e.g. volunteers). The upfront investment in a consolidated resource database that includes a robust crosswalk of caregiver LTSS will be substantial; however, EOA highlighted that the benefits have the potential to far exceed the costs.

2. Reconceptualization of Caregiver LTSS

EOA shared that a fragmented framework has largely limited the county resource databases to services that are contracted through Hawai'i's Aging Network. Consequently, support planning has been limited to generally include services that are contracted or familiar. A consolidated database with a crosswalk of caregiver LTSS will foster a reconceptualization of LTSS for both caregivers and older adults. By focusing resources on the development of a consolidated ADRC resource database, the boundaries on what constitutes a LTSS will be pushed thereby evolving support planning. EOA shared that not only are resources needed to develop the ADRC resource database, but **resources must be invested into training ADRC staff on the criteria for a service to be included in the database, the importance of integrating informal assistance into support planning, and maximizing the utility of the database** once developed.

3. Caregiver LTSS Prioritization

Aligned with all key informants interviewed, EOA noted the ongoing challenge of serving an escalating population of older adults and their caregivers with limited public resources. To meet this rising demand, EOA shared that they are working with the AAAs and ADRC operation's workgroup to develop a prioritization tool for to target public services to older adults most in need. EOA mentioned that TCARE's screening tool enables a similar approach to targeting public services, as it identifies caregivers who are most at-risk based on their burden scores and intention to place their care recipient.

Interviews with TCARE Implementers in Other States

All three of the states interviewed – Washington, Michigan, and Minnesota – have been involved with TCARE since the origin of the program. With each of the states, the interest in using TCARE was influenced by a desire to adopt an evidence-based caregiver program. Minnesota views TCARE as a service lending itself to objectivity, which was highly desired within their state. Washington's legislature wanted to see discernible outcomes for their state's

caregivers, and with TCARE's standardized tools, it was possible to measure the impacts of the program. Each of the three states have administered the TCARE program through their State Unit on Aging (SUA), with implementation through their AAAs. Not all of the AAAs provide the TCARE program as a direct service through their organization, however. Some AAAs subcontract the TCARE program through community organizations. In Minnesota, for example, AAAs function more as planning and advocacy organizations, contracting direct services – like TCARE – out to community providers.

Since inception, each state's TCARE program has evolved and changed. Through this project's evaluation, conversations with each of these states has provided insights to inform the feasibility of TCARE's statewide integration in Hawai'i. Findings from these key informant interviews are summarized into two major themes – (1) operationalizing TCARE, and (2) sustaining TCARE – which are discussed below.

- *Operationalizing TCARE: Grass roots versus State facilitated approaches*

The TCARE operational models for each of the three states interviewed varied significantly. Grass roots approaches were employed by Michigan and Minnesota, both of whom did not mandate TCARE within their AAA contracts. Minnesota, however, requires their AAAs to complete assessments with all caregivers, identifying required elements (all of which are included within TCARE) yet leaving the choice of whether or not to use TCARE up to the caregiver consultant (title given to Minnesota's TCARE assessors). Michigan is looking to follow Minnesota's model, and is currently considering how to change by also requiring caregiver assessment elements, yet not mandating TCARE specifically.

Washington's TCARE model had a very different evolution, as it was facilitated by the SUA through a directive from their state's legislature in 2007, and integrated as a mandatory statewide program within all the AAAs in 2009. The state of Washington has implemented TCARE statewide within each of their 13 AAAs (4 of the AAAs are also ADRCs). Mandated through their contracts with the SUA, each AAA is required to provide TCARE. Some AAAs provide TCARE internally and some contract with community organizations to operate the program. The most common pathway for a caregiver to be connected to Washington's TCARE programs is through information and assistance (I&A) with the AAAs. Washington also utilizes the TCARE screener, which is not a mandatory component of the protocol. The TCARE screener provides Washington with a tool to identify and prioritize caregivers who are most in need and whom would benefit from TCARE's in-home assessment and care planning.

Mandating TCARE for a state's caregiver assessment may reduce many of the challenges identified by Michigan and Minnesota during their key informant interviews. For example,

when discussing the system's impacts of TCARE with Minnesota, they shared that had the State made TCARE mandatory, they may have experienced more robust and wide reaching program impacts. Furthermore, both Michigan and Minnesota noted challenges related to program scalability. As a service intended to augment their state caregiver assessment, it can be difficult to develop sufficient buy-in to substitute TCARE for the caregiver assessment tools currently in place. Consequently, TCARE may become an outlier program, as noted by Michigan, with program sites using the TCARE protocol on a smaller scale.

Once operationalized, all three states identified multiple pathways for caregivers to access their TCARE programs. Most commonly, however, caregivers are connected to these state's TCARE programs through information and assistance (I&A) with their respective AAA. Other conduits into TCARE programs were caregiver support groups, other caregiver programs – such as Powerful Tools for Caregivers, or through senior helplines.

- *TCARE Sustainability*

Michigan, Minnesota, and Washington all attributed the sustainability of their program largely to their investment in TCARE trainers. Attrition of TCARE assessors was an inevitable challenge noted by each state. Through TCARE's Train-the-Trainer program, however, they are able to train TCARE assessors by utilizing trainers within their respective state, reducing ongoing programmatic costs and fostering sustainability. At their program's inception, Washington's partners formed a policy oversight committee charged with developing comprehensive policies for implementation and, in response to budget constraints, establishing restrictive criteria for assessments and costlier services. Almost all of Washington's AAAs have a TCARE trainer, which enables them to train new TCARE assessors and sustain their programs.

Despite the significant reduction in programmatic costs a state experiences over time through their investment in a TCARE Train-the-Trainer model, as evidenced the states interviewed during this evaluation, ongoing resources are required to sustain a state's TCARE program. For example, each TCARE assessor's certification must be renewed annually with Tailored Care Enterprise, LLC. ($500 per TCARE assessor). Creative mechanisms to finance these ongoing costs were shared by each of the states interviewed. Each state highlighted opportunities to utilize grant funding to sustain their TCARE programs at some point in time. As soft sources of funding, though, grant funding cannot permanently sustain a state's program and so other sources of funding must be secured. Michigan, for example, mentioned that they are currently exploring the use of Title IIID funding from the Older American's Act for TCARE.

States must be able to demonstrate the impacts and outcomes of their programs to develop sustainability. A remarkable example of how states can use data to secure additional program

resources was highlighted in Washington. By utilizing TCARE research to demonstrate the need to serve caregivers before they burned out and considered long-term care placement, in 2011, Washington successfully leveraged an additional $3.45 million from their legislature to expand the state's TCARE program. This additional aid also enabled a robust review of the state's investment, as it was assumed the funding would divert seniors from entering into more costly long-term care Medicaid placements by better supporting their caregivers. The review demonstrated that individuals whose caregivers received a TCARE screening were, in fact, less likely to enroll in Medicaid long-term care services. Using TCARE data, which is collected by the AAAs and monitored by the State, Washington continues to be successful in obtaining legislative support to help sustain their program. In addition, Washington is using the data to explore additional long-term aid, such as getting a federal match through a Medicaid waiver application the state is currently working on.

Findings from Focus Group with MCOA Care Managers

The focus group with MCOA care managers focused on experiences piloting the TCARE program and recommendations for change and cultural tailoring. Please refer to the Appendix for the Focus Group Questions. The following section lists questions and describes major findings:

Q: Primary health and other needs of Kūpuna *—are these similar or different from our community [state]?*

A number of primary health and other needs of Kūpuna were identified; some were viewed as similar to other geographic sites and others as unique to Maui County. All agreed that there were pockets of older adults and caregivers who faced social isolation. There was also agreement that Oahu [Honolulu County] has more services than are available on Maui County. Although wide ranges of older adult needs were discussed, the most common response was the need for housing. Three of the six participants stated that housing was a problem ("We do have more resources on Maui in some sense, but what's lacking is housing--senior housing, assisted living;" "I don't see housing needs as extensive on Lanai/ Molokai;" "[There is a] 2-5 year wait for senior housing on Maui after applying"). Other comments shared were around those needs related to transportation, and care for meals/shopping.

Maui County is a rural community and as such health services were viewed by many as limited or in some cases non-existent, as in this comment: "there is only one geriatrician on Maui in Kula". The lack of services is especially evident on Molokai and Lanai ("i.e., no emergency room care so [you] have to stabilize people and then fly them over, "you cannot get a cast for a broken bone"). Others noted that there were virtually no pharmacies on these islands; and on Lanai there is no veterinary care. One participant brought up a comment about elder abuse, noting that that there are no APS offices on Molokai and Lanai. Moreover, reporting abuse to

APS on these small islands can be difficult because of the small population, where residents often know each other.

Q: Your (case manager) communication style?

Participants freely shared their thoughts on their own personal communication style that they perceive as successfully engaging older adults and caregivers in Maui County in the TCARE protocol. Many comments focused on adopting a friendly and caring and respectful style that allows for casual conversation and relationship building prior to beginning the assessment, often described as "talk story" in Hawai`i:

> Talk story part; that's one of the first things I try to start out about. And some humor.
>
> When you go into their home, you notice photos or they have a collection of something. You can use this to talk story; we're not just [a] business
>
> I always thank them for allowing me into their home and being in their space; the respect factor
>
> Talk story is important; social time is so important; I check in during that [assessment] to see how they're doing; I check with them to show that I respect them; I bring treats for their pets, try to remember their names and pet them."

The talk story could be about their family or even the history of Maui. Another commented on the importance of acknowledging the family's pets in the home; as in this: "Pets are key and really important."

Q: TCARE Protocol

This question sought responses to TCARE protocol for accessing entry into a home and communication with families. Participants were enthusiastic in sharing their comments about this question. Many of the staff shared ways in which they adapted the protocol to meet the needs of Maui families:

> That script we had--I threw out the window; I presented instead as 'how can we help you' and how to benefit you not how to benefit the study. I still include it [evaluation], but I do it at the end rather than at the beginning.
>
> Making sure you're addressing people's needs at the beginning.

They also shared their own observations about the needs of caregivers that are often not acknowledged or legitimized by society in general, as in this comment: "Finally people realize how much caregivers are saving the US economy; it hasn't been acknowledged for so long. [Acknowledgment] makes them feel good."

Other examples were shared:

> I like to mention that TCARE was created by a person who is a caregiver herself, not just in a university, I thought this was a good thing to share (2)
>
> "….They like it, they get emotional. They don't feel like they have the right to have feelings because care recipient has so many needs"
>
> "They almost seem to have guilt for having needs when the care recipient has so much need"

Although one mentioned reasons for non-participation ("People don't have time, they don't want to be a part of another study." Other comments focused on what helped the staff get agreement to participate:

> The [caregivers] really wanted to help because they knew that it would help caregivers.
>
> Using UH [University of Hawai`i] provides merit.
>
> I think they feel proud that it's going to be a part of a study with the University. to them, it's local.

Q: What would a new MCOA worker need to know?

This question resulted in multiple and interesting responses. On one hand, noted in an earlier question, staff stated that they did not note too many unique differences about Maui, either compared to other islands or the continent. However, in this question we heard and observed (i.e., nods in agreement) nearly universal staff agreement on the important role of culture in communication and service delivery that staff should be knowledgeable of: ("It's important for them to learn about the culture.") Another added to this statement, emphasizing: "Culture, tradition, foods."

> *Uniqueness of Maui:*
>
> The have to realize that every state, every island is unique.
>
> *Common localisms:*
>
> If you go to someone's house, make sure you take your shoes off, and if they offer you something to drink, don't say no. Those things can be looked at as, why, you better than me? Don't speak so quickly, let there be time for them to be heard.

Don't be offended by what they say to you, it's just them and the way they are.

They aren't trying to be cruel or mean. They're just very outspoken and there's no filter. It's not we're black, we're white. We're a melting pot. Don't take anything personally.

The most important thing is being humble, being respectful, not coming in all arrogant (like you assume things; you think it's an older person, they're frail, they don't know much. You miss the wisdom, life experience. This is a valuable human being with life experience. They know more than you. It's not always a race thing but it can be, it can also be an education thing). If you did not learn how to speak pidgin, don't try.

People are proud of things; they don't want to ask for help. Downplay their needs (Japanese/Asian).

For staff - pay attention!

Paying attention. Not only are you hearing what they're saying but you're watching. You have to look for clues, watch whether they're being well taken care of. Observe body language.

The daughter called and wanted me to come see him. When I got there, she didn't tell him that I was coming so it was a cold call. So I told him that I noticed a lot of seniors living around there, gave him my brochure, talked to him a little bit, and asked him if he wanted to talk a little more. Invited her in. [The} daughter hadn't been home for a while. He hadn't read his mail, done anything, daughter was worried.

Maui is so small, so remind them that this is all confidential. It's also important to watch (your own) body language (e.g. don't put shirt over face if it smells). Respect- don't just open their refrigerator. Don't just overlook the person that you're talking with (i.e. someone with dementia).

Q: Anything additional to share about cultural diversity? Comments were grouped by potential topics in cultural translation (i.e., literacy) and sensitivity to family needs.

Cultural Translation? Although one participant found little need for "local" translation (I didn't find that the questions were difficult for people to understand (4); again others shared a different point of view as in these examples:

Literacy:

Interpreter was needed (especially for Ilocano speaking families – this is what is needed most often)

> Different experience- I had several questions where full English speakers were like what do you mean by that? TV English is not the English they speak in Hawaii. The first round I ask the question exactly as stated but then the second time I break it down
>
> Break it down not using the textbook/ college vocabulary. Use more simple words. It can make them embarrassed. Some people don't even know what the word respite means; it's an industry word. They don't want to ask, so you need to break it down.
>
> *Population Gaps*:
>
> I don't think we get all the Polynesians; I think in the 13 years I've been there, I've had one Tongan family. I don't get that (Micronesians) like in Honolulu. How do we reach those folks? They aren't using services.
>
> I've only had one intake with Micronesian
>
> I think their fear is the communication barrier

One participant offered a different point of view on the role of culture in eldercare: "When I look at culture, I don't see it just as ethnicity or race. It's within that individual family. They can come from the same race, but not have the same culture. Everyone is different going into their homes."

Be Sensitive to Family Needs:

There was some acknowledgement that seeking help outside the family may be shameful to specific populations and staff should be sensitive to this. One suggestion was to use churches to embed services. Others noted that:

> Family is scared she won't be protected; there is a lot of shame associated with getting outside help. You have to get someone from the community to show them that it's okay to get outside help and that it would really benefit them and the family. Won't ever access services outside the family.

Q*: TCARE enhanced ability to make choices?*

Responses were generally positive about the benefits of TCARE, grouped by: a deeper and broader understanding of caregiver needs as a result of using TCARE, and staff increased awareness of limited services.

> *Deeper and Broader Understanding of Caregiver Needs:*

…..be able to express what their feelings/ thoughts are, what they're going through. It's like that pressure cooker, they were able to let go of a lot of that steam and they have more of their selves now. It's a river for them, the questions were very emotional for them and it was like this relief valve and she was able to let go of a lot of the stuff that was in her.

I think it's the permission; you have a right to be happy, too. A lot of them going through the consultation, it was hard making a commitment [to care plan]. It's not always "according to the consultation worksheet." What's your stress relief (e.g. going to dinner with a friend, etc.)"?

TCARE is not for every family.

Limited Resources:

Limitation on the amount of services that are actually available; they don't exist and there are not enough types of resources

Limited Resources….And yet….

It changed my mindset to at least give them the information that was available. The few resources we had to offer them they didn't always use because of time. It got me and them thinking about the other ways to support themselves. I saw a shift in their thinking; they felt really validated. Even though they did not go to the support group (etc.) they felt strengthened and validated and it would kind of help them catch a breath and a lot of them took better care of themselves (I can ask for help, I can set barriers). There was a strengthening part even though they didn't really follow the plan.

Maybe I don't need to go to this formal [service], maybe my neighbor can help me?

Q*: Clear role and responsibilities?*

There was general staff *agreement* over clarity of role and responsibility expectations placed on them but had many questions and comments about the time line required of the protocol.

I think it was kind of clear, but the timeline [TCARE] was not realistic (it took longer). We're in there, listening to everything that's going on, but you cannot expect to be there for just that 45 minutes because that would be rude. Especially when they cry through the whole thing.

Timeline – at least an hour, up to 2 hours.

Sometimes even with hour and fifteen minutes, I felt I was rushing them.

In contrast, one participant stated: “I would get them done in 25 minutes – I usually separated them after the home visit (with care recipient)”

Once again, comments around culture and communication emerged:

> Local style – watching Judge Judy and asking questions in-between – don’t want to be rude
>
> Because we’re so multicultural here, you’re making connections so that they know you’re okay. Importance of talk story

Q: Recommendations about assessment and tool?

Nearly all participants noted the importance of providing a more in-depth caregiver assessment so that they can be more accurate and efficient in identifying family needs, problems, and concerns. The participants noted that the present family assessment tool is inadequate and does not provide information other than demographic and general types of questions (“Families on Maui are important and we haven’t really focused on their needs before”). The multiple needs of family caregivers were noted, and there was agreement [verbally and non-verbally] that more attention needs to be directed to caregivers. There was also agreement that the TCARE [software] should be made more user-friendly

> …That we can [press] “save” along the way
>
> …Printed version of the TCARE materials is unreadable (font is too small)
>
> …it kept kicking us out (all)
>
> …you can’t go back to where you were, you have to sign back in and hope it’s still there
>
> …it was very rigid on the navigation of it
>
> ….when you put in the case name, you have to go back to put in the demographics in another area

Q*: Recommendations about service plan protocol*

Same concerns, system challenges.

> ….it took me 8 hours to input just one (care plan)

Q: Delivery of TCARE processes

We began to hear similar *comments* from earlier questions, with many focused on the limited resources and services that are available to caregivers on Maui County.

> There's a small pool (of services) to work with
>
> Service options felt repetitive [for me]… it's not the program; it's our lack of resources
>
> There are [very limited] services on Lanai and Molokai

Q: Comments on training or supervision/mentoring, anything about written materials and web; any challenges coming up with service recommendations:

With questioning, staff shared a number of different concerns. There was disagreement over the webinars (webinars were and were not helpful to some ("I'm a hands on person. It seemed like the same information over and over and over again" and "I am a hands-on person. Interactive webinars would have been more helpful"). One comment voiced by one participant centered on the difficulty the staff member had in getting caregiver signatures on the care plan that became a barrier. In response to this concern, two participants suggested that service recommendations were framed with families as JUST suggestions, and this made it easier for families to accept the care plan.

A number of additional and constructive suggestions were offered around the training aspect of TCARE:

> We needed more of a bridge between the 2-day training and training on the software… it looked so different from what we had in our book.
>
> …why not just start with the software?
>
> …showing an example of the software at the beginning would have been helpful
>
> …I would need about a ½ day of training on the software

Q: Comments on integration.

MCOA presently uses the Harmony program to assess older adult needs, and this question sought participant Reponses as to their thoughts on potential of TCARE's integration into Harmony. One participant shared her positive view of TCARE, as in this comment: "Overall, I really do like TCARE. Caregivers are an underserved population and we need to beef up our services for them." Others noted that the program needed improvements in a number of areas:

> For a program that's been implemented in so many states, I didn't expect so many

bugs (in software). It's a useful tool.

They need to loosen the rigidity of how we ask questions, the software

[I think the] response card – would be better on pages of assessment

" . . . I marked my assessment."

It was sometimes easier to give the caregiver a copy of the assessment.

Overall Summary and Conclusions from the MCOA Staff Focus Group:

1. *Older Adult and Family Caregiver Needs***.** On Maui County, older adult and Kūpuna needs are both similar (i.e., housing, isolation) and unique (i.e., culture) to the broader community**.**

2. *Caregiver Assessment*. The use of a caregiver assessment tool was found to be helpful in better understanding identifying caregiver needs by MCOA. The present family/caregiver form used by MCOA is not comprehensive as it primarily collects demographic information.

3. *Caregiver Assessment Tool*. A more comprehensive family caregiver tool and protocol such as TCARE assessment and protocol is needed and will benefit older adults, families and service providers.

4. *Importance of Culture in Communication*. Culture plays an important role in communicating with older adults and families and should be integrated into any assessment tool and protocol. Some examples of where culturally responsive communication is beneficial include: 1) when staff are welcomed into a home; 2) the pace of the communication; 3) the pace of the assessment and care planning; and 4) awareness of cultural variations in communication; i.e., agreement may not really mean agreement.

5. *Limited Community Resources*. The assessment is comprehensive and identifies multiple needs that often do not match the community resources; i.e., programs may not be available, affordable or accessible) There is a need to develop more community resources that are linked to the assessment protocol.

6. *Creativity Expanded*. For some, limited resources lead to more creative approaches on their part and the part of family caregivers to meeting needs and addressing problems.

7. *Need to Link TCARE to Resources*. Unlike other TCARE pilot programs, this pilot program did not have web links to community resources. Staff were challenged to provide this. We recommend that if installed, Maui County community resources should be linked to the TCARE protocol for it to be really useful.

8. *Population Gaps.* Micronesians were identified as a population gap for MCOA.

9. *Web Based Program*. The web-based program needs tweaking—not all found the webinars helpful and for some the print was too small (hard to read).

10. *Integration into MCOA*. A number of responses were unclear as to how the integration of TCARE into the MCOA assessment system would be implemented, and more discussion with staff will be important prior to any decision about TCARE on Maui.

Findings on TCARE Processes

Synthesis of qualitative data led to these additional findings from the UH Team: 1) timeliness of TCARE assessment and care planning; 2) mechanics; and 3) service recommendations.

1. Timeliness of TCARE Assessment and Care Planning. The ability for care managers to maintain timeliness between the TCARE assessment processes is an important consideration for statewide expansion. Not only is timeliness important to maintain the fidelity of the TCARE program, but it's imperative for care managers to maintain timely communication as a caregiver's journey is continuously changing. The level of assumed responsibilities for care, an identity change in relation to the care recipient, and a change in identity standards are incessantly evolving with the changes in care recipient need and the context of care.

Program protocol, as defined by Tailored Care Enterprises, LLC., requires no more than three weeks between the TCARE in-home assessment and support plan. The average amount of time between the TCARE in-home assessment and care consultation (where the caregiver and care manager discussed and agreed upon a support plan) was 16.9 days, falling well within program limits. The range, however, varied drastically, with the least amount of time between these processes being 0 days and the most being 89 days. This wide range was due to several factors: care managers' existing workload taking priority over pilot responsibilities, the need to travel to a neighbor island (e.g. Lanai) to meet with caregivers, and caregivers' cancellation of appointments.

2. Mechanics. The evaluation of the TCAREe software was based on observations of the TCARE assessment data entered within the TCAREe database and feedback from care managers. The mechanics of the TCARE assessment tools were consistent with the TCARE program procedures. Minor concerns were addressed through ongoing technical assistance with Tailored Care Enterprises, LLC and UH. Two significant issues, however, required additional training with care managers throughout the pilot project:

First, care managers in the pilot project most often work with older adults as a primary service recipient, and caregivers second. Therefore, many of the triggers in the "triggers for follow-up" section (an open-ended section for notes by the care manager) were focused on issues with the care recipient. Ongoing reminders were necessary to ensure a caregiver-centered approach was maintained by care managers to sufficiently identify triggers that warrant additional follow-up on caregiver needs. It is important for caregivers to understand that they are able to contact their care manager for help if their own condition declines or situations change.

Additionally, the TCARE program should recommend no more than 3-5 services or supports to a caregiver during the care consultation process. Recommending too few services or supports may not provide the caregiver with sufficient options whereas recommending too many may be overwhelming and stifle the caregivers ability to process which supports may be best for them. Several care consultation worksheets identified too many service and support options, at times exceeding 20 choices, and consequently may have overwhelmed the caregiver during the support planning discussion. Mitigated through ongoing training with care managers, care consultations and support plans at the latter end of the pilot project were more conservative in the number of recommendations.

3. TCARE Service Recommendations. TCARE is often commended for the program's ability to alter the paradigm of care managers, not only by broadening their view of caregiver LTSS but also by working with the caregiver to be creative in identifying informal and non-traditional supports that may be leveraged. For example, one support plan that leveraged a caregiver's insurance plan benefits to cover a gym membership. More generally, however, non-traditional caregiver LTSS and informal supports were not included within the TCARE support plans in this pilot project. The services recommended most frequently to caregivers during the TCARE care consultation were services that are commonly referred to through contracted aging service providers. For example, respite, adult daycare, chore, and meal services were often included within the pilot's support plans. Evidenced through the feedback from care managers during the evaluations focus group, these contracted services are in high demand and the supply remains insufficient.

V. DISCUSSION: FEASIBILITY OF TCARE STATEWIDE INTEGRATION

Hawai'i is in the midst of implementing a statewide ADRC. As the State has invested substantial resources into the standardization of a statewide assessment for older adults, it is natural that the next step would extend this standardized assessment approach to caregivers. There are many factors for the State to consider, however, when weighing the feasibility of TCARE's integration within the statewide ADRC.

Unquestionably, sustaining TCARE within the ADRC will require ongoing resources. Caregiver funding streams through the Older American's Act (Title IIIE) and the State's Kupuna Care program may provide an opportunity for TCARE support, however, additional resources will be essential. Utilizing current funding sources may not be deemed feasible by EOA as the 2015 Hawai'i State Legislature reduced appropriations for the State's Kupuna Care Program, which funds many older adult and caregiver respite services. Subsequently, EOA is currently challenged to prioritize a reduced level of funding while efficiently targeting resources to meet the mounting needs of older adults and their caregivers statewide. A potential strategy is to expand of the types of caregiver support services provided by Kupuna Care.

The upfront costs for statewide integration of TCARE into the ADRC will be substantial, and therefore will require EOA to consider TCARE's advantages and strengths relative to other priorities outlined in their strategic plan and current State Plan on Aging. The problem for the State remains that of an inadequate permanent funding stream to provide older adults and families with the needed supports and services that are affordable and accessible.

TCARE can target limited funding streams to caregivers with the highest needs and those who are most economically challenged. Targeting services to those with the greatest need– for example, caregivers who are considering placing their care recipient in a nursing home, assists the State in maximizing limited public resources and, possibly preventing or delaying more costly care. Not only does TCARE have the ability to target services to those most at-risk but it also would provide the State with a mechanism to determine whether support and services are making a measurable difference to caregivers.

There is a growing interest in programs that demonstrate positive outcomes for caregivers. As a person-centered and evidence-based care management program, TCARE has consistently demonstrated improved caregiver outcomes, such as a decrease in identity discrepancy, decrease in the frequency of depressive symptoms, and a decrease in burden.[3] TCARE has also demonstrated a decrease in caregivers' intention to place the person they're caring for in a nursing home.[3] LTSS to sustain older adults and their families are imperative. Investing in caregiver programs, like TCARE, reaps economic benefits that have the potential to far exceed

the costs. Washington, for example, has demonstrated that caregivers screened through TCARE provided care to people who were approximately 20% less likely to enroll in Medicaid long-term care services in the 12 months following their caregiver's screening, compared with prior years.[4]

To maximize the efficiency of TCARE, software system improvements are needed. Collecting data through a statewide database would inform policy through a better understanding of the caregivers being served, their unmet needs, systems of support, and service utilization. Tailored Care Enterprises, LLC. has developed an online software platform, TCAREe, which was used for the Hawai'i Pilot Project. Integrating the TCARE assessment tools and decision algorithms into the State's Harmony Information System should be considered. Embedding TCARE within Harmony Information Systems would enable the State to monitor the program, and in addition, EOA's program evaluator and statistician would be capable of analyzing the data to measure caregiver outcomes, which could be used to inform public policy. Washington was the first State to automate the full TCARE process in this way, through integration into their State's client data system using custom-built software. Working with Tailored Care Enterprises, LLC., Hawai'i can build upon Washington's example if TCARE is embedded statewide.

Further fees would be required for software development. First, it would be important for the State to invest in developing a robust crosswalk of caregiver LTSS in the statewide ADRC resource directory. Currently, each county is responsible for maintaining their ADRC resource database. EOA acknowledges the need for funding to develop a consolidated statewide ADRC resource database, however, it may require innovative approaches to staffing this function (e.g. volunteers). During the project's key informant interview with EOA, the discussion also highlighted a systemic need to broaden the conceptualization of LTSS for both caregivers and older adults. A fragmented framework has largely limited the county resource databases to services that are contracted through Hawai'i's Aging Network. Many of Hawai'i's information and referral (I&R) staff have been certified by the Alliance of Information and Referral Systems (AIRS), a professional I&R credentialing program, which is advantageous as the State considers how to evolve the ADRC's statewide resource database. Building upon the AIRS certification obtained by many ADRC I&R staff, the feasibility of TCARE's integration will also rely on the utility of the ADRC resource database for TCARE care managers. Developing a comprehensive crosswalk of caregiver LTSS within the ADRC resource database will be a challenge. It will require staff capable of developing a robust inventory of caregiver LTSS, as well as funding to contract with Tailored Care Enterprises, LLC. so that the crosswalk can be built upon the AIRS Taxonomy – the North American standard for indexing and accessing human services resource databases. If an investment into the ADRC's statewide database was made, however, the efficacy of Hawai'i's TCARE program would undoubtedly be strengthened.

In addition to system improvement, staff capacity is also a major concern. Findings from this pilot project indicate that care managers were challenged in adding the TCARE program to their existing workload, particularly in conducting the 3-month follow-up. The effective use of the TCARE screener will make the process more efficient. I&R staff can be trained to administer the short TCARE screener over the phone. Only caregivers whose score reaches a certain threshold will be given the full TCARE assessment and support planning process. Similarly, during the follow-up period, the screener can again be used to determine whether a full assessment and modification to the support plan is needed. Better use of the screener will make the most of staff time.

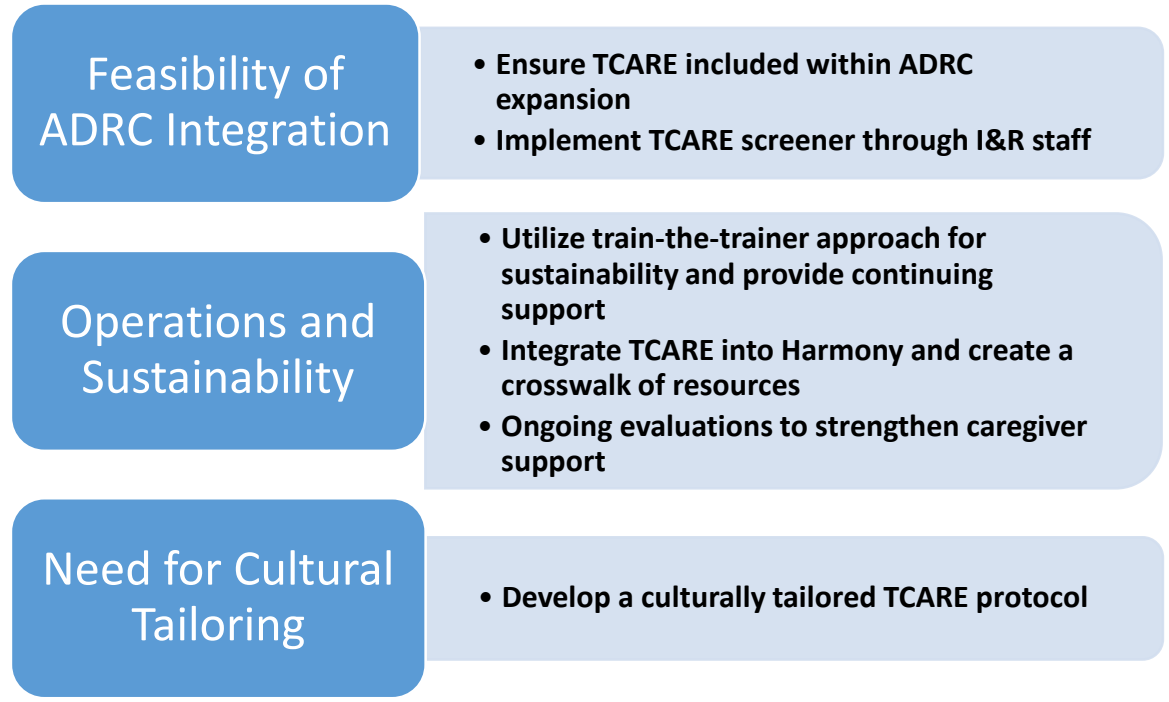
Training of additional TCARE assessors will be necessary for statewide expansion, and a "train the trainer" approach will be most efficient. Currently, only one ADRC site – Maui County Office on Aging, as the project's pilot site – has certified TCARE assessors. Equipping each ADRC site with access to TCARE assessors will be necessary for program expansion and statewide accessibility. Hawaii should identify current local TCARE assessors to become TCARE trainers. Local trainers will be better able to respond to issues and work with care managers to improve their practice. For example, in the prior section of this report, findings suggested that slight adjustments were needed to ensure that care managers think "outside the box" and recommend informal and non-traditional services in addition to traditional services in their support plans. A local trainer will be able to better respond and work with care managers to respond to any issues and ensure fidelity to the TCARE model.

In summary, the upfront investment in TCARE will be substantial but may lead to a number of positive outcomes. First, adoption and integration of TCARE will equip the State with a mechanism to measure caregiver outcomes. It will provide key stakeholders in the aging network with robust data to present to the Legislature when advocating for additional LTSS funding for caregivers. Additionally, an upfront investment in a train-the-trainer approach to TCARE program expansion will enable Hawai'i to sustain and develop additional TCARE certified care managers. TCARE's largest expense is the training and certification of care managers, and so a train-the-trainer program would significantly reduce the program's expenses and aid its sustainability.

See the Appendix for a budget breakdown TCARE costs for statewide implementation.

VI. RECOMMENDATIONS

Based on the findings detailed in the preceding evaluation, the UH Team recommends that EOA embed TCARE within the statewide ADRC. The evaluation finds TCARE to be feasible, but statewide integration through the ADRC will require a large investment of State resources in not only TCARE integration but in ensuring that sufficient LTCSS are affordable and accessible to older adults and their family caregivers. Quality geriatric assessments for older adults and caregivers are only a first step in assuring an improved quality of life for older adults and their caregivers. Supplementary information in the appendices to provide additional information on the evaluation processes and a detailed summary of the resources required for future investments in TCARE.



The following section details UH's recommendations based on TCARE evaluation findings:

1. Ensure TCARE is included within ADRC Expansion

- As TCARE would require substantial resources to implement statewide, it is recommended that EOA embed TCARE similarly through Hawai'i's AAA contracts, thereby enabling program monitoring and evaluation.

- EOA should form an oversight committee prior to statewide integration. This may be more feasible by expanding an established ADRC committee, such as the ADRC operations workgroup, to include these functions.

2. Implement TCARE Screener through I&R Staff

- It is recommended that the State require the TCARE screener as a component of Hawai'i's TCARE protocol. Doing so will enable the ADRC to identify caregivers who are most at risk of burnout and/ or those who are considering placing their care recipient in a long-term care facility. Additionally, if the caregiver requires an in-home assessment, information on their income will be collected which will provide the ADRC with another mechanism to target services to those most economically in need. The addition of the TCARE screener is timely, as EOA and Hawai'i's AAAs are currently in the process of developing a prioritization tool through the ADRC operations workgroup.
- Caregivers in Hawai'i would be identified for the TCARE program through I&A with the ADRC. Aligning with the ADRC's no wrong door approach, it is recommended that EOA and the AAAs strengthen caregiver's accessibility to TCARE by providing information and outreach to community providers and organizations on the TCARE program.

3. Utilize a train-the-trainer approach and provide continuing support

- It is recommended that each of Hawai'i's AAAs have a minimum of one TCARE trainer to aid program sustainability. Equipping each AAA with a TCARE trainer will require the State to invest in the TCARE Train-the-Trainer program. More information on the TCARE Train-the-Trainer program's associated costs can be found in the Appendix.

- As not all AAA staff in Hawai'i meet TCARE's preferred minimum education standards, it is recommended that EOA work with Tailored Care Enterprise, LLC. to ensure all TCARE assessors have developed sufficient clinical skills prior to receiving their TCARE certification. Tailored Care Enterprise, LLC. is willing to provide additional clinical training to AAA staff who do not meet these minimum standards.

- Ongoing TCARE training for each ADRC is recommended. Initially, this training will help develop buy-in. Long-term, ongoing training will maintain proficiency on administering the TCARE program. Tailored Care Enterprises, Inc. has offered to provide free webinar trainings to Hawaii, which will be a valuable resource for the state's TCARE program in the road ahead.

- Ensuring there is adequate support available to each AAA as they implement TCARE within their respective organization will be critical. As such, it is recommended that ongoing technical assistance (from both Tailored Care Enterprises, LLC. as well as technical assistance from the State) is available for the TCARE program.

4. Integrate TCARE into Harmony and create a crosswalk of resources

- It is recommended that EOA integrate the TCARE assessment tools and decision algorithms into the State's Harmony Information System (see the Appendix for more information).

- Strengthening the utility of both the ADRC and TCARE, it is recommended that a crosswalk of caregiver services within the ADRC resource database be developed (see Appendix for more information). Throughout the study's evaluation, the remaining unmet service needs of caregivers were elevated by participants and key informants alike. Developing a crosswalk of caregiver services within the ADRC resource database will enable care managers to utilize a broaden lens of caregiver supports and services during care planning, while more efficiently targeting the scarce public resources that are available to those most in need.

5. TCARE requires ongoing evaluations

- Ongoing evaluations of a statewide TCARE program will be essential. These evaluations will sustain buy-in among those administering the program, and in addition, will foster program sustainability. Data from the TCARE program will be useful in securing

additional program resources (e.g. legislative funding), while concurrently assessing caregivers' remaining unmet needs.

6. Develop a culturally tailored TCARE protocol

- The cultural findings presented within this project's evaluation surface important considerations about the TCARE protocol for statewide implementation. As such, it is recommended that EOA and the UH participate in planning discussions with Tailored Care Enterprise, LLC about the need for a culturally tailored TCARE protocol for Hawai'i.

Conclusion

The University of Hawai`i recommends that the Executive Office on Aging adopt the TCARE model statewide. The evaluation finds TCARE to be feasible, but statewide integration through the ADRC will require a large investment of State resources in both TCARE integration and in the availability and affordability of LTSS for older adults and their family caregivers. UH provides recommendations to improve efficiency by adopting a "train the trainer model" and integrating TCARE tools within Harmony. The Appendix section to follow outlines costs for software integration and training. In addition, the investment in TCARE needs to be framed within its potential benefits. TCARE provides structured, standardized support to caregivers and enables the targeting of resources to those most in need. Adoption of the TCARE model will enhance caregiver support services statewide.

VII. REFERENCES

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APPENDICES

TCARE Final Evaluation Report

Definitions of TCARE Measures

Summary of UH Support Activities

Key Informant Interview Questions

Focus Group Questions with MCOA staff

Projected Budget for TCARE Statewide Implementation

Definitions of TCARE Measures

Relationship Burden: The extent to which the care receiver makes demands for care and attention over and above the level that the caregiver perceives is warranted by the care receiver's condition. The perception that the care receiver is making excessive demands creates a negative psychological state for the caregiver that is directly linked to the caregiver's unique relationship with the care receiver.

Objective Burden: A negative psychological state that results from the perception that caregiving activities and responsibilities are infringing on other aspects of the caregiver's life including time and energy to address other family obligations, leisure activities and personal needs.

Stress Burden: A generalized form of negative affect that results from caregiving. It is not the result of any specific event, task, or interaction.

Uplifts: A positive psychological outcome associated with caregiving. It includes such things as the direct enjoyment of caregiving tasks, an improved relationship with the care receiver, and generalized positive affect.

Depression: An affective disorder characterized by negative affect. This measure is a shortened version of the Center for Epidemiological Studies – Depression Scale (CESD). This measure captures four underlying dimensions: dysphoria, somatic complaints, positive affect, and interpersonal distress.

Identity Discrepancy: A negative psychological state that accrues when the activities and responsibilities that a caregiver assumes with regard to the care receiver are inconsistent with the caregiver's expectations or personal norms concerning these activities and responsibilities.

Summary of UH's Support Activities

Hawaii TCARE Pilot Project	
Date	**Summary of Major Support Activities**
10/28/14	University of Hawai`i Team and EOA TCARE Planning Meeting
12/15/14	In-person team meeting: MCOA and University of Hawai`i Team • Discussion of timeline, expectations of each care manager, pilot project tools (informed consent, script)
1/23/15	Phone conference: University of Hawai`i Team and MCOA • Review of timeline and preparation for pilot project launch
1/30/15	Webex: MCOA, EOA, University of Hawai`i Team • Review of TCARE software
2/12/15	TCARE Administrative Training: University of Hawai`i Team, EOA, Tailored Care Enterprises, LLC • Administrative training to enable access to TCARE software
2/24/15	In-person team meeting: University of Hawai`i Team and MCOA • Pilot project updates from care managers • Discussion of TCARE screener • Review of TCARE timeline • Project support
3/3/15	Phone conference: University of Hawai`i Team and MCOA • Discussion of integration of TCARE screener into Hawaii TCARE pilot project
3/6/15	Phone conference: University of Hawai`i Team and MCOA • Phone conference with Tailored Care Enterprises, LLC • After follow up with Tailored Care Enterprises, LLC, and clarification that a TCARE screen is not a mandatory step within the TCARE processes, the decision to utilize the TCARE screen throughout the pilot project was left to the discretion of each care manager.
4/17/15	In-person team meeting: University of Hawai`i Team and MCOA • Technical assistance call with Jessica Jacobs • Extension of pilot project deadline (initial care plans to be input into TCARE software no later than May 8, 2015; follow-up assessment to be input into TCARE software no later than August 7, 2015). • Pilot project updates from care managers • Project support • Following team meeting, check in with MCOA administrative staff

4/22/15	University of Hawai`i Team and MCOA – individual conference calls with care managers on individual pilot project progress • Individual progress updates from care managers • Review of fidelity of TCARE implementation (with particular attention to review of triggers for caregiver follow up, care planning, outcomes being expressed in caregiver's words, and timeliness between in-home assessment and care planning). • Project support
4/28/15	University of Hawai`i Team and MCOA – individual conference calls with care managers on individual pilot project progress • Individual progress updates from care managers • Review of fidelity of TCARE implementation (with particular attention to review of triggers for caregiver follow up, care planning, outcomes being expressed in caregiver's words, and timeliness between in-home assessment and care planning). • Project support
5/7/15	In-Person Meeting: University of Hawai`i Team and EOA • TCARE Pilot Project Progress Report • Preliminary data and observations • Overview of evaluation protocol and next steps
5/8/15	Phone conference: University of Hawai`i Team and MCOA • Deadline for first phase of evaluation • Project support
7/1/15	Focus Group: University of Hawai`i Team and MCOA
7/10/15	Phone conference: University of Hawai`i Team and MCOA • Review of TCARE informed consent and relevance to pilot project • Review of TCARE 3-month follow-up • Project support

Key Informant Interview Questions

Area Agencies on Aging (AAAs)

1. What is your understanding of the TCARE program/process?
2. What kinds of information do you believe you would need to be able to make an informed decision about your Area Agency on Aging's interest in adopting TCARE?
3. Given access to the above information, what are your thoughts on the feasibility of your office to integrate TCARE into your county's ADRC?
4. What kind of support would your office require to sustain TCARE within your county's ADRC?
5. What is your current status of resources to train your staff in aging-related needs?
6. Would any of these resources be available to allow you to train your staff to become TCARE certified care managers?
7. Are there any concerns you have about adopting TCARE within your organization?
8. Any assessment and referral process is greatly helped or hindered by the availability of key community resources. Briefly, what are the top 3-5 needed community resources in the State for elders and caregivers, and are such resources currently available at your county AAA level?

9. What is your current perception of the needs of your county's caregivers and what kinds of caregiver resources are offered presently? What are your county's challenges with current caregiver services?

The Executive Office on Aging (EOA)

1. How would an area agency on aging in Hawai`i embed TCARE into their county's ADRC?
2. What resources would be required to allow an area agency on aging in Hawai`i to adopt and sustain TCARE within their county's ADRC?
3. What state and/or country resources are presently available to allow for TCARE training to be funded, organized and implemented?
4. What additional resources may be needed to allow for additional TCARE training to be funded, organized, and implemented?
5. Any assessment and referral process is greatly helped or hindered by the availability of key community resources. Briefly, what are the top 3-5 needed community resources in the State for elders and caregivers, and are such resources currently available at the county AAA level?
6. Would the AAA be required to pay the annual fees associated with TCARE?
7. Is there a way to consolidate the TCARE database within Harmony?
8. Could an AAA subcontract the TCARE program?
9. How does TCARE make the ADRC process more efficient and services more accessible to caregivers?
10. Would technical assistance be available to AAAs on TCARE?

States – Washington, Michigan, Minnesota

1. Briefly share with us when the TCARE program was first initiated within your agency/organization?
2. What was your main reason for adopting TCARE?
3. Do you presently have evaluative data on TCARE's effectiveness in your agency/organization?
4. How does your organization sustain the costs related to TCARE, including sustaining sufficient TCARE certified care managers?
5. Can you share about the process of integrating TCARE software within your organization? Did your organization experience any challenges?
6. Are care managers in your organization challenged by an insufficient supply of LTSS for caregivers?
7. Are there any system's impacts you could share as a result of your organization adopting TCARE?
8. Has your organization made any modifications to TCARE protocols?
9. Do you have any "words of wisdom" as we contemplate the use of TCARE in Hawai`i?

TCARE Focus Group Script and Questions

Colette Browne

Myron B. Thompson School of Social Work

Welcome/Introductions

- Thank you for participating in today's group. As you know, Christy Nishita, Heather Chun, and I are working with your Maui County Office of Aging to evaluate the TCARE program for its possible use here in Hawai`i. Our purpose today: **We are interested in learning more about your experiences working with elders and families using TCARE over the past few months**. We have eight (8) questions for you that will complete the focus group session which should take 1-1.5 hours. Immediately following this focus group, we will convene a short break and then meet to update you on TCARE status, solicit your thoughts on a number of administrative questions (10) pertaining to TCARE, and answer any questions you may have at this time.

  For this focus group:

- Remember:
  - There are no right or wrong answers
  - We want to hear from each of you; we will call on quiet folks and ask talkative folks to "hold that thought."
  - Everything you say is confidential, although we are recording it via IPAD.
  - Data will be aggregated, so your words will not be linked to your name in the report.
- Because we need to describe the group, we will ask you to complete a "background sheet."

Q1: Icebreaker: What is your name, and how do you define a Kūpuna?

Cultural Translation:

Q2: In this community, what do you think are the primary health and other needs of Kūpuna?

Q3: In your opinion, are the needs of Kūpuna and their `ohana caregivers on Maui different or the same from other elders and caregivers in our community?

Q4: Is there anything you do (i.e., your communication "style") that you believe works well with elders/families here? (Prompt: "tips" that may enhance client safety, trust/openness with you?)

Q5: Specific to TCARE, when you think about TCARE's protocol for accessing entry and communication with families? Would you recommend any changes? [Prompt: may have to sum up the protocol for answers].

Q6: If a new MCOA worker was hired here, what would you want him or her to know about working with elders and their families on Maui?

Q7: [Sum up main points from Q6 and then ask:] Do you think these community needs are the same for elders and families on our other islands?

Q8: Do you think you learned anything new about the cultural diversity here on Maui? What would be some examples? [Prompt: care/service preferences? preferred communication patterns?]

That is the end of our questions. Is there anything else you'd like to share on this subject? Or perhaps you have questions for us. [Take questions]

Wrap up:

- We appreciate your help.
- Our findings will become a component of the TCARE evaluation. We have also interviewed key individuals in the community as well as leaders in other states who are currently using TCARE in their own communities.
- If you have questions, please contact Heather Chun at hmchun@hawaii.edu.
- Thanks again.

BREAK

RECONVENE—MEETING

Questions on TCARE Administration:

Q9: One of the goals of TCARE is to enhance your ability to make choices with your client [family]. Tell us about any positive or negative experiences with reaching this goal. [Prompt: Did you find any barriers to meeting family needs?]

Q10: Were the roles and responsibilities of your work with TCARE clear to you? Examples?

Q11: Do you have any recommendations for improvement here?

Q12: Do you have any recommendations about the assessment protocol and tools?

Q13: Do you have any recommendations about the service plan protocol?

Q14: The delivery of the TCARE processes? [Prompt: Questions about service options, availability, etc.]

Q15: Do you want to share anything about your experience with 1) training; or 2) TCARE supervision/mentoring that may be helpful?

Q16: Were the written and other materials (i.e., web information) easy to access, use, and understand by you? By families? If not, can you explain more about this?

Q17: Did you have any challenges coming up with the service recommendations? [Prompt: is a particular service not available on Maui?]

Q18: Do you have any thoughts about the integration of TCARE into the ADRCs?

Is there anything else you would like to share at this time?

Thank you for your frankness and your time.

Projected Budget for TCARE Statewide Implementation

Product	Details	Cost
TCARE Assessor Training	This fee is charged for each TCARE Assessor who participates in a TCARE Assessor Training conducted by TCARE Certified Trainers employed by the Licensee. The fee covers: a User and Training Manual to be shipped to the licensee using standard 3-5 day shipping; (2) access to the eLearning Training Site and (3) TCARE Certification and (4) TCARE License. Certification to use TCARE is required for all new TCARE® Assessors after completion of the TCARE Assessor Training (regardless of whether they are trained by a TAILOREDCARE or TAILOREDCARE Certified TCARE Trainers). TCARE Certification consists of an on-line proficiency examination administered by TAILOREDCARE. Individuals successfully completing the TCARE Certification will be authorized to use the Licensed Materials for one year with payment of accompanying Annual License Fee. Completion of the TCARE Certification Exam prior to licensure is required for **all new** TCARE Assessors. A TCARE Assessor is *not* required to take a recertification exam to renew a license if the Assessor has completed 5 or more assessments in the prior year	$1200 per Assessor
TCARE Blended Training	**Step #1**: Two-Three weeks prior to the <u>one-day</u> in-person training (less travel expenses for both trainer(s) and trainees), trainees are given access to an online training curriculum where they review 10 presentations on the background and process of TCARE and how to implement the program. Each presentation is followed by a short quiz so that our team knows if the trainee is comprehending the material presented. **Step #2:** Trainee participates in a one-day in-person training where they practice completing the TCARE process using the web-based TCARE Software. **Step #3:** Trainee completes the full TCARE process with a caregiver that they are already working with, and then participates in a two-hour webinar with the Tailored Care team to review the cases and trouble shoot issues and concerns completing the process. **Step #4:** Trainee completes a web-based Certification Exam. Trainee is notified immediately after submitting if they passed or failed.	$500 Annual License

	Once all four steps are completed and the trainee passes the certification exam, they are licensed as a TCARE Assessor. **Yearly License Includes:** Access to the eLearning software Access to the web-based TCAREe software Ongoing technical support	
TCARE Train-the-Trainer	Requirements to become a Licensed TCARE Trainer include: (i) being a Licensed TCARE Assessor, (ii) use of the TCARE process for at least six months prior to attending the Train-the-Trainer Training, (iii) participation in the two-day in-person Train-the-Trainer program conducted by TAILOREDCARE Trainer(s), and (iv) conducting a full TCARE Assessor training while mentored by TAILOREDCARE Trainer(s). To have a successful group of trainers, Licensee is encouraged to select individuals who are; comfortable presenting in front of groups, have good communication skills, are comfortable using computers and technology, and understand the importance and benefits of TCARE.	$7,400 (up to 4 trainers-Travel Not Included) Additional annual $500 licensing fee
Mentored TCARE Training	During the Mentored TCARE Training, TAILOREDCARE Trainer will mentor the apprentice trainers while they conduct each step of the TCARE training, including; (i) introducing TCARE and registering trainees in the eLearning training site, (ii) organizing training location and logistics, (iii) conducting the one-day in-person training at Licensee facility, (iv) trainers' review of case studies, (v) conducting the Review Webinar, and (vi) registering trainees to take the Certification Exam. Licensee is required to provide meeting rooms, AV equipment, and food for assessors and trainers (food to include morning snack, lunch and afternoon snack). An additional fee will be charged for reasonable travel costs for a TAILOREDCARE Trainer.	$17,500 for up to 8 Assessors (travel not included) Additional annual $500 licensing fee
Software Integration	Integration of TCARE assessment tools within Harmony Information Systems This would include Tailored Care Enterprises, LLC working with the team to check fidelity and consistency of the program and also work to make any updates.	$9,600 (year 1) $2,000 Annual license fee
ADRC Resource Database	Develop a crosswalk of caregiver resources within the ADRC Resource Database	$6,400 (one-time fee)