

Evaluation of the State of Hawai'i, Executive Office on Aging's
Hawaii Community Living Program

Final Report

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by

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Executive Summary

The Community Living Program (CLP) was a 3-year pilot program that began in September 2009, with support from an Administration on Aging grant awarded to the State of Hawaii Executive Office on Aging (EOA). The first two years were spent in project design and development, as well as staffing and procuring contractors; the third year was the implementation of the pilot program. The pilot was originally scheduled to close on September 29, 2012, however, a no-cost extension was granted, which modified the final closing date of the program to March 31, 2013. The goal of the program was to empower participants to direct and determine the type of services and supports needed to live independently in the community. Eligible participants were given a monthly budget and with the support of a Program Coach, developed a support plan and spending plan for needed home and community-based services and goods/supplies. EOA contracted with the University of Hawaii Center on Aging (COA) to conduct program evaluation of the implementation phase of the pilot project.

Inclusion Criteria

Participants met four inclusion criteria: 1) not currently living in a care facility such as a nursing home, adult residential care home, extended care home, shelter, foster care home or group home operated by a public or private entity; 2) not currently receiving Medicaid, not on a Medicaid wait list, or waiting for determination of Medicaid eligibility; 3) have income between 101% - 300% of the federal poverty level, and an asset amount less than \$43,500 (excluding primary residence, one car, burial plot, and cash value of life insurance); and 4) have one of the following: three or more activities of daily living (ADL) impairments, physician's diagnosis of Alzheimer's Disease or Related Dementia (ADRD), or a nursing home or adult residential care home stay within the last six months.

Key Players in CLP

The following are the key players in the CLP pilot program:

- **Program Specialist:** The Program Specialist at EOA was responsible for overseeing all aspects of the grant.
- **Program Manager:** The Program Manager was responsible for overseeing the day-to-day operations of the program.

- **ADRC Workers:** Aging and Disability Resource Center (ADRC) Workers on Kauai, Maui and Hawaii Islands were responsible for initial screening and intake of potential participants as well as referral to the Program Manager.
- **Program Coaches:** There were five people that served as Program Coaches for CLP. Their overall goal was to train participants to be self-supporting, i.e., be able to perform necessary tasks for participation in the program independently.
- **Fiscal Agent:** EOA contracted with the fiscal agent, Acumen, to process employee background checks, paychecks (e.g., insuring proper deductions such as withholding tax were made), payment checks for vendors, and reimbursement checks for participants.
- **Participants:** Program participants (with assistance from their Coaches) were responsible for deciding what needs they had, the best way to meet those needs, and how to allocate their monthly budgets in order to have those needs met.

Quantitative Methods

A program evaluator from COA created an Excel spreadsheet to track participant and program data. In addition, COA had access to the fiscal agent's secure online share file, which allowed for remote data collection. All data were coded and transferred to a data analysis software program: Statistical Package for the Social Sciences (SPSS). Quantitative analysis was conducted using descriptive statistics, frequency counts, and t-tests, and is reported in the quantitative findings section below.

Participant Characteristics

In total, CLP received 112 referrals, 105 of which met the eligibility criteria for inclusion in the pilot program. These individuals were offered the option of receiving supports in the participant-directed model (i.e., enrolling in CLP) instead of traditional services, and enrollment in the project was voluntary. Of the 112 referrals, 91 (81%) successfully completed enrollment and implemented spending plans. Fifty-eight (63.7%) participants were female and participants ranged in age from 50 - 98 years ($M = 78$ years). Less than half of participants ($n = 38$, 41.8%) were receiving services prior to enrolling in CLP, either from Kupuna Care, Title III services, or other sources. Sixty-five (71.4%) participants appointed an authorized representative to make decisions for them, either due to circumstance or illness (e.g., moderate Alzheimer's disease).

Thirty-four participants (37.4%) had a diagnosis of ADRD and the majority of participants (n = 84, 92.3%) had three or more ADLs.

Outcomes of Participants

Recruitment began in December 2011 and the final month for allocation of funds for participants was February 2013. At that time, 68 (74.7%) of the 91 participants were still enrolled and 23 (25.3%) were no longer active in the program. Reasons for inactivity include: participant passed away (n = 14, 15.4%), institutional placement (n = 5, 5.5%), spend down to Medicaid (n = 2, 2.2%), and non-compliance with program guidelines (n = 2, 2.2%). An independent samples t-test was conducted to compare outcomes (length in program in days) between those with and those without an authorized representative. Findings indicated that there was no significant difference in days spent in the program between those with and without an authorized representative. In addition, there was also no significant difference in total days spent in the program between those with and without a diagnosis of ADRD.

Budget Amounts

Participants were allocated a monthly budget which ranged from \$650 to \$800 ($M = \$750.00$, $SD = \$60.92$). Program Coaches and participants worked together to establish a support plan and a spending plan that met the participants' needs. Due to the participant-directed nature of CLP, as the needs of participants changed, they (in collaboration with their Program Coach) were able to change their support and spending plans to reflect these new needs.

Allocation of Funds on Spending Plans

Participants could utilize their CLP funds in a way that suited their individual needs:

- Participants reported receiving *unpaid, informal support* from individuals (n = 63, 69.2%), family (n = 23, 25.3%), friends (n = 7, 7.7%), their community/church (n = 7, 7.7%), and other sources (n = 5, 5.5%).
- Participants were able to *hire individuals as employees* to provide in-home care (n = 66, 72.5%) including personal care services, such as assistance with feeding and bathing (n = 43, 47.3%); homemaker services, such as meal preparation (n = 20, 22.0%); chore help, such as cleaning the house or doing laundry (n = 12, 13.2%); and companion services (n = 3, 3.3%).

- Participants were able to *hire vendors* (i.e., businesses or companies that were operating prior to the start of the pilot program) to provide in-home care, such as personal care (n = 14, 15.4%); homemaker services (n = 12, 13.2%); support for family caregiver, usually in the form of respite (n = 10 11.0%); chore help (n = 5, 5.5%); technology for safety and independence such as internet service (n = 4, 4.4%); and companion services (n = 4, 4.4%).
- Participants were also able to purchase (or be reimbursed for the purchase of) health and household-related *goods and supplies*. In total, 48 participants (52.7%) chose to utilize CLP funds for the purchase of goods and supplies.

Employee, Vendor, and Goods Purchased Across All Participants

This section summarizes the total numbers of employees hired and vendors utilized across all participants in the pilot program. These numbers are provided to give an indication of the potential for economic growth and job creation as a result of participant-directed programs such as CLP.

Table 1: Financial Data for Employees, Vendors, and Goods - Aggregated Across the Pilot	
<u>Employee Information</u>	
Number of Participants who Hired Employees	67 (73.6%)
Number of Employees Hired	83
Employee to Participant Ratio*	1.2
Number of Employees Hired by Multiple Participants	1
Number of Participants who Hired 2+ Employees	20
Mean Hours Worked by Employees Per Pay Period	31.1, range: 2 - 108, <i>SD</i> = 16.4
Mean Hourly Wage of Employees (not including taxes)	\$11.57, range: \$8.50 - \$25, mode = \$10
Mean Amount Paid Per Employee Over the Pilot	\$3,802.71, range: \$41.70 - \$9,971.55
Mean Length of Employment (in months)	6.13 months, range: 0.06 - 11 months
<u>Vendor Information</u>	
Number of Participants who Utilized Vendors	57 (62.6%)
Number of Vendors Utilized	46
Vendor to Participant Ratio*	0.81
Number of Vendors Utilized by Multiple Participants	8

Table 1: Financial Data for Employees, Vendors, and Goods - Aggregated Across the Pilot	
Mean Length of Vending (in months)	3.59, range: 0.03 - 11, <i>SD</i> = 3.06
Mean Payment to Vendor Over the Pilot	\$2,653.83
<u>Goods and Supplies</u>	
Number of Participants who Purchased Goods	48 (52.7%)
Total Amount Spent on Goods	\$78,377.37
Amount Spent on Goods per Participant Over the Pilot*	\$1,632.86
*Ratios and per participant calculations are based on participants who utilized that particular method of spending	

Qualitative Methods

In order to understand the perceptions and experiences of those involved with the pilot program, interviews were conducted with the program participants and key leadership within CLP (i.e., EOA Program Specialist and CLP Program Manager) and a focus group was conducted with the Program Coaches.

Qualitative Findings

Key Findings from Participant Interviews

- Overall, participants had a varied knowledge of long-term care services available in their communities and the long-term care services they or their loved ones needed to live at home. These responses point to a need for Coaches to be able to educate participants on how to assess needs, and how to locate services available to meet those needs.
- Overall, participants had little to no confidence they would have remained living at home had they not been involved with CLP. Of the participants that were very confident, several indicated that although they (or their loved one) would have remained living in the home, the financial and physical strains would have been much greater without the support of the CLP.
- Participants appreciated their ability to make their own choices. Specifically, they liked the ability to choose how to use their funds and who to hire.
- Although most did not have complaints about the program, a few participants commented about the administrative requirements of the program, including the amount of paperwork required (i.e., time sheets and employee tax forms) and the time constraints (i.e., tight timeline in submitting time sheets to fiscal agent). These tight timelines were primarily a result of adhering to Hawaii Department of Labor laws, which require employers to pay their employees within seven calendar days of the end of a pay period.

- All participants reported that they would recommend this program to others in their communities

Key Findings from Coach Interviews

- Coaches reflected on their roles and responsibilities and indicated that key skills and competencies that Coaches should possess include past experience with participant-directed services, patience, knowledge of cultural practices and expectations, and ability to maintain the boundaries of the Coach-participant relationship.
- A clear program benefit was the *empowering* of individuals. Coaches reiterated that CLP allowed participants and their families to have a voice and a real role in the decision-making process.
- Coaches' challenges included working in a rural setting because access to technology was limited.
- Coaches said that the most frequent challenges faced by participants were: 1) Finding people to provide services and 2) Conducting the interview and the hiring process. Participants needed a lot of help and training in this area.
- There was an unanticipated outcome of increased job pool/job creation. Some participants hired multiple employees in an effort to provide jobs for as many people as they could. For example, one participant hired four different employees to provide in-home care. The participant's needs did not require that four employees care for her. She chose to hire four people to create four jobs instead of one.

Key Lessons Learned from Interviews with Program Specialist and Program Manager

- Fidelity: The referral and enrollment process was outlined on page 20. In practice however, it was not clear whether all staff completed the required steps. For example, the 4-page referral form was not consistently completed, which meant the program manager had to go back to the intake person to clarify information.
- Compensation: Coaches were compensated for face-to-face and telephone interactions with participants and authorized representatives. They were not paid for time spent on administrative duties, such as phone calls with the Program Manager. A main lesson learned for the future is to include these types of administrative items in coaches' contracts, as well as adding time for team meetings and travel to rural areas.
- Reassessment: Participants need to be reassessed after a year to review and discuss difficulties and concerns of participants. In addition, a protocol and tool for participant non-compliance is needed.

- Participant compliance: Upon enrollment, participants need to be notified in writing of their responsibilities to ensure compliance with the CLP, inform participants of non-compliance as it occurs, and offer opportunities to remedy issues prior to termination.

Commendations, Challenges and Recommendations

The main participant benchmarks were to: 1) enroll 90 participants, and of these participants, 2) 80 participants (89%) will avoid institutionalization, and 3) 80 (89%) will avoid Medicaid spend down. This section summarizes the progress made toward the three benchmarks, as well as the experience of participants in the program., project's commendations, challenges, and the evaluators' recommendations for the CLP.

●Commendations

- The program met the 1st benchmark one by enrolling 91 participants. Of these participants, 84 (92.3%) avoided institutionalization and spend down to Medicaid. A small percentage of participants were institutionalized (5.4%) or spent down to Medicaid (2.2%). Therefore, the 2nd and 3rd benchmarks were also met.
- Interviews with participants indicated that they were highly satisfied and all supported the sustainability of the program. Many (60%) said they would not be able to remain at home without the CLP program.
- The program developed a comprehensive Participant Guidebook that described the CLP, outlined participant responsibilities, and the roles of the Coach and fiscal agent. A similar guide, the Policy and Procedures Manual was successfully developed for the Coaches.
- Coaches were proud and enthusiastic about the CLP model. They were supportive of the program's philosophy of participant empowerment and worked hard to implement the program properly.
- Coaches were very creative, particularly in working in a rural island population. They faced difficulties in getting goods and supplies shipped to Molokai and finding services on the island.

●Challenges

- Qualitative interviews noted concerns over boundaries between Coaches and participants. Certain participants needed a greater level of support in determining the type and amount of goods and services needed. As a result, some Coaches had to provide more to support certain participants. The line between "doing for" and "doing with" needs to be better understood by participants and Coaches.
- It is important for ADRC intake staff and Coaches to maintain fidelity to CLP's protocols for referral, enrollment, and the roles of Coach and participant. Maintaining fidelity is necessary to ensure that the program supports the philosophy of participant

direction in all areas of the program. Qualitative interviews with CLP Coaches and leadership indicated that in a few cases, referral forms were incomplete, the referral process did not proceed in a timely manner, and Coaches were required to provide a significant amount of support to certain participants

- The frequent challenges expressed by participants related to administrative requirements of the program, including paperwork (time sheets and tax forms), meeting deadlines to submit time sheets, and use of technology (i.e., fax machines) to submit paperwork.

● Recommendations

- Coaches would benefit from training on motivational interviewing and health coaching models. These models emphasize the need to “lead from behind”, empowering participants to make their own decisions. The training should also clearly outline the roles of Coaches versus responsibilities of participants. This will address concerns related to boundaries between Coach and participant.
- Coaches should meet quarterly, either in person or via a video conference call, to discuss successes and challenges with participants. At the close of the Coaches’ focus group, several mentioned how productive and reassuring it was to talk in person with the other Coaches. In the future, regular discussions between Coaches may function as a training tool, allowing Coaches to offer suggestions or examples of how they handled challenging situations. It could also allow for oversight by a program manager.
- Standardized tools and protocols need to be adopted and deployed to ensure program quality and fidelity. The participant handbook should be expanded to include tools that need to be developed or adopted from other states to help participants:
 - Better understand participant responsibilities in the program, through written case studies or scenarios, and samples of completed forms.
 - Gauge their readiness to perform CLP requirements through a readiness self-assessment. Such an assessment can help to gauge a person’s motivation to participate in CLP and complete the program’s requirements. Motivation was mentioned by program leadership and Program Coaches as a key quality participants need to have.
 - Participants should be given a separate form, detailing a list of roles and responsibilities on the part of the program and the participant, and this document should be signed by participants and Coaches.
 - A termination agreement should be developed and utilized for non-compliance with basic requirements of the participant-direction program, for example, misuse of funds.
 - A protocol for termination should be implemented, that should include (but not be limited to): informing participants of the decision, offering the ability to appeal or review the decision, developing a plan to return to agency services, developing a new service plan, and ensuring there is no break in services.

- A quarterly reassessment form to monitor participants' progress in CLP
- Fidelity monitoring should be required at set time periods, e.g., quarterly. A program staff person should be responsible for quality assurance and conduct periodic reviews of support plans and spending plans to ensure fidelity to protocols. Furthermore, satisfaction surveys should be conducted semi-annually or annually with participants to ensure quality of life, stability (minimal ER/hospital visits), and that they have the supports needed for community living.
- Participant information from the CLP should be incorporated into the statewide ADRC database. The new ADRC system uses a uniform assessment tool that includes socio-demographic and health information. This system should be integrated with CLP data in order to track participant outcomes and program progress statewide. This centralized statewide database will facilitate quality assurance monitoring.
- More evaluation and analysis is needed to determine the appropriateness of the tiered approach to budget amounts. For example, an examination of the ratio of CLP funds utilized to personal funds utilized may be beneficial in assessing the long-term sustainability of the program and aid in preventing spend-down to Medicaid. This is recommended because a Coach indicated one participant utilized their own funds in conjunction with CLP funds to pay for in-home care. In addition, Coaches indicated participants with a diagnosis of ADRD and/or greater ADLs required more supports overall.

Background

The Community Living Program (CLP) was a 3-year pilot program that began in September 2009, with support from an Administration on Aging grant awarded to the State of Hawaii Executive Office on Aging (EOA). The first two years were spent in project design and development, as well as staffing and procuring contractors; the third year was the implementation of the pilot program. EOA contracted with the University of Hawaii Center on Aging (COA) to conduct program evaluation of the implementation phase of the pilot project. The pilot was originally scheduled to close on September 29, 2012, however, a no-cost extension was granted, which modified the final closing date of the program to March 31, 2013.

The goal of the program was to allow participants to direct and determine the type of services and supports needed to live independently in the community. This pilot program was part of a larger federal policy movement that emphasizes participant direction and choice in home and community-based long-term care. Participant directed services, also called consumer-directed or self-directed services, are home and community based services that help people of all ages and all types of disabilities maintain their independence and determine for themselves what mix of supports and services work best for them. Participant direction empowers each program participant (or a representative authorized by the participant) to utilize choice and control over decisions made about his or her services. This model reflects the belief that participants understand what is best for them and have the right to make their own decisions.

The CLP represents a major paradigm shift from traditionally provided services. In the traditional service delivery model, decision-making and managing authority is vested in the professional using a traditional model. In contrast, participants in a participant-direction model are free to spend their pool of funds on the services and supports that best meet their particular long-term care needs and avoid institutionalization. Similarly, CLP participants were empowered, with the support of a Program Coach, to put together a package of long-term care services and goods that would support independence in the community.

The CLP was an ambitious pilot that targeted persons at risk of institutionalization because of physical or mental impairment or a recent stay in a care facility. It also served those with limited income and assets, for example, those just above the financial eligibility criteria for

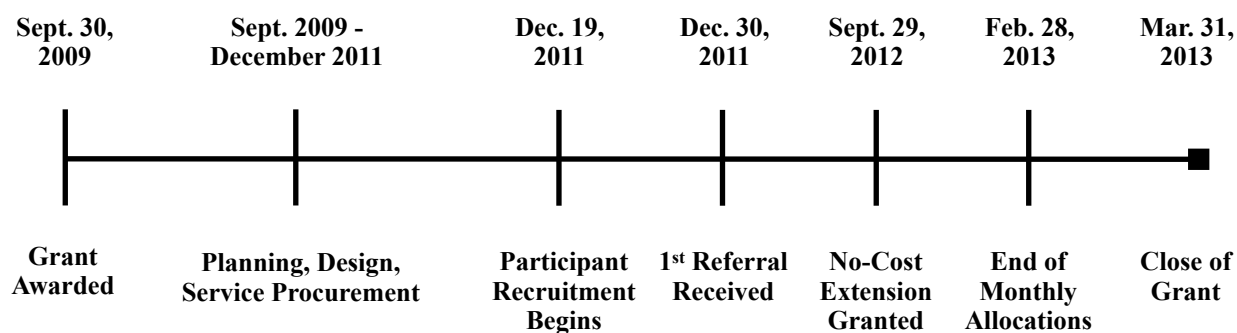
Medicaid. These elders are often forced to deplete their finances (i.e., spend down) to be eligible for Medicaid in order to a pay for long-term care. As such, key leadership at EOA set forth the following benchmarks for the pilot program: (1) 90 persons will enroll in the program, (2) 80 individuals will avoid institutionalization, and (3) 80 individuals will avoid spend down to Medicaid.

Community Living Program Description

Pilot Program Timeline

The Hawaii State Executive Office on Aging was awarded a three-year grant on September 30, 2009. Year 1 (September 2009 - September 2010) and Year 2 (September 2010 - December 2011) were used as planning years to design the program, and procure and implement the infrastructure for the CLP. Year 3 (December 2011 - September 29, 2012) was used as the implementation portion of the pilot program. Recruitment of participants began on December 19, 2011, and the first referral was received on December 30, 2011. The pilot was originally scheduled to close on September 29, 2012, however, a no-cost extension was granted, which modified the final monthly allocation of funds to February 28, 2013. The final closing date of the program was March 31, 2013.

Figure 1: Time Line for CLP Grant



Inclusion Criteria

For a person to have participated in the program, he or she needed to meet four inclusion criteria: 1) not currently living in a care facility such as a nursing home, adult residential care home, extended care home, shelter, foster care home or group home operated by a public or private entity; 2) not currently receiving Medicaid, not on a Medicaid wait list, or waiting for determination of Medicaid eligibility; 3) have income between 101% - 300% of the federal

poverty level, and an asset amount less than \$43,500 (excluding primary residence, one car, burial plot, and cash value of life insurance); and 4) have one of the following: three or more activities of daily living (ADL) impairments, physician's diagnosis of Alzheimer's Disease or Related Dementia (ADRD), or a nursing home or adult residential care home stay within the last six months.

Key Players in CLP

Key players in the CLP included the Program Specialist from EOA, the Program Manager (also at EOA), Aging and Disability Resource Center (ADRC) workers, Program Coaches, the fiscal agent (Acumen), and program participants. Responsibilities of each of the players are outlined below.

EOA Program Specialist: The Program Specialist at EOA was responsible for overseeing all aspects of the grant. She was involved in the writing and submission of the grant to AOA, and oversaw all aspects of the planning and procurement phase once the grant was awarded. In addition, the Program Specialist oversaw the financial aspects of the program, worked closely with the fiscal agent, and provided general oversight to ensure adherence to program protocol.

CLP Program Manager: The CLP Program Manager was responsible for overseeing the day-to-day operations of the program. She was responsible for reviewing referrals, making determinations of potential participants' eligibility, determining monthly allotment amounts, and routing the referral to the appropriate Coach. The Program Manager supervised Program Coaches and was in constant contact with them regarding any issues with participants and the day-to-day operations of the program. She was responsible for designing the standard spending plan utilized during the pilot, and also reviewed and approved each participants' support plan and spending plan, along with any revised versions of those documents. The Program Manager had extensive contact with the fiscal agent, and was responsible for uploading spending plans and other documentation to the fiscal agent's secure share folder online. The Program Manager also served as the Program Coach for Kauai.

ADRC Workers: Aging and Disability Resource Center (ADRC) Workers on Kauai, Maui (including Molokai and Lanai) and Hawaii counties were the initial points of contact for

potential participants. Oahu was not included in the pilot. They were responsible for initial screening and intake of potential participants, completion of referral forms, and transmission of referral forms to the Program Manager. If participants did not meet eligibility criteria, or decided not to enroll in the CLP, ADRC workers were responsible for following up with them to offer options counseling.

Program Coaches: The EOA Program Specialist conducted the State's competitive procurement process via Requests for Proposals to select contractors to perform coaching duties. There were five people that served as Program Coaches for the CLP. Two Coaches served the Big Island, two Coaches served Maui County (Maui, Molokai, and Lanai), and one Coach served Kauai. Oahu was not included in the pilot study. Coaches were responsible for presenting details of the program to potential participants, enrolling participants in the program, supporting participants in the creation of support and spending plans, training participants to hire and manage employees, monitoring participants via monthly contact, and aiding with changes to support and spending plans. Coaches were also responsible for educating participants on how to complete paperwork, and how and when to submit paperwork to the fiscal agent. Their goal was to empower and train participants to be self-supporting, i.e., be able to perform necessary tasks for participation in the program independently. Payments to Coaches came directly from CLP grant funds and did not impact participants' budget allotments.

Fiscal Agent: Selection of the fiscal agent was also conducted via the State's competitive procurement process. EOA contracted with the fiscal agent, Acumen, to oversee the financial aspects of the program. Specifically, Acumen was responsible for processing employee background checks, processing paychecks (e.g., insuring proper deductions such as withholding tax were made), processing payment checks for vendors, and processing reimbursement checks for participants. Acumen served as participants' IRS agent of record in all matters related to the CLP. In addition, Acumen was responsible for ensuring the items billed for by participants were those listed on the approved spending plans. Acumen was paid a flat rate per participant per month for their services. This fee was paid directly by EOA with grant funds, and did not impact participants' monthly budget allotment.

Participants: Program participants (with support from their Coaches) were empowered to determine their needs, the best way to meet those needs, and how to allocate their monthly budgets in order to have those needs met. They were responsible for working with their Coach to create a support plan and a spending plan, finding and hiring person(s) to provide those services, or a place to purchase needed supplies, as outlined in their plans. They were responsible for acting as employers of individuals they hired, and submitting time sheets for these employees to the fiscal agent. For the hiring of vendors (i.e., businesses or other agencies) or purchasing of supplies, participants were asked to submit requests for payment to the fiscal agent. Finally, participants were responsible for notifying their Coaches about any changes in their needs or sentinel events, such as emergency room visits or hospitalizations. Monthly allotments for participant came from a combination of the CLP grant funds and state funds for services that EOA administers.

Referral and Enrollment Process

This section includes the referral and enrollment protocol for the CLP:

1. Potential participants (or their representative, such as a spouse or child) made contact with their local ADRC.
2. Once contact was made with the ADRC, a face-to-face intake was completed by an ADRC worker. All information collected by the worker was self-reported by the potential participant or an representative authorized by the potential participant (authorized rep).

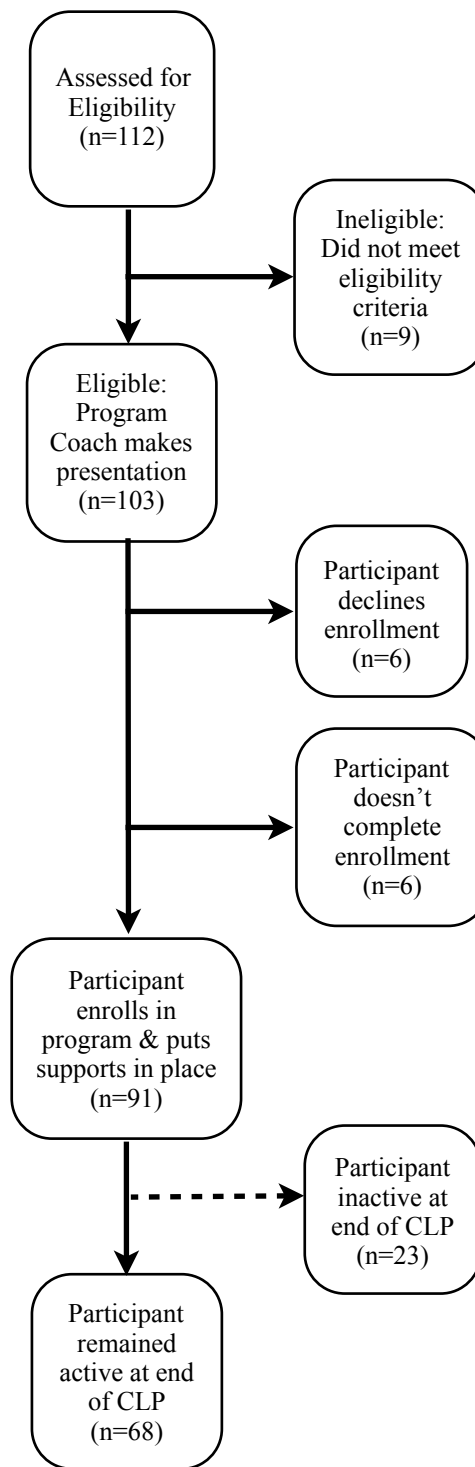


Figure 2: Referral and Enrollment Process

3. The worker completed an intake referral form, and obtained a physician’s confirmation of ADRD diagnosis (if applicable) in writing via the Statement of Physician’s Diagnosis form. These forms were faxed to the Program Manager at EOA.
4. The Program Manager screened the referral form for completeness and if information was missing, unclear, or conflicting, the Program Manager called the ADRC worker making the referral for clarification. Once the referral information was complete, the Program Manager made a determination as to whether the potential participant met inclusion criteria.
 - If the potential participant did not meet the criteria, the referral was returned to the ADRC worker, who notified the individual and may have offered traditional services administered by the Area Agency on Aging (AAA), if the person was eligible.
 - If the potential participant did meet inclusion criteria, the Program Manager determined the CLP budget amount the participant was eligible for (\$650 - \$800 per month), and information on the participant was sent to a Program Coach.
5. The Coach made contact with the potential participant and arranged a time to visit his or her home to present information about the program, how it works, and the pros and cons of enrolling in the CLP.
6. At this point the participant could choose whether to enroll in the program.
 - If the potential participant decided not to enroll in the CLP, he or she was referred back to the ADRC worker who made the referral for options counseling.
 - If the person decided to enroll in the program, but was unable to self-direct, an authorized representative may have been appointed by the participant to make decisions regarding enrollment for him or her.

7. Once the participant chose to enroll, the Coach and participant (or authorized rep) worked together to create a support plan outlining the supports needed to allow the participant to remain in the current living situation, and completed the necessary program paperwork (e.g., informed consent, etc.).

- The support plan, which functioned as a narrative of what participants needed to remain in their current living situations, also included a back-up plan, as well as an emergency preparedness plan (see Table 2).

8. Using the support plan, a spending plan was created detailing the supports the participant already had available, supports the participant needed, who would provide the supports, and the cost of the supports (see Table 2). The

Table 2: Comparison of Support and Spending Plan Functions*	
<u>Support Plan</u>	<u>Spending Plan</u>
• Narrative Format	• Budget Format
• Described Supports Available	• Listed Supports Available
• Described Supports Needed	• Listed Supports and Supplies Needed
• Indicated Who Provides Supports	• Listed Who Provides Supports
• Included Back-up Plan	• Included Allocation of Funds
• Included Emergency Preparedness Plan	• Included Hours and Pay Rates of Employees
*See Appendix A for a sample Support Plan and Spending Plan	

spending plan acted as a budget plan for participants. The Coach and participant (or authorized rep) signed the support plan and spending plan.

9. Once the program paperwork (CLP enrollment form and authorized representative), support and spending plans were complete they were faxed to the Program Manager at EOA.
10. The Program Manager determined whether all paperwork was complete, and if so, approved and uploaded the spending plan to the fiscal agent's secured shared file.
11. The fiscal agent printed, processed, and signed the spending plan, then re-uploaded it to the secured shared file.
 - If the participant decided to hire an individual to provide services, (e.g., in-home care, meal preparation), the individual hired became an employee of the participant. Employees completed standard employee paperwork, such as W-2 forms and I-9 forms, and were required to pass a criminal background check.
 - If the participant decided to hire a company or business to provide services, the company or business was considered a vendor, and was required to complete the necessary tax forms (i.e., W-9). Vendors were businesses or companies that were operating prior to the start of the pilot program.
12. Once all the necessary paperwork from the participant was completed, submitted to and approved by the Program Manager, uploaded to the fiscal agent's shared file, and processed and approved by the fiscal agent, the participant was considered "Good-to-Go" (meaning the participant was cleared to implement the spending plan and start using the CLP funds). Paperwork for employees and vendors was sent directly to the fiscal agent for processing.

Spending Plan Implementation

Participants then began to implement their spending plans. Participants were given a monthly budget between \$650 - \$800. The amount received was determined by the Program Manager and was based on a combination of the number of ADLs and whether there was a diagnosis of ADRD. A larger budget was allotted to those with a greater number of impairments. Specifically, budget allotments were as follows: those with 3 ADLs received \$650, those with 4 ADLs received \$700, those with 5 ADLs received \$750, those with 6 ADLs received \$800, and those with a diagnosis of ADRD (regardless of the number of ADLs) received \$800.

There were three categories of supports available: employed services (provided by individuals hired by the participant), vendor services (provided by a vendor hired by the participant), and purchased goods. It was up to the participant to choose how to utilize the supports, and there were few restrictions on how a participant could allocate funds. Restrictions included the purchase of illegal substances, firearms, and alcohol, services covered by a health

plan or other insurance, service or purchases benefiting another person, room and board (including mortgage payments), personal items and services not related to the participant's needs, experimental treatments, vacation expenses, insurance, home modifications that added square footage, vehicle maintenance (except for modifications due to disability), and tickets to recreation events. Program Coaches contacted participants monthly to monitor progress and make adjustments to support and spending plans as the participants' needs changed.

The CLP is a participant-direction based program, therefore, participants were able to choose their service providers. Participants could choose to employ individuals (including family members), or vendors to provide services. Examples of services included both services provided in the home (e.g., chore help, homemaker services, companion services, personal care services, and support for family caregivers - usually in the form of respite), and other services provided in the community (e.g., escort services, transportation services, home delivered meals).

If participants chose to hire individuals, participants became their employers. Proper tax forms were completed by participants and their employees and sent to the fiscal agent. In addition, potential employees were required to pass a criminal background check. Participants submitted time sheets for employees to the fiscal agent, and the fiscal agent was responsible for processing payments based on these time sheets. Employees had three options to receive payment: direct deposit (which most chose), pay card, or a paper check. In most participant-directed programs, the fiscal agent would send paper checks and pay stubs directly to participants, who would then distribute them to their employee(s), however, due to Hawaii State Law requiring that paper checks and pay stubs be in the hands of employees within seven calendar days of the end of a pay period, and the fiscal agent's location (Arizona), a different process was implemented in the CLP to insure adherence to the law. Paper checks and pay stubs were addressed to individual employees and bundled together in an envelope, which was sent overnight via UPS to EOA. Upon arrival to EOA, the UPS package was signed for by the clerical staff and given directly to the CLP Program Specialist (or EOA Program Manager if the Program Specialist was not immediately available). The Program Specialist unpacked the bundle and walked the checks to the Post Office located nearest EOA. The UPS packing slip was time stamped and signed by the CLP Program Specialist, and kept on file. If neither the Program

Manager or Program Specialist was available, the clerical staff followed the procedure outlined above. This ensured paper paychecks and pay stubs reached employees no later than seven calendar days after the close of a pay period.

A second option for participants was to contract with vendors to purchase services. Vendors are companies or businesses that existed prior to the start of the pilot program. Examples of vendor services include those listed for employed services above as well as: health related services; home modifications; adult day care; and technology for safety and independence. Participants were required to submit invoices for services to the fiscal agent. The process then follows the process of payment for employed services.

The third option for participants was to purchase goods or supplies needed. Examples of goods purchased include: health related equipment and supplies (e.g., shower chair, grab bars, personal care supplies); technology for safety and independence (e.g., fax machine, computer, internet service); and reimbursement for expenditures not covered by insurance, such as co-payments for prescriptions and personal care products. After purchasing goods, participants completed a request for reimbursement form, which was signed by participants and their Coaches. These forms, along with documentation in the form of receipts, were uploaded to the fiscal agent's secure shared file for processing and payment.

In addition to monthly spending, participants had the option to set aside a fixed dollar amount each month in order to accrue funds to purchase higher priced items, such as a scooter or new bed. In these cases, participants waited for the funds to accrue, then made a request to the fiscal agent. If the purchase was for less than \$500, a gift card in the exact amount of the item listed on their spending plan was issued. They had to provide documentation of the cost, usually in the form of a pre-arranged receipt from the vendor or an online shopping basket. Once approved, the fiscal agent mailed a gift card to participants, who had 30 days to make the purchase and provide substantiation of the purchase (i.e., a receipt) to EOA. EOA then uploaded the receipt to the fiscal agent's secure shared file for documentation purposes. Larger purchases could be invoiced through a purchase order with payment issued directly to the vendor. After the vendor received payment, delivery of the item was arranged between the participant and the vendor.

Once the spending plan was in place, participants were required to notify their Program Coach of any changes that would impact the support plan and/or spending plan. In addition, Program Coaches made monthly visits to each participant and checked in over the phone as needed. If the needs of participants changed, the Program Coach worked with them to create a new spending plan, and when necessary, an updated support plan. The modified spending plan then went through the same process as the original spending plan (i.e., faxed to the Program Manager, approved and uploaded to the fiscal agent's secured shared folder, etc.).

Quantitative Methods

A program evaluator from COA traveled to EOA on multiple occasions to gather participant data. The Program Manager at EOA gave an Excel spreadsheet of participant data to COA which was the basis for creation of the spreadsheet used to track participant and program data. The spreadsheet was housed on a laptop that was password protected; the spreadsheet file was also password protected.

Once the spreadsheet was created, a program evaluator from COA went through each participant file to gather data. In addition, the Program Manager from EOA arranged for COA to have access to the fiscal agent's secure online share file, which allowed for remote data collection. When questions arose regarding participant information, COA emailed the Program Manager for clarification.

Once data collection was complete, COA reviewed and coded the data. All data was examined for accuracy, and when questions arose, COA contacted EOA for clarification. For example, if the reason for changes in spending plans were not evident, EOA was asked for (and provided) explanation for the change. All data were coded and transferred to a data analysis software program: Statistical Package for the Social Sciences (SPSS). This allowed for analysis of program and participant characteristics. Quantitative analysis was conducted using descriptive statistics, frequency counts, and t-tests. Comparisons were made between CPL participants and Kupuna Care participants on age range and number of ADLs to provide a snapshot of how CLP participants compare to other populations served by EOA. Results are reported in the quantitative findings section below. The study protocol was approved by the Institutional Review Board (IRB) of the University of Hawai'i at Mānoa.

Quantitative Findings

Referral and Enrollment in CLP

In total, the CLP received 112 referrals, 103 (92.0%) of which were found eligible for participation in the program (see Figure 3). Nine referrals (8.0%) were deemed ineligible for participation. Of the 103 referrals found eligible for participation, 95 people (92.2%) decided to enroll in the program, 6 people (5.8%) declined enrollment, and 2 people (1.9%) became non-responsive (i.e., didn't respond to phone calls or letters) (see Figure 4).

Figure 3: Eligibility of Total Referrals (n=112)

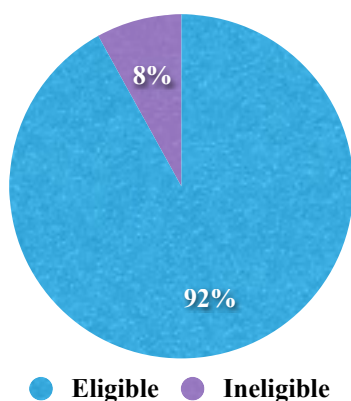
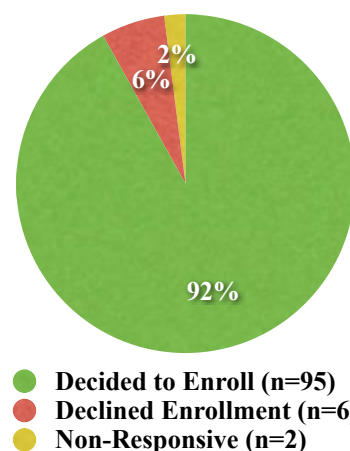


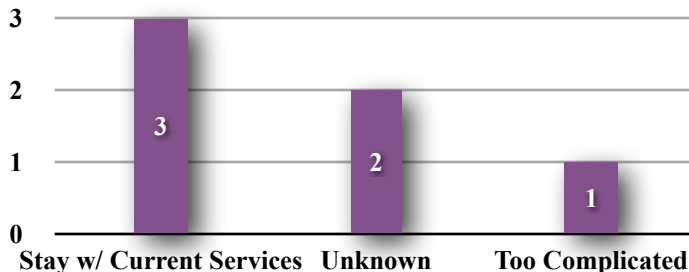
Figure 4: Eligible Referrals Decision on Enrollment (n=103)



Ineligible Referrals: Reasons for ineligibility include: not meeting the income or asset requirement (n = 5, 4.5%); not having a diagnosis of ADRD or three or more ADL impairments or a nursing home stay in the past six months (n = 2, 1.8%); or currently being hospitalized (n = 2, 1.8%).

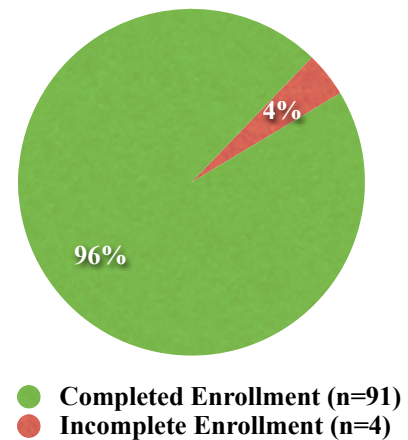
Declining Referrals: Of the 103 eligible referrals, there were 6 (5.8%) people who did not enroll in the program (see Figure 5). One person initially interested in the program declined participation because the person thought it was too complicated (n = 1, 1.0%). Other reasons for declining participation include: deciding to stay with current services such as private pay services (n = 3, 2.9%), or unknown reasons (n = 2, 1.9%).

Figure 5: Reasons for Declining Participation in CLP (n=6)



Completion of Enrollment: Of the 95 people who decided to enroll in the program, 91 (95.8%) successfully completed enrollment and implemented spending plans (see Figure 6). Four participants (4.2%) did not complete the enrollment process. One person (1.1%) began the enrollment process, then decided to withdraw for unknown reasons, 1 (1.1%) was in the process of applying for Medicaid and did not notify the Coach of acceptance into Medicaid until midway through the enrollment process, and 2 (2.1%) participants passed away prior to completing enrollment.

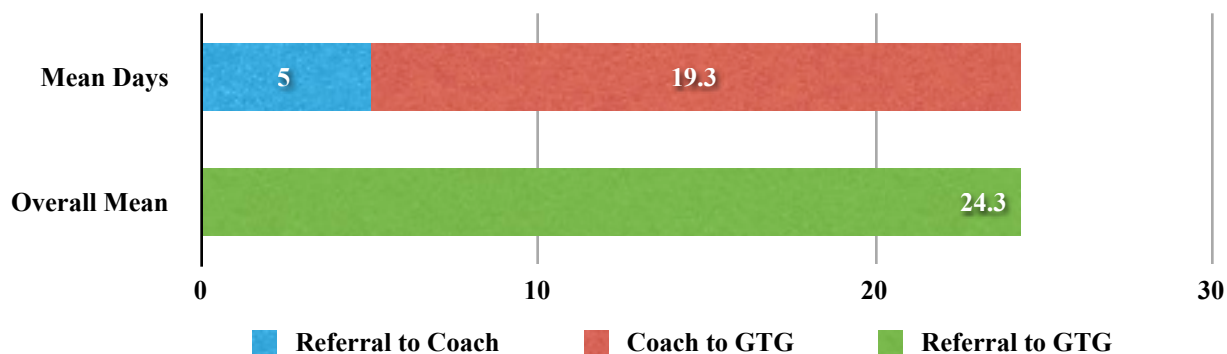
Figure 6: Completed Enrollment Rate (n=95)



Referral and Enrollment Timelines : When a referral was received by the Program Manager, it was reviewed for eligibility, and if it was found eligible, it was sent to a Program Coach. Depending on completeness of the referral information, it took anywhere from 0 - 81 days ($M = 5.10$ days, $SD = 11.0$) for a referral to get from the Program Manager to the Program Coach. Delays in referrals being sent to Program Coaches were a result of incomplete referral information, or a lag in confirming unclear information on the referral form.

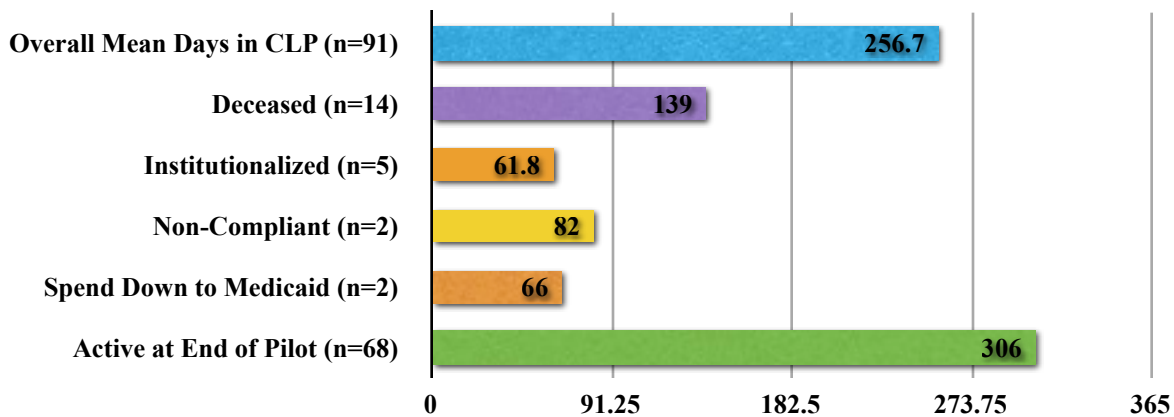
Once the Program Coach received the referral, he/she scheduled a visit to the potential participant. If the participant decided to enroll, the Coach and participant completed program paperwork and developed a support plan and spending plan. This process of completing paperwork and the two plans took anywhere from 0 - 123 days ($M = 20.0$ days, $SD = 23.1$) to complete. Once all the paperwork for the participants and their employees was completed, signed off on by the Program Manager, uploaded to the share file on Acumen's website, and processed by Acumen, a participant was considered Good-to-Go (GTG). It took anywhere from 0 - 30 days ($M = 19.3$ days, $SD = 3.8$) between support and spending plan completion and participants being considered GTG (see Figure 7). The entire referral to GTG process took anywhere from 0 - 167 days ($M = 24.3$ days, $SD = 24.6$).

Figure 7: Referral and Enrollment Timeline (in days)



Mean Days Spent in CLP: Once participants were considered GTG, they remained in the program anywhere from 4 - 384 days ($M = 256.7$ days, $SD = 104.5$). Twenty-three participants became inactive prior to the close of the pilot. These inactive participants spent anywhere from 4 - 270 days ($M = 110.9$ days, $SD = 76.9$) in the program. Of these inactive participants, 14 participants passed away prior to the end of the pilot spent anywhere from 4 - 270 days ($M = 139$ days, $SD = 85.6$) in the program, 5 participants who were institutionalized spent anywhere from 23 - 103 days ($M = 61.8$ days, $SD = 36.4$) in the program, 2 participants who were non-compliant spent 63 and 103 days ($M = 82$ days, $SD = 28.9$) in the program, and the two who spent down to Medicaid were in the program for 57 and 75 days respectively ($M = 66$ days, $SD = 12.7$). The program's end date for participant spending was February 28, 2013, and the 68 participants who remained active at the close of the program spent anywhere from 149 - 384 days ($M = 306.0$ days, $SD = 54.5$) in the program (see Figure 8).

Figure 8: Mean Days in Program by Participant Outcome (n=91)



Enrolled Participant Demographics and Characteristics (n=91)

Of the 112 referrals made to the CLP, 91 people (81.3%) completed the enrollment process and implemented support and spending plans. This section, along with the figures and tables below, summarizes basic demographic information and characteristics of these 91 participants. These demographics are self-reported by participants, and were recorded on the initial referral sheet.

Fifty-eight (63.7%) participants were female (see Figure 9), and participants ranged in age from 50 - 98 years old (*M* = 78 years) (see Table 3). The evaluators compared the age ranges of the CLP participants to their Kupuna Care counterparts, a state program providing home and community-based services to non-Medicaid individuals using a traditional service delivery model. In comparing the age ranges of CLP participants with their Kupuna Care counterparts on Maui, Kauai, and Hawaii Islands (*n* = 2,416), there is a greater percent of participants in Kupuna Care in the 85+ age range (see Figure 10). (Note: Kupuna Care data was taken from the Fiscal Year-End Reports for 2012 for Maui County, Kauai County and Hawaii Island County, and include only those for which age range information was available.)

Figure 9: Gender of Enrolled Participants (n = 91)

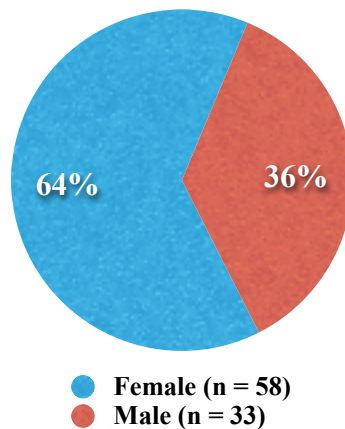
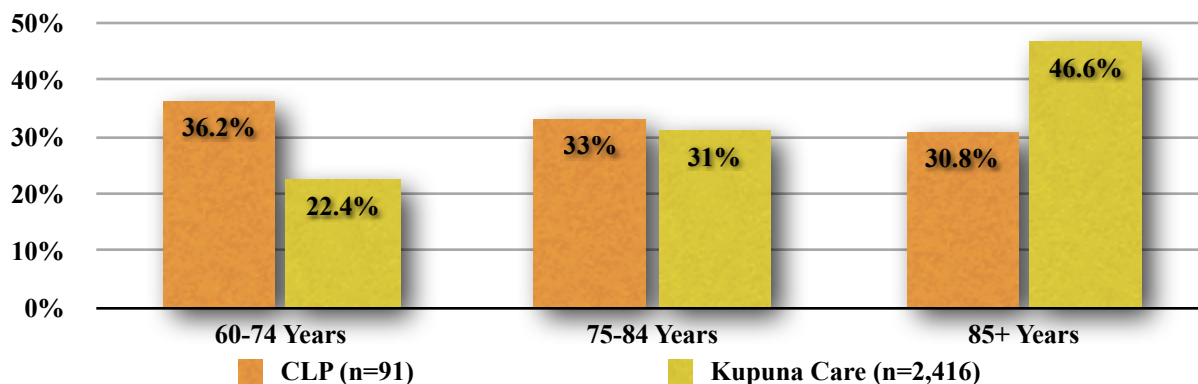


Table 3: Age (in years) of Enrolled Participants (n = 91)

Minimum	50 years old
Maximum	98 years old
Mean	78 years old

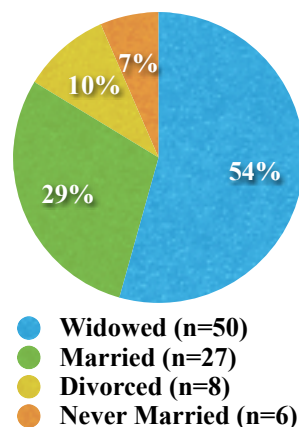
Figure 10: Comparison of CLP and Kupuna Care Participants - Percent of Participants in a Given Age Range



Participants reported their marital status as: widowed (n = 50, 55.0%), married (n = 27, 29.7%), divorced (n = 8, 8.8%) and never married (n = 6, 6.6%) (see Figure 11). Participants categorized themselves as Caucasian (n = 30, 33.0%), Native or Part-Hawaiian (n = 25, 27.5%), Filipino (n = 13, 14.3%), Japanese (n = 13, 14.3%), American Indian/Alaska Native (n = 3, 3.3%), Chinese (n = 3, 3.3%), Mixed (other than Part Hawaiian) (n = 2, 2.2%), Korean (n = 1, 1.1%), and Puerto Rican (n = 1, 1.1%) (see Table 4).

Ethnicity	Count	Percentage
Caucasian	30	33.0%
Native/Part Native Hawaiian	25	27.5%
Filipino	13	14.1%
Japanese	13	14.1%
American Indian/Alaska Native	3	3.3%
Chinese	3	3.3%
Mixed (other than Part Hawaiian)	2	2.2%
Korean	1	1.1%
Puerto Rican	1	1.1%

Figure 11: Marital Status of Enrolled Participants (n=91)



Regarding living arrangements, 26 participants (28.6%) lived with an adult child, 24 (26.4%) lived alone, 15 (16.5%) lived with only their spouse, 12 (13.2%) lived with both their spouse and others, 11 (12.1%) lived with a non-relative such as a friend, and 3 (3.3%) lived with

a different relative, such as a nephew or sibling, categorized as “other relative” (see Figure 12). Incomes for participants ranged from \$961.00 - \$5,458.00 per month, with a median monthly income of \$1,700 ($M = \$1,938.87$ per month, $SD = \$896.78$). Asset amounts, which excluded participants’ primary residence, one car, a burial plot, and cash value of life insurance, ranged from \$0 - \$41,700, with a median asset amount of \$1,475.00 ($M = \$5,008.87$, $SD = \$8,749.14$) (see Table 5).

Figure 12: Living Arrangements of Enrolled Participants (n=91)

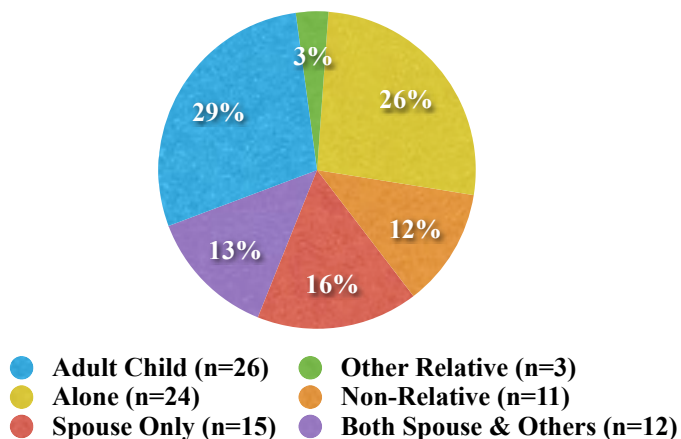


Table 5: Monthly Income and Asset* Amounts of Enrolled Participants (n=91)	
Monthly Income Amount	
Minimum	\$961.00
Maximum	\$5,458.00
Mean	\$1,938.87
Median	\$1,700.00
Standard Deviation	\$896.78
Asset* Amount	
Minimum	\$0.00
Maximum	\$41,700.00
Mean	\$5,008.87
Median	\$1,475.00
Standard Deviation	\$8,749.14
*excludes primary residence, one car, burial plot, and cash value of life insurance	

Prior Use of Long-Term Care Services: Less than half of participants (n = 38, 41.8%) were receiving services prior to enrolling in the CLP (see Figure 13). Of those 38 participants who were receiving services prior to the CLP, the majority (n = 34, 89.5%) were receiving services through Kupuna Care. Two (5.3%) were receiving Older Americans Act Title III services, 1 (2.6%) was receiving services through Kaunoha Senior Services on Maui, and 1 (2.6%) was receiving private pay services (see Figure 14).

Figure 13: Percent of Participants who Received Prior Services (n = 91)

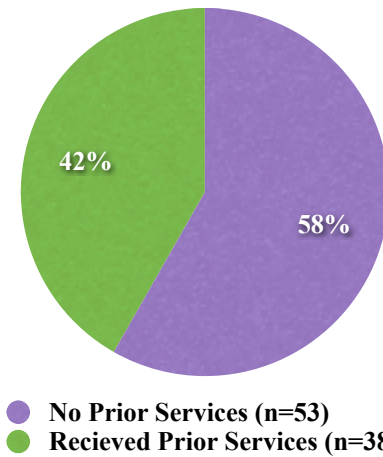
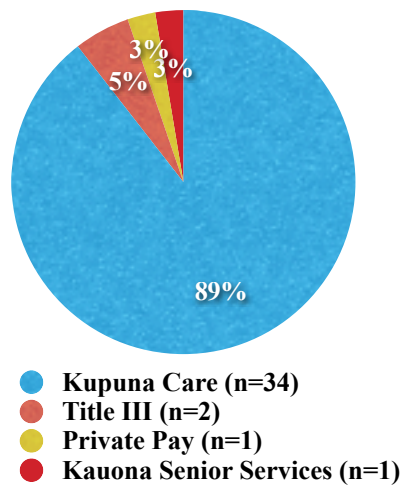


Figure 14: Prior Services Providers (n = 38)



Health Status: If participants were unable to make decisions for themselves, either due to circumstance or illness (e.g., moderate Alzheimer's), they were able to appoint someone to make decisions for them; an authorized representative (authorized rep) was able to act on their behalf. Sixty-five (71.4%) participants designated an authorized rep, and the remaining 26 (28.6%) did not (see Figure 15). Thirty-two (49.2%) of the 65 participants with authorized reps designated their child, 19 (29.2%) designated a spouse, 5 (7.7%) designated a friend, 4 (6.2%) designated a grandchild, 4 (6.2%) designated a different family member (e.g., sibling), and 1 (1.5%) designated a caregiver (see Figure 16).

Figure 15: Percent of Participants with an Authorized Rep. (n=91)

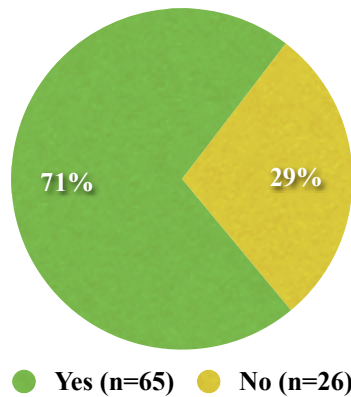
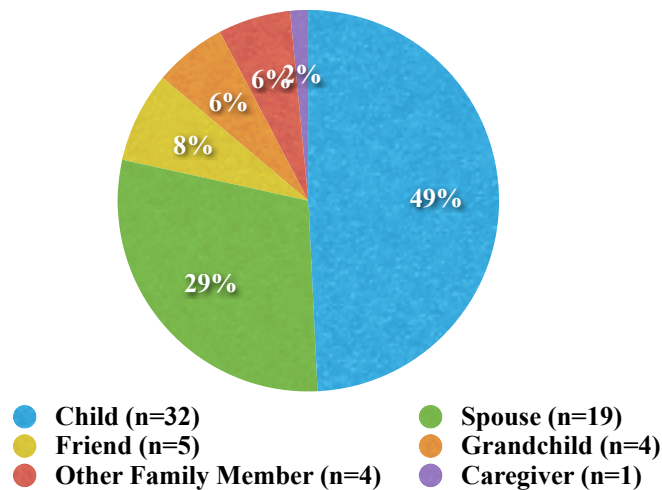


Figure 16: Designated Authorized Representatives (n=65)



The fourth inclusion criteria for participation in the CLP was health related; participants must have had one of the following: 1) three or more activities of daily living impairments, 2) physician’s diagnosis of Alzheimer’s Disease or Related Dementia (ADRD), or 3) a nursing home or adult residential care home stay within the last six months. None of the enrolled participants had a nursing home or adult residential home stay within the last six months. Thirty-four participants (37.4%) had a diagnosis of ADRD (see Figure 17). In addition, the majority of participants (n = 84, 92.3%) had three or more ADLs (see Figure 18). For a breakdown of the percent of participants with a given number of ADLs, see Figure 19.

Figure 17: Percent of Participants with ADRD Diagnosis (n=91)

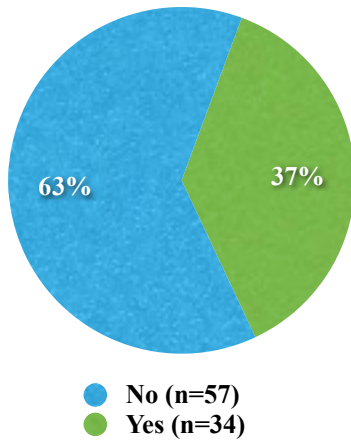


Figure 18: Percent of Participants with 3+ ADLs (n=91)

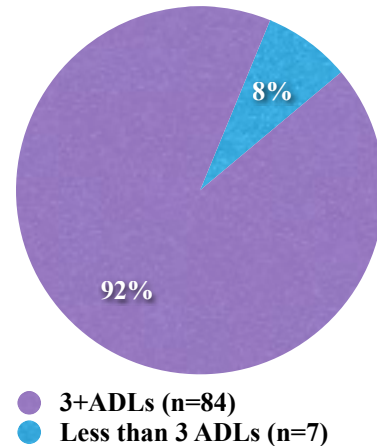
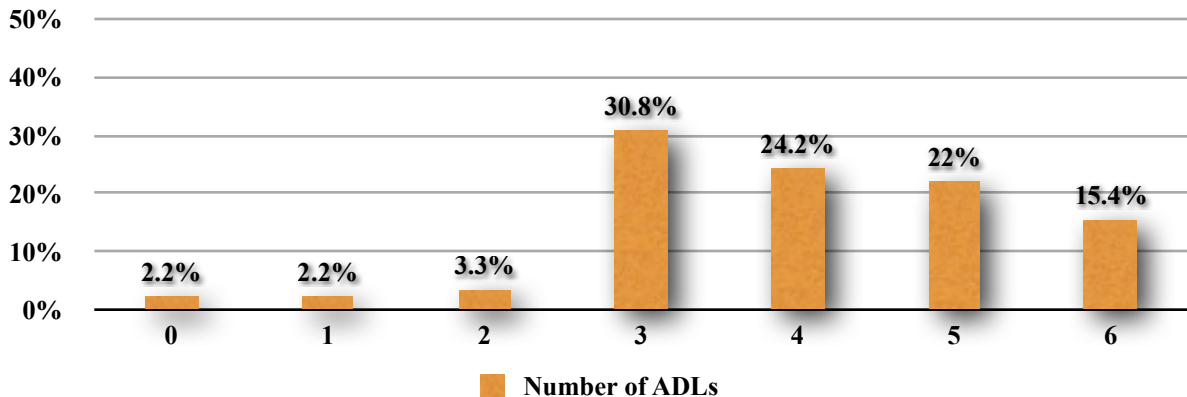
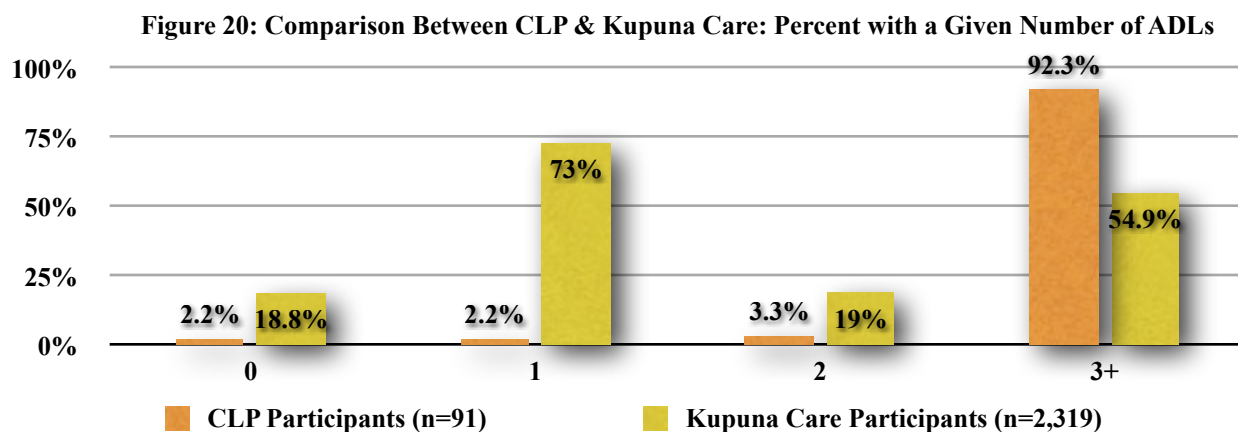


Figure 19: Percent of Participants with a Given Number of ADLs (n=91)



In comparing the percent of CLP participants with three or more ADLs to their Kupuna Care counterparts on Maui, Kauai, and Hawaii Islands (N = 2,319), the percent of CLP participants (n = 84, 92.3%) with three or more ADLs is greater than the percent of Kupuna Care participants (n = 1,273, 54.9%) with three or more ADLs (see Figure 20). This is logical given the difference in each programs' inclusion criteria: CLP requires three or more ADLs; Kupuna Care requires two or more ADLs. (Note: Kupuna Care data was taken from the Fiscal Year-End Reports for 2012 for Maui County, Kauai County and Hawaii Island County, and include only those for which ADL information available.)



Among CLP participants, the most common type of ADL impairment was bathing (n = 83, 91.2%), followed by walking (n = 75, 82.4%), then transferring (n = 70, 76.9%), followed by dressing (n = 62, 68.1%), then toileting (n = 56, 61.5%), and last, eating (n = 20, 22.0%) (see Figure 21). Participants were also asked about other health conditions diagnosed by a physician. More than half reported a mobility disability (n = 57, 62.6%), and/or chronic disease (n = 54, 59.3%). Table 6 details the other health conditions reported by participants.

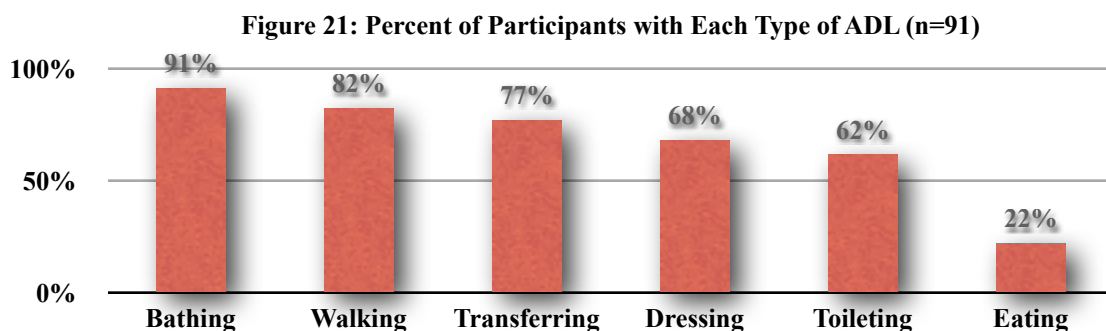


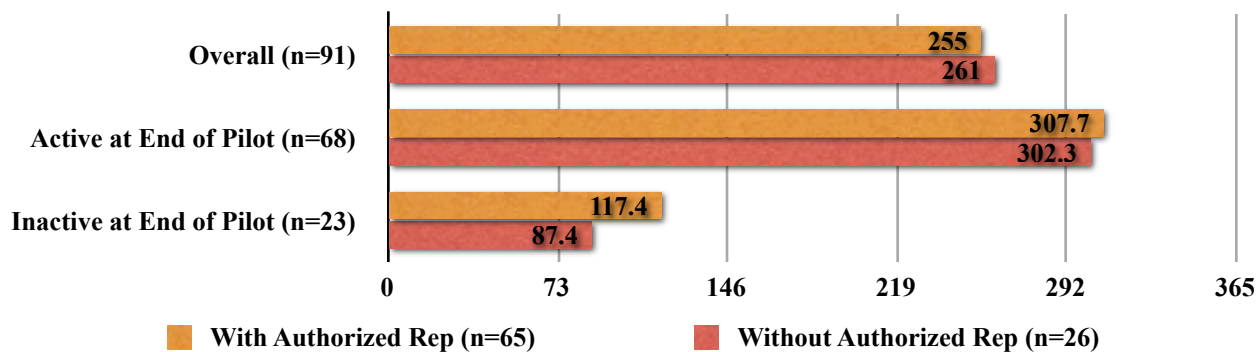
Table 6: Other Health Conditions Diagnosed by a Physician (n=91)		
Other Health Concerns	n	%
Mobility Disability	57	62.6%
Chronic Disease	54	59.3%
Other	33	35.1%
Blind/Visual Impairment	26	29.3%
Hearing/Speech/Sensory Impairment	21	22.3%
Cognitive Impairment	20	21.3%
Mental/Behavioral Illness	6	6.4%
Spinal Cord Injury	4	4.3%
Alcohol/Drug/Substance Abuse	3	3.2%
Traumatic Brain Injury	2	2.1%

Emergency Room Visits and Hospitalizations: Participants who went to the emergency room or had short-term hospital stays were permitted to remain in the program, however, services were suspended for the duration of their stay(s). Aggregate information on frequency and reasons for emergency room and hospital visits of CLP participants was not available, however, data regarding ER visits and hospitalizations were collected from those who participated in telephone interviews (see qualitative methods and results sections for further details regarding these interviews). Table 7 below summarizes these findings.

Table 7: Emergency Room and Hospitalizations of Interviewed Participants (n=25)	
Percent of interviewed participants with ER visits that did not lead to hospitalizations (n=5)	20%
Mean number of ER visits without hospitalizations (n=16)	3.2
Percent of interviewed participants with ER visits that led to hospitalizations (n=6)	24%
Mean number of ER visits followed by hospitalizations (n=7)	1.2
Percent of interviewed participants with hospitalizations not preceded by ER visits (n=5)	20%
Mean number of hospitalizations not preceded by ER visits (n=7)	1.4

Timeline Comparisons Between Participant Populations: An independent samples t-test was conducted to compare length in program (in days) between those with and those without an authorized representative. There was no significant difference between those with ($M = 255$ days, $SD = 104.1$) and without ($M = 260.9$ days, $SD = 107.5$) an authorized representative in terms of total days spent in the program; $t(89) = .243$, ns. Of those with an authorized representative ($n = 65$), the 47 participants with an authorized representative who remained active at the end of the pilot spent anywhere from 198 - 364 days ($M = 307.7$ days, $SD = 48$) in the program, and the 18 inactive participants with an authorized representative spent anywhere from 4 - 270 days ($M = 117.4$ days, $SD = 82.9$) in the program. Of those without an authorized representative ($n = 26$), the 21 participants who remained active at the close of the pilot spent anywhere from 149 - 384 days ($M = 302.3$ days, $SD = 68$) in the program, and the 5 inactive participants spent anywhere from 46 - 168 days ($M = 87.4$ days, $SD = 49.7$) in the program (see Figure 22).

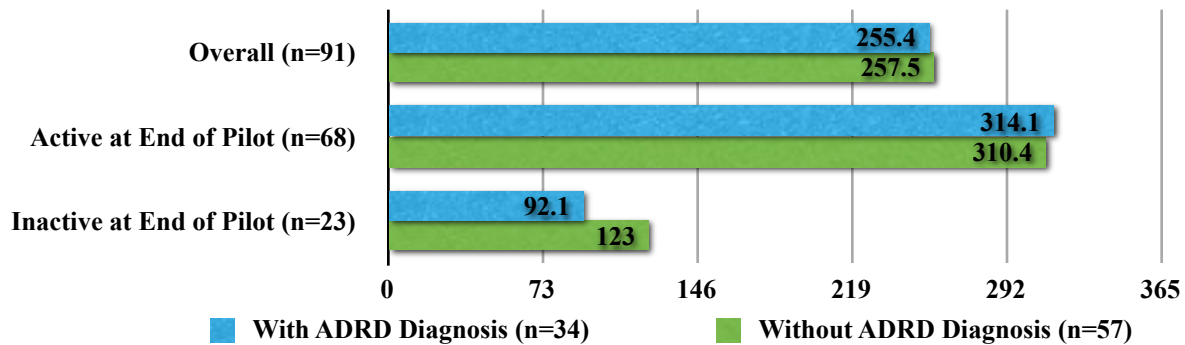
Figure 22: Length in Program - Comparison of Participants With & Without an Authorized



An independent samples t-test was conducted to compare length in program (in days) between those with and those without a diagnosis of ADRD. There was no significant difference between those with ($M = 255.4$ days, $SD = 112.5$) and without ($M = 257.5$ days, $SD = 100.5$) in length of time spent in the program; $t(89) = .1$, ns. Overall, there were 34 participants with a diagnosis of ADRD. The 25 participants with a diagnosis of ADRD who remained active at the end of the pilot spent anywhere from 198 - 364 days ($M = 314.1$ days, $SD = 48.5$), and the 9 participants with an ADRD diagnosis who were inactive at the close of the pilot spent anywhere from 4 - 196 ($M = 92.11$ days, $SD = 66.2$) days in the program. Of the 57 participants without an ADRD diagnosis, the 43 participants who were active at the end of the pilot spent anywhere

from 149 - 384 days ($M = 301.4$ days, $SD = 57.7$) in the program, and the 14 inactive participants without and ADRD diagnosis spent anywhere from 31 - 270 days ($M = 123$ days, $SD = 83.2$) in the program (see Figure 23).

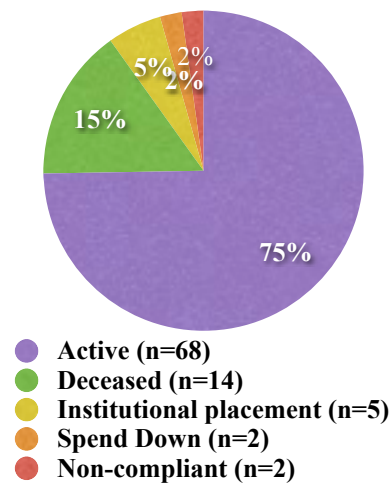
Figure 23: Length in Program - Comparison of Participants With and Without a Diagnosis of ADRD (n=91)



Participant Status at Close of Pilot:

The final month for allocation of funds for participants was February 2013. At that time, 68 (74.7%) of the 91 participants were still enrolled and 23 (25.3%) were no longer active in the program (see Figure 24). Reasons for inactivity include: participant passed away (n = 14, 15.4%), institutional placement (n = 5, 5.5%), spend down to Medicaid (n = 2, 2.2%), and non-compliance with program guidelines (n = 2, 2.2%).

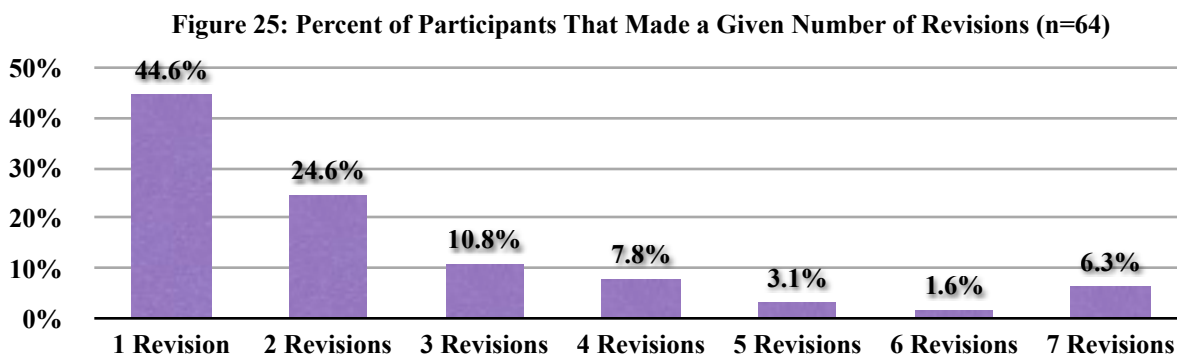
Figure 24: Participant Status at Close of Pilot (n=91)



Spending Plans and Allocation of Funds

Budget Amounts: Participants were allocated a monthly budget which ranged from \$650 to \$800 ($M = \$750.00$, $SD = \$60.92$). Program Coaches and participants worked together to establish a support plan and a spending plan that met participants’ needs. Due to the participant-directed nature of the CLP, as the needs of participants changed, they (in collaboration with their Program Coach) were able to change their support and spending plans to reflect these new needs.

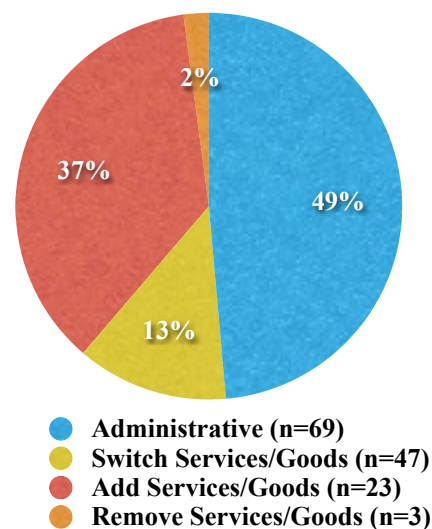
Spending Plan Revisions: More than half of the participants made revisions to their spending plans (n = 64, 70.3%) (see Figure 25). Of those 64 participants, 29 (44.6%) made one revision, 16 (24.6%) made two revisions, 7 (10.8%) made three revisions, 5 (7.8%) made four revisions, 2 (3.1%) made five revisions, 1 (1.6%) made six revisions, and 4 (6.3%) made seven revision. In total, there were 142 revisions to spending plans over the course of the pilot program.



Reasons for Spending Plan Revisions: Reasons for revisions vary; some were administrative (e.g., adding an employee’s name to a spending plan, changing an employees rate of pay, correcting a participant ID number), and others were due to changes in supports needed by the

participant (e.g., adding hours or a type of services, deciding to purchase supplies). Of the 142 revisions made, almost half (n = 69, 48.6%) were administrative (see Figure 26). Sometimes, participants chose to add services (n = 52, 36.6%) or remove services no longer needed (n = 3, 2.1%). Alternately, participants sometimes chose to swap out one service or good for another (n = 18, 12.7%), for instance, if funds were allocated to purchase a fax machine, and the purchase was complete, the participant may have chosen to allocate those funds to a different good or services for the following months.

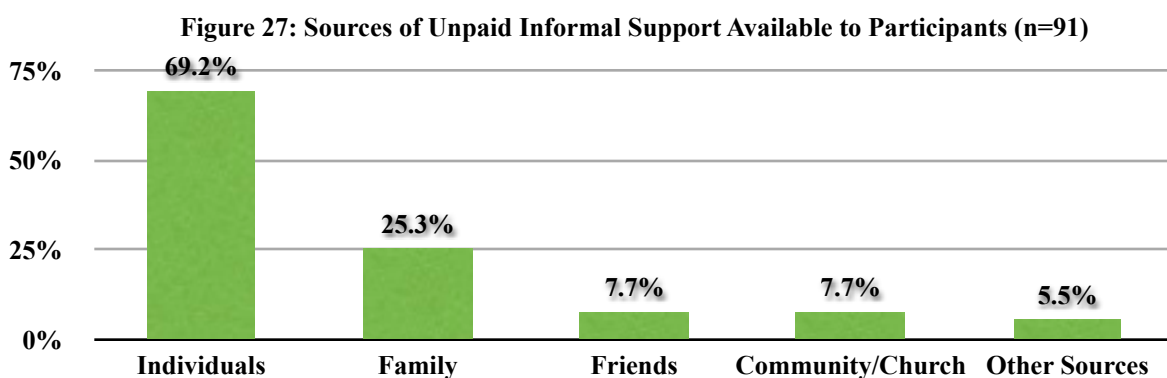
Figure 26: Reasons for Revisions (Total Revisions=142)



Allocation of Funds on Spending Plans

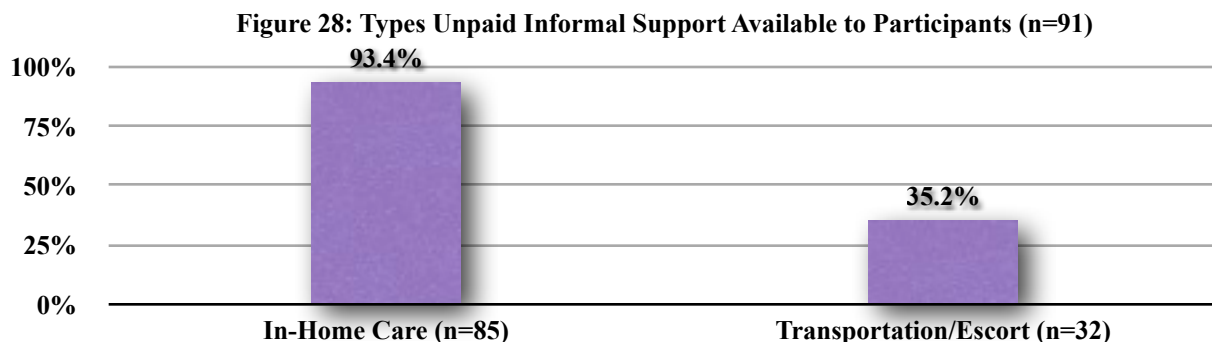
Participants could choose to utilize their CLP funds in a way that suited their individual needs. As such, spending plans and the allocation of funds changed multiple times during the course of the program. The following section includes the information from any and all iterations of participants' spending plans without duplication of information. For example, if a participant had three spending plan revisions, and all three plans showed funds allocated toward in-home personal care, that was counted as one instance of personal care being utilized.

Unpaid, Informal Supports: As part of the process of creating the support and spending plans, participants listed sources of unpaid, informal supports available to them from various sources. Participants reported receiving unpaid, informal help from individuals (n = 63, 69.2%), family (n = 23, 25.3%), friends (n = 7, 7.7%), their community/church (n = 7, 7.7%), and other sources (n = 5, 5.5%). Individuals may include family members, however, for data collection and analysis purposes, the source of unpaid, informal support was listed in the individual category if the individual's name was listed on the support plan. The support is categorized as family if the participant specified family on the support plan. Therefore, there may be some overlap in the individual and family categories. Twenty (22.0%) participants reported receiving unpaid, informal support from multiple sources.

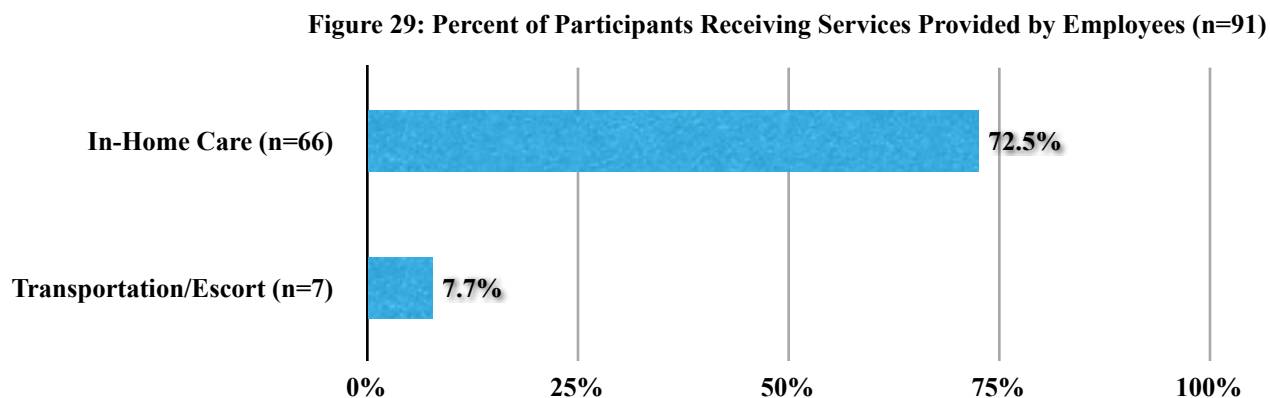


Types of unpaid, informal support reported by participants included in-home care (n = 85, 93.4%), such as: emotional support (n = 54, 59.3%); homemaker services (n = 51, 56.0%); personal care (n = 40, 44.0%); chore help (n = 29, 31.9%); and support for family caregiver, usually in the form of respite (n = 13, 14.3%). Participants also reported other types of services,

such as transportation or escort services (n = 32, 35.2%). Seventy participants (76.9%) reported having more than one type of unpaid, informal support.



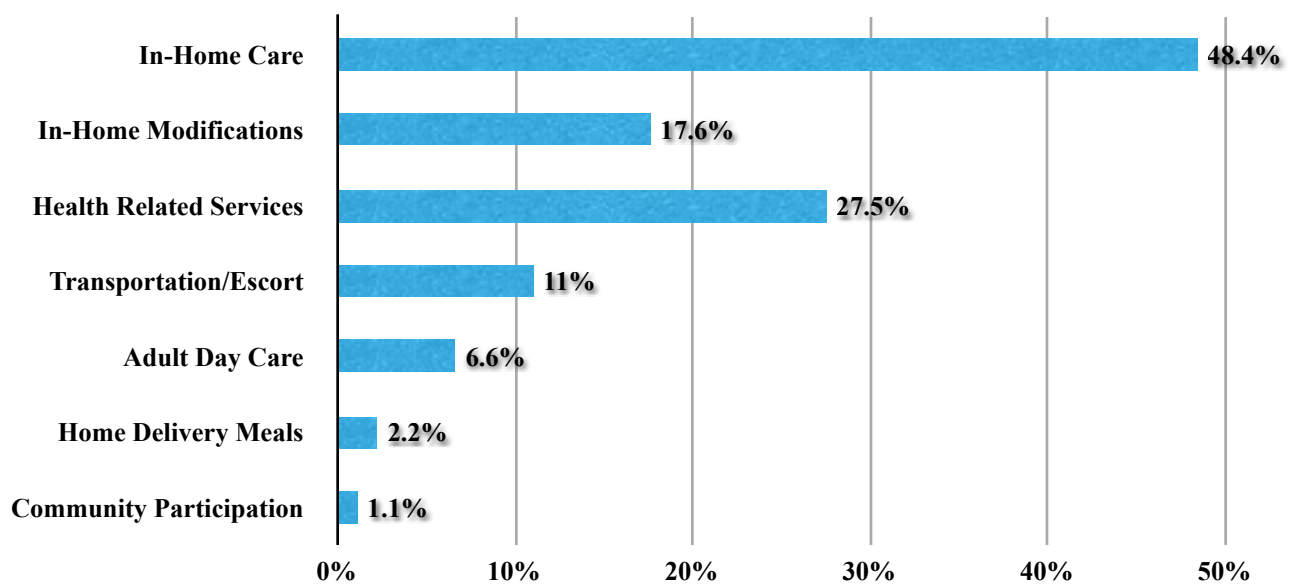
Employee Services: Participants were able to hire individuals as employees to provide in-home care or transportation/escort services (see Figure 29). In-home care (n = 66, 72.5%) included: personal care services, such as assistance with feeding and bathing (n = 43, 47.3%); homemaker services, such as meal preparation (n = 20, 22.0%); chore help, such as cleaning the house or doing laundry (n = 12, 13.2%); and companion services (n = 3, 3.3%). The figures listed under in-home care do not total 100% because a hired individual may have performed multiple duties. For instance, a participant may have hired an employee to provide personal care, however, the duties may have also included chore help and homemaker services. Employees were hired to provide transportation/escort services to seven participants (7.7%).



Vendor Services: Participants were able to hire vendors (i.e., businesses or companies that were operating prior to the start of the pilot program) to provide in-home care and/or perform work at their homes, or to provide other types of services in the community. In-home

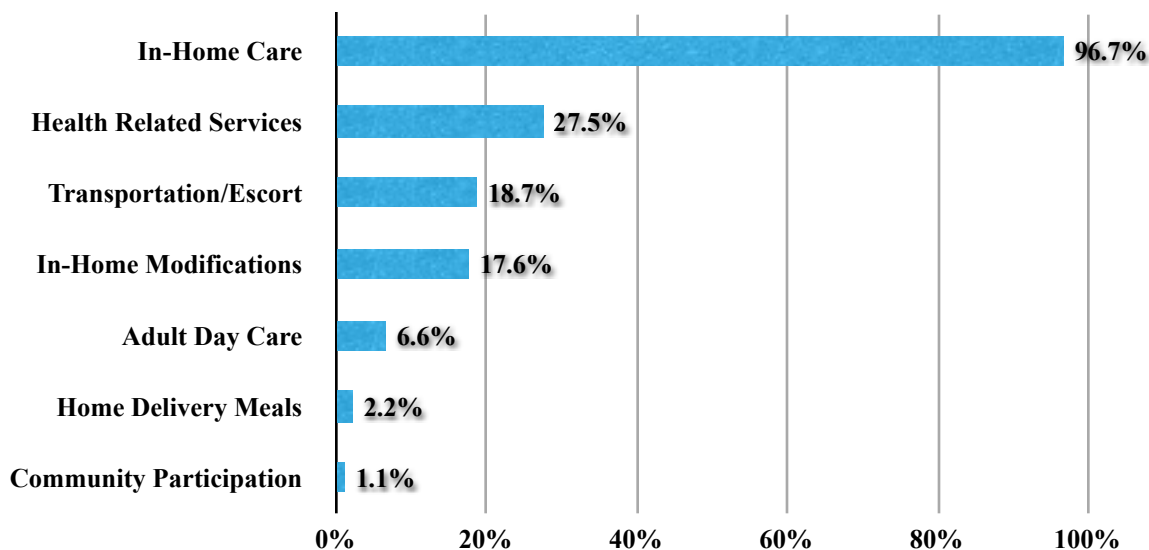
care (n = 44, 48.4%) included: personal care (n = 14, 15.4%); homemaker services (n = 12, 13.2%); support for family caregiver, usually in the form of respite (n = 10, 11.0%); chore help (n = 5, 5.5%); technology for safety and independence such as internet service (n = 4, 4.4%); and companion services (n = 4, 4.4%). Participants also utilized vendors for health related services (n = 25, 27.5%). Work performed at participants' homes included environmental and household modifications (n = 16, 17.6%), such as refrigerator repair, resurfacing or installing floors, repairs on plumbing/toilets, modification of a bathroom to make it ADA compliant, installation of a tub unit, repair of a wall, moving services, and carpentry work. See Figure 30 for a complete breakdown of vendor services.

Figure 30: Percent of Participants Receiving Services Provided by Vendors (n=91)



Summary of Services: To provide an overall picture of services utilized by participants, this section combines employee and vendor services. Overall, 88 participants (96.7%) utilized in-home care, and twenty-eight participants (30.8%) utilized other types of services in the community, the majority of which were health related services (n = 25, 27.5%). See Figure 31 for a complete summary of the services provided by employees and vendors.

Figure 31: Percent of Participants Receiving Services Provided by Employees and/or Vendors (n=91)

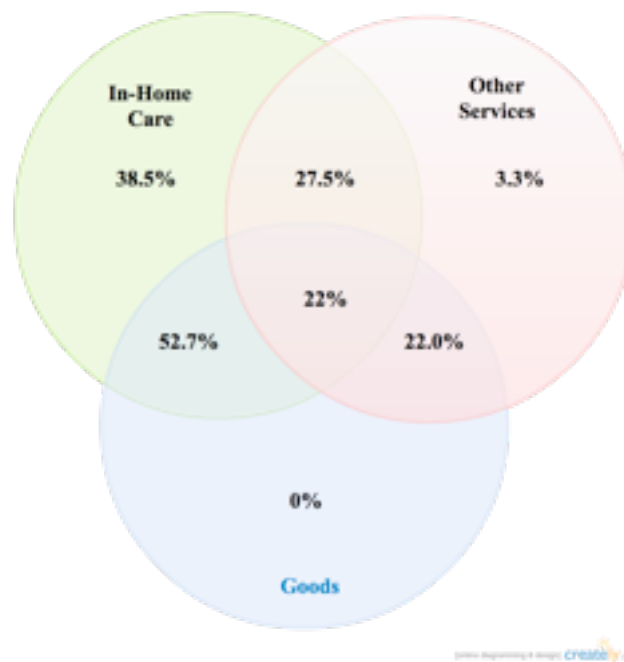


Goods and Supplies: A third option for participants was to purchase (or be reimbursed for the purchase of) goods and supplies. In total, 48 participants (52.7%) chose to utilize CLP funds for the purchase of goods and supplies. Table 8 shows a complete breakdown of items purchased. These types of purchases related most often to health related equipment and supplies (n = 33, 36.3%). Items related to technology for safety and independence were purchased by 19 participants (20.9%), and 15 participants (16.5%) purchased items related to the household. Twelve participants (13.2%) purchased items related to transportation, 3 participants (3.3%) purchased items related to environmental modifications, 1 participant (1.1%) purchased home delivery meals, and 1 participant (1.1%) made a purchase categorized as “other.”

Table 8: Goods and Supplies Purchased by Participants	
<u>Category</u>	<u>Items</u>
Health Related Equipment and Supplies	Eye Exam and Glasses Repair of False Teeth Oxygen Concentrator Shower Chair Shower Nozzle Transport Chair Transfer Bench Wheelchair Maintenance and Adaptation Lift Chair Chair Recliner Crutches Hospital Bed Walmart Gift Card Pharmacy Purchases (e.g., Exelon patch) Prescription Co-Payments Personal Care Items Incontinence Supplies (e.g., Depends, Ensure, Chux) Bottled Water
Technology for Safety and Independence	Fax Machine Personal Emergency Alarm/Security System Netbook Kindle Various Electronics
Household Related Items	Washing Machine Bed Mattress and Sheets Freezer Microwave Rice Cooker Flea Control Supplies as Needed
Transportation	Air Fare for Doctor Visit Hotel for Doctor Visit Ground Transportation for Doctor Visit Car Rental for Doctor Visit Ferry Ticket Ferry Ticket Book Bus Pass
Environmental Modifications	Wheelchair Ramp Walk-in Shower Shower Grab Bar
Home Delivery Meals	Home Delivered Meals
Other	Funds for Relocation to Different Island

Multiple Methods of Spending: Participants often utilized multiple methods of spending, for example, utilizing both in-home care and purchasing goods (n = 48, 52.7%). Twenty participants (22.0%) utilized other types of services in the community and purchased goods. In addition, the same number of participants (n = 20, 22.0%) utilized all three: in-home care, other types of services in the community, and purchased goods (see Figure 32).

Figure 32: Percent of Participants Utilizing a Specific Type of Spending (n=91)



Employee, Vendor, and Goods Purchased Across All Participants: This section provides total numbers of employees hired and vendors utilized across all participants in the pilot program. These numbers are provided to give an indication of the potential for economic growth and job creation as a result of participant-directed programs such as the CLP. Pay rates for employees were not standardized across participants - it was part of the participant's responsibility to negotiate pay rates with their employees. Table 9 below includes a summary of financial information for employees (number of participants who hired employees, number of employees hired, employee to participant ratio, number of employees hired by multiple participants, mean hours worked per pay period, mean hourly wage, mean amount paid per employees, mean length of employment), vendors (number of participants who hired vendors,

number of vendors utilized, vendor to participant ratio, number of vendors utilized by multiple participants, and mean amount paid to vendors over the pilot), and goods purchased (number of participants who purchased goods, total dollar amount spent on goods, and amount spent on goods per participant).

At the start of the pilot program, some individuals were hired as vendors instead of employees. If these individuals did not meet the criteria for being a vendor according to the Hawaii Department of Labor regulations, they were reclassified as an employee. Employee forms were completed, payment adjustments were made as needed, and employment taxes were deducted retroactively. There were nine individuals in this category, meaning they began as vendors and later became employees. Consequently, there may be some overlap in the numbers listed on the table below.

Table 9: Financial Data for Employees, Vendors, and Goods - Aggregated Across the Pilot	
<u>Employee Information</u>	
Number of Participants who Hired Employees	67 (73.6%)
Number of Employees Hired	83
Employee to Participant Ratio*	1.2
Number of Employees Hired by Multiple Participants	1
Number of Participants who Hired 2+ Employees	20
Mean Hours Worked by Employees Per Pay Period	31.1, range: 2 - 108, <i>SD</i> = 16.4
Mean Hourly Wage of Employees (not including taxes)	\$11.57, range: \$8.50 - \$25, mode = \$10
Mean Amount Paid Per Employee Over the Pilot	\$3,802.71, range: \$41.70 - \$9,971.55
Mean Length of Employment (in months)	6.13 months, range: 0.06 - 11 months
<u>Vendor Information</u>	
Number of Participants who Utilized Vendors	57 (62.6%)
Number of Vendors Utilized	46
Vendor to Participant Ratio*	0.81
Number of Vendors Utilized by Multiple Participants	8
Mean Length of Vending (in months)	3.59, range: 0.03 - 11, <i>SD</i> = 3.06
Mean Payment to Vendor Over the Pilot	\$2,653.83

Table 9: Financial Data for Employees, Vendors, and Goods - Aggregated Across the Pilot	
Goods and Supplies	
Number of Participants who Purchased Goods	48 (52.7%)
Total Amount Spent on Goods	\$78,377.37
Amount Spent on Goods per Participant Over the Pilot*	\$1,632.86
*Ratios and per participant calculations are based on participants who utilized that particular method of spending	

Qualitative Methods

Study Design

Qualitative research methods, such as surveys and interviews, are appropriate for measuring attitudes and opinions of a population one cannot observe directly¹. Common practices in qualitative research are the use of questionnaires, interviews, and focus groups with key players. For the purposes of evaluating the CLP, utilization of these methods allows for examination of perceptions, opinions, and experiences of individuals with direct knowledge of the program, as well as the emergence of common themes and concepts across the span of the pilot.

Key Players

Key players were interviewed in order to understand the perceptions and experiences of those involved with the pilot program. Interviews were conducted with the program participants and key leadership within the CLP (i.e., Program Specialist and Program Manager). A focus group was conducted with Program Coaches. The study protocols and interview questions were approved by the Institutional Review Board (IRB) of the University of Hawai'i at Mānoa

Data Collection Procedures

Program Participants: A random sample of participants were interviewed over the telephone. In order to ensure a distribution of participants that matched the overall sample, participants were divided in to three groups: (1) active participants who self-direct, (2) active participants with authorized reps, and (3) inactive participants. For groups one and two, a randomized sampling procedure was used: lists were made of participants in each category and

¹Babbie, E. (2001). *The Practice of Social Research*, Cape Town: Oxford University Press

every fourth participant (or their authorized rep) on the list was contacted via phone. Participants who self-directed were contacted/interviewed directly. Authorized representatives were contacted/interviewed in cases where participants did not self-direct. In one case, a participant who had an authorized representative was interviewed because the authorized representative did not understand English well enough to participate in the interview. If the participant was non-responsive after three attempts, the next person on the list was contacted as a replacement. For the third group (inactive participants), all those who had contact information for an authorized representative were contacted.

Interviews with program participants took place in late January and early February 2013, and lasted anywhere from 10 - 20 minutes. Coaches informed participants that an evaluator from COA might be contacting them. When contacting participants, the COA evaluator introduced herself and explained the purpose of the call. Participants were read a consent form over the phone, and asked whether they consented to being interviewed and audio recorded. All participants contacted consented to the interview; only one participant did not consent to the audio recording. The interviewer used a standardized list of questions for each interview, which included quantitative and qualitative measures, and took careful notes. Audio recordings were transcribed and compared with notes taken by the interviewer for accuracy.

Program Coaches: In January 2013, the CLP Coaches traveled to Oahu and participated in a 3-hour focus group facilitated by two program evaluators from the Center on Aging. Coaches completed a consent to participate in the focus group, and filled out an informational form, which included demographic information about the Coaches and their participants, frequency of contact with participants, and details of administrative responsibilities. They were also asked whether they would choose to continue as a Program Coach. Coaches then participated in a semi-structured focus group discussion which was audio-recorded. During the focus group, an evaluator from COA took notes on a laptop which was projected on a screen in the room. Coaches were asked to double-check the screen for accuracy, and to correct any errors or misinterpretations recorded by the evaluator. In addition to these notes, the audio recording of the focus group was transcribed, compared to the notes taken during the focus group, and content analyzed for major themes.

Key Leadership: One-on-one interviews were conducted with the EOA Program Specialist and the CLP Program Manager. Each interview lasted approximately one hour. An evaluator from COA took careful notes during the interviews, and responses were audio recorded. Recordings and notes taken were compared to ensure accuracy, and content analyzed for major themes.

Measures

The goal of these interviews and focus groups was to ascertain the experiences and perceptions of the CLP from key players. This included discovering challenges and successes faced by key players, their level of satisfaction with the pilot, and suggestions on improving the program in order to make it more sustainable. With this in mind, four separate questionnaires were developed: (1) participant interview questions, (2) Coaches' focus group questions, (3) EOA Program Specialist interview questions, and (4) CLP Program Manager interview questions. For complete lists of questions, see Appendix B.

Qualitative Results

Program Participants

In order to better understand the experience of program participants, one-on-one telephone interviews were conducted with a random sample of participants. The following section describes participants' responses to interview questions.

Out of the 91 enrolled participants, 25 (27.5%) were interviewed. Of the 25 participants interviewed, 14 (56%) were female. They ranged in age from 50 - 91 years old ($M = 75.25$ years), and 17 (68%) were active at the close of the pilot. If participants had appointed an authorized rep, the interview was conducted with the authorized rep; 19 (76%) participants fit this criteria, so their authorized reps were interviewed.

There were two quantitative measures included in the interviews that were used to gauge participants' knowledge of long-term care options prior to starting the CLP. They were: "On a scale from 1 to 10, 1 being none and 10 being completely aware, before enrolling how aware did you feel you were about long term care services available in your community?" and "On a scale from 1 to 10, 1 being none and 10 being completely aware, before enrolling how aware did you

feel you were about long term care services you (your loved one) needed to help you (your loved one) live at home?” Responses to these questions are detailed in Table 10 below.

Table 10: Participants’ Understanding of Long-term Care	
On a scale from 1 to 10, 1 being none and 10 being completely aware, before enrolling how aware did you feel you were about long term care services available in your community?	<i>M</i> = 5.3* <i>SD</i> = 3.6 range: 1 - 10
On a scale from 1 to 10, 1 being none and 10 being completely aware, before enrolling how aware did you feel you were about long term care services you needed to help you live at home?	<i>M</i> = 5.9* <i>SD</i> = 3.8 range: 1 - 10
*1 = Not at all aware, 10 = Completely Aware	

These responses indicate that overall, participants had a varied knowledge of long-term care services available in their communities, and the long-term care services they or their loved ones needed to live at home. These responses point to a need for Coaches to be able to educate participants on how to assess needs, and how to locate services available to meet those needs.

Participants were also asked “If you had not participated in this program, how confident are you that you would still be living in your current living situation?” Responses were: (0) Not at all confident, (1) Somewhat confident, (2) Confident, and (3) Very confident. Responses to these questions are detailed in Table 11 below.

Table 11: Participants’ Confidence in Current Living Situation Without CLP	
If you had not participated in this program, how confident are you that you would still be living in your current living situation?	<i>M</i> = 1.0* <i>SD</i> = 1.2 range: 0 - 3
*0 = Not at all confident, 1 = Somewhat confident, 2 = Confident, 3 = Very confident	

Responses to this third question indicate that, overall, participants had low to no confidence they would have remained living at home had they not been involved with the CLP. Of the participants that were very confident, several indicated that although they (or their loved one) would have remained living in the home, the financial and physical strains would have been much greater without the support of CLP.

The following section details participants' responses to qualitative, open-ended questions asked during the telephone interviews.

1. How did you find out about CLP?

Participants found out about the CLP program through 2 main sources. First, a staff member at their Area Agency on Aging (AAA) told them about the CLP either because they had a prior relationship with their AAA or they contacted their AAA through the phone book. Other professionals in the aging network also told participants about the CLP, including a public health nurse or other agency worker (e.g., Meals on Wheels worker), who knew about the program. From there, ADRC intake staff worked with participants to do the initial screening and complete referral forms.

2. Why did you decide to enroll in CLP?

There were several reasons participants enrolled in the CLP. Participants said that they needed help, either financial help or needed services, and could see that it would help them remain in the community. Furthermore, they liked what the Coach said about the program, particularly the ability to choose services and caregivers.

3. What were your hesitations/concerns about enrolling in the program?

Most respondents indicated that they either had no concerns or the concerns that they had were addressed by the Coach. Some were concerned whether they would be able to qualify for the program. Others were concerned about their responsibilities and requirements of the program.

4. What did you like about the program?

Participants liked their Coaches and the support Coaches provided to them. They also liked that their own individual physical and financial needs were being met. Furthermore, participants appreciated their ability to make their own choices. Specifically, they liked the ability to choose how to use their funds and who to hire. Hiring people of their choosing allowed participants to have confidence in the workers and relieved the stress of worrying about a loved one when away from the home.

“Before this program we didn't realize there was so much help. It's a nice thing to be able to have [my parent] home”

5. What did you not like about the program?

The majority of participants indicated that they had nothing negative to say about the program. The remaining participants commented about the administrative requirements of the program. For example, participants did not like the amount of paperwork required by the program (i.e., time sheets and employee tax forms) and the time constraints in the program (i.e., tight timeline in submitting time sheets to fiscal agent). Several participants expressed that it was confusing to speak with Acumen.

6. How do you feel about your Coach?

All participants had positive experiences in working with their Coach. Responses indicated that Coaches were:

- Easy to understand
- Kind, friendly and caring
- Responsive

7. How did you Coach help you?

Participants indicated that Coaches helped participants in a number of ways. They indicated that Coaches explained procedures and guidelines to them, often multiple times. They helped educate participants on options in the community and the availability of services and supplies. They also helped participants complete required paperwork. Over the pilot period, Coaches also checked in with participants to see how they were doing.

8. Participants' Experiences in Developing Support and Spending Plans

The majority of participants indicated that generating support plans was easy ($n = 20$, 80%) because they either already had a knowledge of their needs and the availability of services or the Coach did a good job at walking the participant through the process and answering questions. Similarly, creating the spending plans was also easy for the majority of participants ($n = 24$, 96%) because some already knew about available service options, the Coaches helped with the development, or developed the plan for the participant. When asked whether developing these plans was challenging, participants responses included the following challenges:

- It was difficult to prioritize needs
- It was something new to learn
- It was challenging at first, but with Coaches' help it became easier

9. How did you find people or agencies to help you?

Participants used a range of methods to find persons or agencies to help them. Many participants already knew of persons or agencies (i.e., family member, friend, agencies that previously provided services). In other cases, participants received recommendations from friends or other community members. The Coaches also played a large role in identifying persons or agencies in the community.

10. Were you satisfied with the goods and services you purchased?

All participants reported being satisfied with the goods and services they purchased. These goods and services were crucial because they needed them to live and could not have afforded them otherwise. Many reported being on a fixed income and the purchases helped relieve stress.

11. What is your experience in working with Acumen?

Participants indicated that Acumen helped them by answering questions or making corrections on errors made to time sheets and other financial paperwork. Some did not have contact with Acumen; either they did not need to have contact with them or the Coaches contacted the fiscal agent for them. Among participants who did have contact with Acumen, there was diversity in their responses, ranging from great or helpful to sometimes abrupt and challenging.

12. What are your suggestions for improving the program?

The majority of participants did not think any improvements needed to be made (n = 22, 88%), other than to continue it. Some recommended that the program decrease the amount of paperwork that participants are required to complete. Another suggestion was to provide fax machines to participants at the start of the program in order to comply with program requirements to fax time sheets to the fiscal agent. In this way, participants would not have to use their monthly budget to purchase a fax machine. Finally, it was recommended that Coaches need to be aware of local culture and expectations, especially the patience and time needed to earn the trust of elders in the community.

“I think again to know who you're talking to and to give them a little more time. I think because we are all people of different race and background they need to hear the voice and tell them local people get hilahila (not outgoing, bashful)...be yourself.”

13. Do you recommend the continuation of the CLP program?

All participants reported that they would recommend this program to others in their communities. Every respondent recommended that this program continue for the following reasons:

- It helped them stay in the home
- Wonderful experiences with Coaches and service providers
- Great alternative to institutionalization
- Created more financial stability (they could recycle funds into the home)
- Stress reduction due to ability to choose own providers

“I would recommend the program continue because it may be one person's last choice before entering a facility. Thank you very much”

“Yes, lots of people taking care of parents, aunties, uncles and can't afford places for elderly care or someone coming in. Before starting with the program I didn't know about everything. Before they were in doubt about how long mom could stay at home. This program helped me gain knowledge and how to cope - gave me ideas and greatly reduced our stress. It's an awesome program”

Program Coaches

Coaches' Work and Responsibilities: Findings from the Coaches' informational form indicated that they worked part-time as Program Coaches and were responsible for anywhere from 8 to 33 participants at any given time during the course of the pilot. Two of the five Coaches felt the time that they allocated to work as a Coach was inadequate due to the rural distribution of clients in their geographic region. The amount of time and effort that Coaches

spent with participants varied by participant and the most time consuming phase was during the enrollment of participants. In addition, when asked “how much does the frequency of contact vary from participant to participant?,” Coaches indicated the frequency of contact varies greatly from participant to participant ($M = 8.25$ on a 10-point scale, 1 = does not vary at all, 10 = varies a lot). Coaches reported contact with participants, on average, 5.9 times per month over the phone and 2.6 times per month in person during the enrollment process. This decreased post-enrollment to 3.4 times per month over the phone and 1.8 times in person per participant per month. Four of the five Coaches indicated they would like to continue as a Coach if the CLP continued.

Qualitative Findings from Coaches Focus Group: The following section summarizes the responses to focus group questions, including: the reason for becoming Program Coaches, key skills needed to be a successful Program Coach, reasons that the program was successful, challenges for Coaches and participants, needed improvements to the program, and unanticipated outcomes of the program.

1. Why did you become a Coach?

Coaches expressed a love for working with seniors, some commenting on positive experiences with aging family members. They strongly supported the CLP’s philosophy of empowering individuals to be able to make decisions and do things for themselves rather than having someone do things for them. They recognized the importance of serving a “gap group” of those just above the income eligibility cut off for Medicaid, but who cannot afford to pay for services over the long-term.

2. What do you think are the key skills that Coaches should possess?

Coaches reflected on their roles and responsibilities during the pilot program. They indicated that there are key skills and competencies that Coaches should possess. These include:

- Good organizational skills, especially at administrative duties
- Past experience with participant-directed services
- Social work background
- Patience - training participants takes time
- Knowledge of cultural practices and expectations
- Ability to maintain boundaries of Coaching relationship

3. Please describe the successes of the CLP program.

A major theme that emerged regarding program successes was the *empowering* of individuals. Coaches reiterated that the CLP allowed participants and their families to have a voice and a real role in the decision-making process. This was frequently contrasted with

traditional services, where the decisions are made for participants, including the details of who will provide services and when. In addition, the CLP was *flexible* and allowed participants to make changes as their needs changed. This is highly valuable for those with complex and dynamic needs.

4. Challenges from the Coaches' Perspective:

Coaches were asked about the challenges that they experienced, including:

- Rural island setting: Working in a rural setting was challenging because access to technology was limited. Participants often didn't have access to fax machines, computers, etc., which were essential for submission of paperwork. It was difficult for Coaches to arrange for the shipment of supplies because some companies do not ship to neighbor islands, particularly Lanai and Molokai. In addition, access to power was limited. Some participants used a generator, which sometimes complicated in-home visits.

"..I'll never forget...when she called me and she said, "well honey, I'll make sure the generator's up and running that day." And I went - holy cow - you know I mean, it's bad enough sitting on an upside down 5-gallon paint can in their carport doing whatever and then to have to worry about a generator..."
- Working with the Fiscal Agent: Coaches expressed the need for a single contact person at the fiscal agent's office. Each time Coaches or participants called for assistance, a different person answered the phone, and often gave conflicting answers to the same question. It was challenging to get a consistent answer. Participant statements were also confusing. For example, monthly spending amounts were listed in alphabetical order by month rather than chronological order. This was challenging for Coaches and participants.
- Purchasing of goods and supplies: Participants were on a fixed income. Participants often did not have the financial ability to purchase items up front in order to be reimbursed with CLP funds at a later date.
- View of participant challenges: Coaches said that the most frequent challenges faced by participants were: 1) Finding people to provide services and 2) Conducting the interview and the hiring process. Participants needed a lot of help and training in this area. Coaches also indicated that some participants had difficulties with family members who were also employees. Navigating the boundaries between family member and employee was challenging. For example, some participants had difficulty correcting an employee family member who was doing something incorrectly.

5. What are your suggestions for improvement?

Coaches were asked to provide suggestions to improve the CLP program. Suggested administrative changes included the following:

- Coaches suggested that the CLP paperwork should be revised so that it is more efficient. Specifically, Coaches indicated that the categories within the spending plan should be

broader so that minor adjustments don't require resubmission of plans. For example, instead of listing specific medical equipment, list items as "durable medical equipment."

- The hiring process needs to be expedited. It sometimes took three weeks to hire an employee, meaning participants had to wait for services.
- CLP leadership should develop an approved vendor list that contains a list of vendors who have already completed tax forms (i.e., W-9). It would allow participants to make purchases, and vendors could be confident they would be paid for the purchase even if participants could not pay them up front. This list should be updated regularly as more vendors are utilized.
- Fiscal agent should assist participants with completion of employer/employee hiring process. The fiscal agent is the agent of record with the IRS, consequently, all contact regarding employer/employee issues should be handled between the fiscal agent and the participant, not via the Coach.

Coaches suggested the following changes to the referral process:

- Screening process should be more rigorous - there is a need to ensure that participant-direction is an appropriate choice for participants.
- Coaches acknowledged that although participant direction is empowering for participants, the participant-direction format is not appropriate for everyone. Participants need to be motivated and able to learn how to work independently, and have the time to complete necessary paperwork.
- Participants also need to be able to transmit paperwork to the fiscal agent for processing, consequently, the ability to learn to use technological devices is also essential for participation.
- It was noted that approximately 10% of participants should have not been enrolled in a participant-directed program and would have been better served by more traditional services arranged by a case manager.

Coaches suggested the following changes to improve their role in the program:

- Contracts need to be restructured to allow for the scope of activities Coaches perform. For example, there is a large amount of administrative work, especially when participants are going through the enrollment process, and Coaches are not compensated for this time.
- Coaches should be provided with portable technology that would allow them to change spending plans during an in-home visit, which would expedite the process greatly.

Needed items include:

1. Laptop
 2. Printer/Scanner
 3. Air Card
 4. Smart Phone
 5. Luggage to carry items (if traveling to outer island)
- Build relationships with discharge personnel at local area hospitals and facilities. Discharge planners could be key sources of referrals to the project if they had knowledge of the program and how it operated. Also, they could include the CLP in their discharge

planning process and know that the CLP would provide the patient with the services and supports to safely live in the community.

Unanticipated Outcomes: One area of discussion that emerged was unanticipated outcomes of implementing this program. There were three areas discussed by Coaches as positive outcomes they did not anticipate but emerged during the course of the pilot program:

1. Increased job pool/job creation: some participants hired multiple employees in an effort to provide jobs for as many people as they could. For example, one participant hired four different employees to provide in-home care. The participant's needs did not require that four employees care for her. She chose to hire four people to create four jobs instead of one.

"...[the participant] ended up hiring four different people - she was like this little economic engine, and she divided up the hours, she self-directed, and she gave four little bits of money to four different people...and that's what this is - it's like the unintended consequence...and I think that's really important because home and community based services can be that for a community, especially for the rural area"

2. Entrepreneurship and small business development: Employees and vendors would sometimes work for multiple participants. For example, one employee worked for multiple participants providing care. The implication of this from the Coaches' perspectives is the opportunity for entrepreneurship and small business development in a geographic area with limited service availability.

"...that was one of the unintended consequences - economic development - with this whole thing - putting money back in to the community."

3. Supporting household finances: Families that were on the edge financially, i.e., at risk for spend down to Medicaid, were able to use CLP funds in a way that infused the money back into the household. This aided in keeping the family more financially stable than they would have been otherwise.

"...for most of my families, without this money they are...on the edge...so the fact that this money can be kept within the family unit is really saving a lot of them - from losing homes or whatever..."

CLP Program Leadership

Separate semi-structured interviews were conducted with the CLP Program Manager and EOA Program Specialist at the end of the pilot period. Instead of discussing their experiences as CLP leaders, their interviews focused on lessons learned from implementing the program, including key Coaching skills, needed participant supports, and necessary changes to program operations. First, interviewees were asked to describe the key skills that Coaches in a participant direction model need to possess and reflect on the work of the Coaches in this CLP pilot. It was clear that the key role of a Coach is to provide support and training. Coaches need to be able to

work with participants or authorized representatives to identify resources in the community, teach responsibilities as an employer, and provide ongoing support and training as needed. The Coaches' role as a support person needs to be clear and distinct from other professionals (e.g., case managers) and Coaches need to understand their boundaries and limits. Coaches need to be both good trainers and utilize culturally competent approaches in working with participants. Coaches in the CLP were generally very successful in these areas but a few had issues with boundaries and limitations and did too much for participants rather than empower them.

Second, the interview questions asked the Program Manager and Program Specialist to reflect on the supports and training provided for participants/authorized representatives and key lessons learned. Generally, Coaches were successful in supporting participants during enrollment and creation of the support and spending plan. However, a key lesson learned is that the Coaches need tools to help a participant understand requirements of the CLP. One suggestion was to utilize examples/cases/scenarios via print or video to help participants understand their responsibilities and requirements as participants in the CLP. In the future, a self-assessment tool for participants and a tool for Coaches is needed to aid in determining whether a participant direction program is appropriate for the participant and whether the right training and support could help the participant become successful in the CLP.

Interviewees were also asked to discuss the role of the fiscal agent (Acumen) and needed changes to program protocols. One challenge was the use of the spending plan. A standardized spending plan was developed for the pilot. However, during the pilot's implementation, it was found that the spending plan was inefficient and created additional work for Coaches. Specifically, with every small change to the spending plan the Coach was required to submit a new spending plan to Acumen. For example, if an employee was providing personal care, and the following month added chore help, a new spending plan had to be uploaded. These types of changes did need to be tracked by the program, but not the fiscal agent. This problem could be addressed by creating an internal spending plan that noted small changes versus a spending plan for Acumen that contained only the information needed by the fiscal agent. Second, interviewees indicated that the role of the fiscal agent needs to be clarified. Specifically, protocols need to

describe in detail when participants and Acumen should communicate directly and when Coaches need to be involved in communication.

Finally, the Program Specialist and Program Manager discussed lessons learned from the implementation of the program and changes for the future operation of the CLP:

- Fidelity: the referral and enrollment process was outlined on page 20 above. In practice however, it was not clear whether all staff completed the required steps. For example, the 4-page referral form was supposed to be completed in a face-to-face visit, which would allow for confirmation of inclusion criteria such as number of ADLs, but this was not always done. In addition, the forms themselves were not consistently completed, which meant the Program Manager had to go back to the intake person to clarify information.
- Compensation: Coaches were compensated for face-to-face and telephone interactions with participants and authorized representatives. They were not paid for time spent on administrative duties, such as phone calls with the Program Manager. A main lesson learned for the future is to include these types of administrative items in coaches' contracts, as well as adding time for team meetings and travel to rural areas.
- Reassessment: Participants need to be reassessed after a year to review and discuss difficulties and concerns of participants. In addition, a protocol and tool for participant non-compliance is needed.
- Participant compliance: Upon enrollment, participants need to be notified in writing of their responsibilities to ensure compliance with the CLP and inform participants of non-compliance as it occurs, and offer opportunities to remedy issues prior to termination.

Commendations, Challenges and Recommendations

Participant Outcomes and Experiences

The main participant benchmarks were to: 1) enroll 90 participants, and of these participants, 2) 80 participants (89%) will avoid institutionalization, and 3) 80 (89%) will avoid Medicaid spend down. This section summarizes the progress made toward the three benchmarks, as well as the experience of participants in the program.

● Commendations

- The program met the 1st benchmark by enrolling 91 participants. Of these participants, 84 (92.3%) avoided institutionalization and spend down to Medicaid. A small percentage of participants were institutionalized (5.4%) or spent down to Medicaid (2.2%). Therefore, the 2nd and 3rd benchmarks were also met.

- Interviews with participants indicated that they were highly satisfied and all supported the sustainability of the program. Many (60%) said they would not be able to remain at home without the CLP program.

●Challenges

- Qualitative interviews noted concerns over boundaries between Coaches and participants. Certain participants needed a greater level of support in determining the type and amount of goods and services needed. As a result, some Coaches had to do more to support certain participants. The line between “doing for” and “doing with” needs to be better understood by participants and Coaches.
- The frequent challenges expressed by participants related to administrative requirements of the program, including paperwork (time sheets and tax forms), meeting deadlines to submit time sheets, and use of technology (i.e., fax machines) to submit paperwork.

●Recommendations

- A standardized self-assessment is recommended to help participants decide the types and amount of support needed and their motivation to complete the tasks required by the CLP. Hawaii’s CLP can adopt a self-assessment tool employed in other states’ participant direction programs. Potential questions would include: what services do you want and need? Who will you hire to help you? How will you train your worker? How will you tell them they are doing the work correctly?
- Utilizing lessons learned and experiences from the CLP, program leadership should more explicitly detail the roles of participant and Coach in the Participant Guidebook and the Policy and Procedures Manual. In addition, at enrollment, participants should receive and sign a “roles and responsibilities form” that clearly outlines the roles of participants and Coaches. This will address concerns related to boundaries between Coach and participant.
- Better participant training is recommended that utilizes cases or scenarios via print or video to help participants understand their responsibilities and requirements of the CLP. Training would be tailored to an individual’s needs but could include lessons on completing paperwork and using technology.

Appropriateness of the Program for Participants

The goal of a self-direction program is to determine how to make participant direction work for the individual and to determine the level of support needed. This section summarizes the Coaches’ and program’s efforts at ensuring that participants understand program requirements and perform program responsibilities, and also their work in supporting participants who have dementia.

●Commendations:

- The program developed a comprehensive Participant Guidebook that described the CLP, outlined participant responsibilities, and the roles of the Coach and fiscal agent. A similar guide, the Policy and Procedures Manual was successfully developed for the Coaches.
- The Coaches are commended for their work with participants in understanding their needs and making decisions. Participants had high levels of satisfaction with their Coaches, indicating that they were helpful, friendly, and always responsive to participants' questions or concerns.
- The support plan contained a back up plan and emergency preparedness plan. The process of completing the support plan helped participants understand potential risks, and balanced that with benefits gained by living as independently as possible.
- A significant proportion (37%) of participants included persons with Alzheimer's Disease or Related Dementias (ADRD) in the program. All participants with ADRD were able to designate an authorized representative to understand and carry out their preferences for care. Furthermore, analyses indicate that outcomes of participants with ADRD versus other participants were equal. There was no significant difference between the mean number of days ADRD and non-ADRD participants remained in the community. These findings support earlier research (done in Arkansas) which indicated that participants with a mental health diagnosis had equal or better outcomes under a participant direction program as compared to those utilizing traditional services.

●Challenges:

- It is important for ADRC intake staff and Coaches to maintain fidelity to the CLP's protocols for referral, enrollment, and the roles of Coach and participant. Maintaining fidelity is necessary to ensure that the program supports the philosophy of participant direction in all areas of the program. Qualitative interviews with CLP Coaches and leadership indicated that in a few cases, referral forms were incomplete, the referral process did not proceed in a timely manner, and Coaches were required to provide a significant level of support to certain participants, consequently, empowering participants to make their own decisions rather than making decisions for them was difficult.
- A few clients, known to be challenging for traditional service agencies, were "dumped" by being referred to the CLP program. These individuals were less likely to perform program responsibilities and this led to more intensive work, personally and administratively, on the Coaches' part that may have not been appropriate for participant direction. In one case, this led to termination due to non-compliance.

●Recommendations:

- Intake workers should be trained to fill out the referral form thoroughly and assist participants in choosing the right path - traditional services (through Kupuna Care) vs CLP.

- The participant handbook should be expanded to include tools that need to be developed or adopted from other states to help participants:
 - Better understand participant responsibilities in the program, through written case studies or scenarios, and samples of completed forms.
 - Gauge their readiness to perform CLP requirements through a readiness self-assessment. Such an assessment can help to gauge a person's motivation to participate in the CLP and complete the program's requirements. Motivation was mentioned by program leadership and Program Coaches as a key quality needed by participants.
- Thorough intake and Coach training is needed on the types of participant issues they may face and mechanisms for addressing concerns. Concerns include potential abuse or neglect, caregiver stress and burden, history of noncompliance with medication or diet, challenging behaviors, mental illness, and high risk for falls. Key steps for managing concerns should include effective training for participants, Coaches, and other staff. Also, Coaches should share their concerns with participants and collaborate with the participant in developing strategies and alternative back up plans.
- A quarterly reassessment form should be developed and implemented. The form could be completed in-person or telephonically, and would check on participants to see if they are having any challenges or concerns, need any changes to their support or spending plans, or had any ER/hospital visits in the last quarter.
- Future programs should include more evaluation and analysis to determine the appropriateness of the tiered approach to budget amounts. For example, an examination of the ratio of CLP funds utilized to personal funds utilized may be beneficial in assessing the long-term sustainability of the program and aid in preventing spend-down to Medicaid. This is recommended because a Coach indicated one participant utilized their own funds in conjunction with CLP funds to pay for in-home care. In addition, Coaches indicated participants with a diagnosis of ADRD and/or greater ADLs required more supports overall.

Role of the Coaches in Participant Direction/Experience of Coaches

Program Coaches must embrace a paradigm shift in adopting the participant direction model. In contrast to the traditional services model, in which a professional agency or case manager determines needs and oversees the provision of services, the participant direction model empowers the participant to make decisions. The Coach should consider himself or herself a partner who collaborates with the participant to complete the enrollment, assessment, the support and spending plans, a risk management plan, monitor outcomes, and amend plans as necessary. In the participant direction model, participant involvement is critical. The Coach assists participants in determining their needs and helps the participant develop goals and outcomes. This section summarizes the work and experience of Coaches in the CLP.

●Commendations:

- Coaches were proud and enthusiastic about the CLP model. They were supportive of the program’s philosophy of participant empowerment and worked hard to implement the program properly.
- Coaches were very creative, particularly in working in a rural island population. They faced difficulties in getting goods and supplies shipped to Molokai and finding services on the island.
- Coaches used culturally appropriate practices in working with participants, including utilizing a “talk story” approach when meeting with participants. Their cultural sensitivity helped to foster strong working relationships.
- Participants were highly satisfied with Coaches, indicating they were very patient, responsive and always available. Several participants commented on the availability of their Coach, saying if the Coach didn’t answer the phone when they called, the Coach always called back right away.
- A few Coaches developed a best practice by going around the community and introducing the program before the enrollment process began. As a result, agencies were already familiar and supportive of the program when participants and Coaches arranged for services.

●Challenges:

- Coaches faced difficulties in identifying services in rural areas and getting goods and supplies shipped to rural areas.
- Completing the paperwork requirements of the CLP was the main challenge expressed by Coaches. Participants often had numerous revisions to the spending plan, which needed to be submitted to Acumen. In addition, Coaches were unclear on the type of information and detail needed by Acumen.
- Coaches commented on the need to establish and maintain boundaries. For example, Coaches noted in a few cases, needing to complete forms for participants, forms that are the responsibility of participants to complete.

●Recommendations:

- In the focus group, Coaches provided valuable information on the needed skills and qualifications of Coaches. This feedback should be incorporated as the CLP project expands statewide and new Coaches are selected.
- Coaches would benefit from training on motivational interviewing and health coaching models. These models emphasize the need to “lead from behind”, empowering participants to make their own decisions. The training should also clearly outline the role of Coaches versus responsibilities of participants. This will address concerns related to boundaries between Coach and client.
- Coaches should meet quarterly, either in person or via a video conference call, to discuss successes and challenges with participants. At the close of the Coaches’ focus group, several mentioned how productive and reassuring it was to talk in person with the other Coaches. In the future, regular discussions between Coaches may function as

- a training tool, allowing Coaches to offer suggestions or examples of how they handled challenging situations. It could also allow for oversight by a Program Manager.
- Coaches would benefit from additional training on CLP paperwork. Coaches commented that they faced a learning curve on the correct way to complete the support and spending plans.
 - Resources are needed for Coaches to have a complete “mobile office” with computer, printer/scanner, and internet access to maximize the efficiency of Coaches’ work. Future RFPs should acknowledge these supplies are needed as part of the coaching role.
 - CLP should develop an approved vendor list. Coaches recommended that developing and establishing relationships with vendors (e.g., Young Brothers to ship goods to Molokai) could expedite and streamline Coaches’ work with participants. This list would still be in line with the participant direction philosophy because participants still need to determine what they need. However, participants would be able to refer to a vendor list to see if a vendor supports their needs, and would still need to evaluate and “vet” the vendor.
 - Similarly, the CLP should develop an approved employee list. Acumen maintained a list of employees that were willing to work with other participants. This list would be valuable to Coaches and participants.

Program Operations

Developing and implementing a participant-direction program can be complex. The program needs to ensure a strong partnership between Coach, participant, and the fiscal agent. In addition, the program needs to ensure adequate participant support in recruiting, hiring, managing, and dismissing employees, managing individual budgets and purchases, and completing payroll and tax forms.

● Commendations:

- Program leadership developed the CLP by using an established national model promoted by the National Resource Center for Participant-Directed Services.
- CLP leadership successfully obtained buy-in from three County Offices on Aging: Hawaii Island, Kauai, and Maui.
- Program leadership successfully identified and contracted with Coaches in Hawaii County and Maui County to serve each county through the RFP process. The Program Manager served as the Coach for Kauai County, which gave the Program Manager a unique perspective on the day-to-day operations of the program.
- CLP leadership identified and contracted with a fiscal agent with extensive experience in participant direction.
- CLP leadership developed and implemented key tools in a participant direction program: referral forms, enrollment forms, participant guidebook, support plan, spending plan, and participant handbook.

●Challenges:

- It is important for ADRC intake staff and Coaches to maintain fidelity to the CLP's protocols for referral, enrollment, and the roles of Coaches and participants. As mentioned previously, qualitative interviews with CLP Coaches and leadership indicated that in a few cases, referral forms were incomplete, the referral process did not proceed in a timely manner, and Coaches were required to provide a significant level of support to certain participants, and empowering these participants to make their own decisions rather than making decisions for them was difficult.
- Paperwork was challenging for the Program Manager, Coaches and participants. As mentioned previously, Coaches discussed a learning curve in accurately completing the support plan and spending plan. At times, paperwork was inefficient. Revisions to the spending plan required Coaches to input revised information, as well as to repeat the information in other sections, even though there were no changes to these sections.
- Coaches expressed interest in more training on the information needed by the fiscal agent to process payments.

●Recommendations:

- Standardized tools and protocols need to be adopted and deployed to ensure program quality and fidelity. Tools include:
 - A participant (or representative) readiness self-assessment to help participants understand their roles and responsibilities and their motivation to complete these tasks.
 - Participants should be given a separate form, detailing a list of roles and responsibilities on the part of the program and the participant, and this document should be signed by participants and Coaches.
 - A termination agreement should be developed and utilized for: 1) non-compliance with basic requirements of the participant-direction program, for example, misuse of funds.
 - A protocol for termination should be implemented, that should include (but not be limited to): informing participants of the decision, offering the ability to appeal or review the decision, developing a plan to return to agency services, developing a new service plan, and ensuring there is no break in services.
 - A quarterly reassessment form to monitor participants' progress in the CLP should be developed and utilized.
- Fidelity monitoring should be required at set time periods, e.g., quarterly. A program staff person should be responsible for quality assurance and conduct periodic reviews of support plans and spending plans to ensure fidelity to protocols. Furthermore, satisfaction surveys should be conducted semi-annually or annually with participants to ensure quality of life, stability (minimal ER/hospital visits), and that they have the supports needed for community living.
- Participant information from the CLP should be incorporated into the statewide ADRC database. The new ADRC system uses a uniform assessment tool that includes socio-demographic and health information. This system should be integrated with CLP data

in order to track participant outcomes and program progress statewide. This centralized statewide database will facilitate quality assurance monitoring.

- Two versions of the spending plan should be created and implemented: the original spending plan, with a comprehensive listing of services and goods needed, and a short form for revisions to changed sections only.

Summary

EOA is at the cutting edge of federal trends in long-term care by piloting a participant-direction program in the state. The philosophy of the CLP is to empower individuals to make their own decisions and determine the supports needed to age-in-place in their homes and communities. The Coaches played a key role in the CLP because of their role in empowering, educating, and training participants to determine the amount and types of home and community-based supports they need and to support participants' ability to manage employees and vendors over time. The pilot project is to be commended for meeting its benchmarks for enrolling its targeted number of participants, and minimizing institutionalization and Medicaid spend down among its participants. Interviews with Coaches and participants indicated both were very positive about the pilot's goal to empower participants and want the program to continue. From a systemic perspective, the pilot led to unanticipated benefits including job creation, and opportunities for entrepreneurship and small business development in geographic areas with limited service availability. A key area to address for future expansion and sustainability is a clear protocol on communication with the fiscal agent, specifically, what information is required by the fiscal agent, and how this information is to be communicated between the fiscal agent, Coaches and participants. In addition, the evaluators recommend modifications to other CLP protocols (e.g., more clarity on the role of Program Coaches and boundaries between Coaches' responsibilities and participants' responsibilities), as well as additional Coach training and tools to gauge participant readiness, and for quarterly participant follow-up. These modifications will support the next phase of ADRC, and the broader implementation and integration of the CLP within the ADRC system statewide. This is a very promising program that deserves to be available to all elders and persons with disabilities who have a preference to live independently in the community.

Appendix A: Sample Support and Spending Plans

Coaching Agency: Senior Assistance, Inc.
 Coach Name: Bonnie Tokunaga

Client Name: Jane Yee
 Date: July 1, 2012
 SAMS ID: #####

Problem(s) Identified	Goals	Activities/Actions	Who will complete	Date Completed
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CLP SUPPORT PLAN

<p>1. Jane has diabetes, chronic back pain and arthritis in her knees. She walk with a walker and uses a wheelchair when she is too tired to walk and for doctor appts. She needs assist with all of her activities and instrumental activities of daily living except that she can feed herself.</p>	<p>1.To develop a Support Plan that will allow Jane to live at home in a clean and safe environment.</p>	<p>1.Upon acceptance into the Community Living Program (CLP), CLP Coach will help Jane and her son, Keoni Yee to understand CLP and develop a monthly budget for the services that she needs.</p>	<p>1. CLP Coach, Jane and Keoni</p>	
	<p>2.To implement the Service and Support Plan by having trained and caring support staff in the home to assist with personal care activities</p>	<p>2. Personal care assistance is needed 10.5hrs/week (maximum of 46 hrs./mo). Personal care activities may include but are not limited to: assistance and supervision with bathing, dressing, toileting, grooming, etc. Aide will also assist with laundry, change bed linens and other activities.</p>	<p>2. Keoni Yee</p>	
	<p>3.To assure that an alternative plan is in place should scheduled staff be unavailable.</p>	<p>2a. Complete requirements for Employer/Employee and review all procedures for payments of vendors and reimbursements.</p>	<p>2a. Jane and Keoni with assistance of CLP Coach</p>	
	<p>4.To assure that the family is prepared to care for Jane in the event of a Civil Defense Emergency.</p>	<p>2b. CLP funds will be used to pay for the personal care services that Jane receives.</p>	<p>2b. CLP, Jane, Keoni, and Acumen</p>	
	<p>5.To assure that the services are provided as stated and the stated goals are attained..</p>			
	<p>6. To provide an adequate Support Plan to meet Jane's changing needs.</p>			

Coaching Agency: Senior Assistance, Inc.
 Coach Name: Bonnie Tokunaga

Client Name: Jane Yee
 Date: July 1, 2012
 SAMS ID: #####

Problem(s) Identified	Goals	Activities/Actions	Who will complete	Date Completed
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CLP SUPPORT PLAN

		<p>3. BACKUP PLAN: Susan Yee, daughter-in-law will be Keoni's back up if he is unable to perform the services.</p> <p>4. Jane, with the help of her son, Keoni will hire and train staff and will provide oversight of worker performance. They will determine work schedule.</p> <p>5. CLP funds of \$800 per month will be used to pay for personal care services upon approval of the CLP Support Plan. Funding will continue until 7/1/13 or until such time as Jane or Keoni informs CLP Coach to terminate her enrollment in CLP, whichever comes first. Keoni will submit timesheets to Acumen according to payment schedule.</p> <p>6. CLP coach will monitor CLP services through semi-monthly contact with Jane and Keoni</p>	<p>3. Susan Yee</p> <p>4. Jane with Keoni</p> <p>5. CLP, Jane, Keoni and Acumen</p> <p>6. CLP Coach, Jane and Keoni</p>	
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Coaching Agency: Senior Assistance, Inc.
 Coach Name: Bonnie Tokunaga

Client Name: Jane Yee
 Date: July 1, 2012
 SAMS ID: #####

Problem(s) Identified	Goals	Activities/Actions	Who will complete	Date Completed
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CLP SUPPORT PLAN

		<p>7. Keoni will contact the CLP Coach if needed, to reassess, review and update the CLP Support Plan.</p> <p>8. Keoni will notify Acumen (Fiscal Agent) of any changes in the status of employees.</p> <p>9. EMERGENCY PLAN: In the event of a Civil Defense Emergency, Keoni and Susan plan to Shelter-In-Place with Jane at their residence, as it is a sturdy structure. If Civil Defense official recommend evacuation, Keoni and Susan will accompany Jane to the nearest open Emergency Shelter and will remain there until such time as the All Clear signal is sounded and people are allowed to return home.</p>	<p>7. Keoni and CLP Coach</p> <p>8. Keoni and Acumen</p> <p>9. Keoni and Susan (d-i-law)</p>	
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I have reviewed, understand and agree with the CLP Support Plan as outlined above.

Client/Caregiver: _____ Date: _____

CLP Coach: _____ Date: _____

**Spending Plan for : Jane Yee
Total Monthly Allocation \$ 800.00**

For Unpaid Supports:		SAMS ID:#####				
What type of help?		Identify the source of		How often?		
Emotional Support & Friendly Visits		Church Friends		Weekly		
For Employee Services:						
Service Type	Employee Name	Hours per Week	Hourly Wage	Total Wage	Hours per Month	Total Monthly Cost
PC	Keoni Yee	10.5	\$15.00	\$17.37	46	\$799.02
						\$0.00
						\$0.00
						\$0.00
Total Monthly Cost for Employee Services:						\$799.02
For Other Purchased Services:						
Service Type	Provider	Frequency	Unit Cost	# Units per Month	Total Monthly Cost	
					\$0.00	
					\$0.00	
					\$0.00	
Total Monthly Cost for Other Services:						\$0.00
Good	Purchased from Who	Proposed Date of Purchase	Estimated Cost	Estimated Months to Save	Monthly Saving Amount to set aside	
					\$0.00	
					\$0.00	
					\$0.00	
Total Monthly Cost for Purchased Goods:						\$0.00
Total Monthly Amount Planned:						\$799.02
This is <input checked="" type="checkbox"/> the initial plan or <input type="checkbox"/> a revision						
Date of this Plan _____			Spending Plan Effective Date: _____			
Participant signature: _____						
Coach signature: _____						
CLP Manager signature: _____			Approved Date: _____			
Acumen (Fiscal Agent) signature: _____			Approved Date: _____			

Appendix B: Interview and Focus Group Questions

Participant Interview Questions:

1. On a scale from 1 to 10, 1 being none and 10 being completely aware, before enrolling how aware did you feel you were about long term care services available in your community?
2. On a scale from 1 to 10, 1 being none and 10 being completely aware, before enrolling how aware did you feel you were about long term care services you needed to help you live at home?
3. How did you find out about the program?
4. Why did you enroll in the program?
5. What concerns, if any, did you have about enrolling in the program?
6. What do you like about the program?
7. What do you not like about the program?
8. How did you like working with your Coach? How did he/she help you? What additional support did you need from your Coach?
9. Did you have a hard time developing your support plan? Why or why not?
10. Did you have a hard time developing your spending plan? Why or why not?
11. Think back to before you heard about the CLP - were you aware of the services you included in your spending plan?
12. What services did you purchase?
13. Were you aware of these services before enrolling in CLP?
14. Are you satisfied with the services you utilized? Why or why not?
15. Who did you hire to perform these services? How did you find the person(s) you hired?
16. How satisfied were you with the person(s) you hired?
17. What goods did you purchase?
18. Were you aware of these goods before enrolling in CLP?
19. Were you satisfied with the goods you purchased? Why or why not?
20. What were your experiences working with the fiscal agent, Acumen? How did Acumen help you?
21. What suggestions do you have for improving the program?
22. Would you recommend this program to others in your community?
23. Since enrolling, have you gone to the emergency room? (when, where, why, how many times, length of stay)
24. Since enrolling, have you had to stay overnight in the hospital? (when, where, why, how many times, length of stay)
25. If you had not participated in this program, how confident are you that you would still be living in your current living situation? (Not at all confident, Somewhat confident, Confident, Very confident)
26. Do you recommend that this program continue? Why or why not?
27. *If the person has already disenrolled from the program:* Why did you disenroll from the program?

Coaches' Focus Group Questions:

1. How did you become involved in CLP?
2. Why did you decide to become a CLP Coach?
3. What makes the program successful?
4. What adjustments are needed to improve the program?
5. What are common concerns from participants? (*clarify when - pre or post enrollment*)
6. How did participants contact you in the event of an ER visit or hospitalization?
7. How involved were you with discharge and/or discharge planning?
8. Were there any challenges for participants living in rural or remote areas to purchase goods and services? (*clarify local - rural or remote*)
9. Were there differences between participants with and without authorized rep? In what way?
10. Were there different needs for participants with ADRD as compared to those without? In what way?
11. Were there differences in needs for participants with Hospice care? In what way?
12. Were there cultural issues that arose which impacted decision to enroll, enrollment or choice of services?
13. If the CLP was implemented on a permanent state-wide basis, what suggestions do you have for sustaining the program?

Program Specialist Interview Questions:

1. How did you conceptualize the model for CLP?
2. What kind of design and planning was involved?
3. How did you recruit Coaches? What characteristics/skills/experience were required of Coaches?
4. How did you find the fiscal agent, Acumen?
5. Previously we discussed unanticipated consequences of the program - what are some of those? What surprised you the most?
6. Do you have plans to integrate CLP within the ADRC system. What would that look like?
7. How do you see the roles of options counselors vs. Coaches?
8. What are the take-aways from this pilot - what are the lessons learned?
9. What are the next steps for CLP?

Program Manager Interview Questions:

1. When starting CLP, what were the scope of your responsibilities at the start of the grant?
2. What additional responsibilities have you taken on, how have those responsibilities changed during the pilot process?
3. What was the referral process?

4. What are the specific duties of a Program Coach? (scope of duties, frequency and type of contact)
5. What are common concerns from Program Coaches? How were they addressed?
6. What skill sets do you think are necessary for someone to be a successful Coach? (experience, geographic location) What tools are needed?
7. How much contact did you have with Acumen?
8. What did you discuss with Acumen?
9. What adjustments are needed to improve the program?
10. What do Coaches need that they did not have during the pilot ?
11. What do program managers need that you did not have during the pilot?
12. What are the take-aways from this pilot - what are the lessons learned?