Report on the Feasibility of Providing Consumer Directed Services for Non-Medicaid Eligible Older Adults and Persons with Disabilities in the State of Hawai`i

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Executive Summary and Recommendations

Introduction

Hawai`i has a growing older adult population. It is estimated that in the year 2010 older adults (age 60 and above) in the state will number about 270,000. The survey of Hawai`i elders completed in the fall of 2007 noted that we have a high percentage of elders with Instrumental Activities of Daily Living (IADL) and Activities of Daily Living (ADL) impairments. Additionally, respondents reported a high level of unmet need, as did their caregivers in a related survey (Arnsberger and Lum, 2007; Arnsberger, 2008). Furthermore, although Hawai`i has the lowest estimated percentage of people with disabilities in the country (11.1%) this population has special challenges due to a lower socio-economic status than the population as a whole. As a result, these individuals have unmet health insurance, housing and personal care needs (Centers for Disease Control State Chartbook, 2006). In response to this impending crisis, the Joint Legislative Committee on Family Caregiving requested the Executive Office on Aging to undertake a study investigating the feasibility of implementing a consumer directed program entitled Cash and Counseling. The University of Hawaii School of Social Work was contracted to conduct this study. This approach to providing care differs substantially from other programs currently underway in Hawai`i in that it would provide a flexible monthly cash benefit to elders, those with a disability and their caregivers. Furthermore, this benefit would be available to all elders and those with disabilities who have an expressed level of unmet need.

Summary of Recommendations

1. Based on the findings of the attached report and the ensuing community input, it is recommended that the State of Hawai`i undertake a three year demonstration to

test the effectiveness of this model of service delivery. Three possible sites for this program would be: (1) Kauai County with both developmental disability and elderly providers in coalition, (2) Health plan providers for DHS, and/or (3) Kupuna Care in Honolulu (EAD).

2. It is recommended that the demonstration enroll 200 consumers who will receive up to $750/month to purchase needed care and services as defined by their care plan, including the ability to hire family members as caregivers if they wish. The amount of the monthly benefit should remain flexible, allowing the consumer the freedom to "save up" a portion of the benefit and make a one-time purchase of a needed item or have a costly consultation.
3. Eligibility for the program should be determined by four criteria: (1) Requiring assistance with two or more ADL's (note: not IADL's); or (2) Having a cognitive impairment; (3) Not being Medicaid eligible but being uninsured or underinsured; (4) Not eligible for similar benefits under Medicare (including the disability benefit), the Veteran's Administration or other similar programs.
4. It is recommended that the Aging Disability Resource Centers (ADRC) sites serve as the enrollment sites for the project and assist with outreach and project enrollment. The purpose of ADRC is to ensure consumer access to services and streamline the process by which that occurs, so they are a natural site to provide this service.
5. It is recommended that the program will have two components: (1) Counselors whose responsibility is to meet with potential consumers, determine eligibility, develop a flexible monthly budget, establish a service plan and monitor service delivery on a quarterly basis; and (2) A fiscal component which acts as a fiscal

agent/employer proxy for the consumer to establish representative payees early in the program, develop forms for employers' reporting responsibilities, and report state and federal taxes.

6. It is recommended that a project director be hired, to provide both contract and fiscal oversight, and to assess after the demonstration, whether or not these functions should be separated later on in the program. This individual should also be responsible for overall quality assurance to determine that services are delivered as outlined in the service plan and that providers, especially personal care providers, are meeting client needs and that funds are only being spent on items specified in the care plan.
7. It is recommended that an evaluation of the demonstration be put into place at the beginning, with consumers assigned to treatment (consumer directed) and comparison groups (standard Kupuna care or other). Baseline and ending measures will assess whether or not reduction of unmet need, consumer satisfaction, health and cost outcomes vary between treatment and comparison groups.

If these general program guidelines are adhered to, after the planning year (for which funds are already in place) it is estimated that program implementation costs will be $1,375,000 in the second year (from 2009 to 2010) and for the third year of the demonstration $1,550,000 (from 2010 to 2011). However it is important to note that during the planning year, aspects of this original outline may change as Hawai`i gathers feedback from the few other states that are beginning to provide consumer directed services to non-Medicaid populations. Specific points in these states' current plans for implementation that will be under discussion in the next year include:

- Whether or not to have limits on income and non-exempt assets (cars, homes and certain other assets are excluded from this limitation) essentially targeting the Medicaid “spend down” population.
- How to accommodate language barriers and cultural values (a significant point for Hawai`i).
- The best way to work with the Area Agencies on Aging and the National Family Caregiver Support Program and local community-service providers including service providers for the disability community.
- Whether or not to consider a model where caregivers are allotted a specified dollar amount annually for respite services (Recently Hawai`i has begun to compile a respite agency/care provider list that will be useful for this).

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Aging Population Estimates

Hawai`i has a growing older adult population. It is estimated that in the year 2010 older adults (age 60 and above) in the state will number about 270,000. Those 85 years and older will number around 30,000, and are of special interest because of their higher projected rate of unmet needs, will number around 30,000. Most are in Honolulu (around 70%) with 13% in Hawai`i County, 9% in Maui County and 5% on Kauai. After 2010 these percentages are expected to shift slightly with the percentage of elders in Maui and Hawai`i Counties expected to increase to 15% and 11% by 2015. Honolulu is expected to decrease (not in actual numbers just percentage).

Twenty-two percent (22%) of the state's elders are on Medicaid, but this percentage varies greatly by county. Honolulu is at 27% while the other three islands are all 11-12% depending on the source. It is estimated that 7-9% of elders live below the poverty line; however, up to an additional 22% of the older population live on fixed incomes barely above poverty (National data has suggested that twice the percentage of a state's elder Medicaid population might be considered near poor). The per capita income for elders in Hawai`i is only $21,525 annually as compared with DHS poverty guidelines for a household of 4 people at $23,000.

It is estimated that 18% of Hawaii's elders live alone. It is also noteworthy that those who live alone are more likely to be female (68%) and poor (17%). In addition, if national estimates are correct, around 40% of those over age 60 have one or more disabilities (for those above the age of 5 almost 200,000 people in Hawaii have a disability!). However, the percent of those experiencing limitations because of these disabilities is likely to be much lower. Nine percent (9%) have self care deficits; 12% have a mental impairment; 14% are impacted by sensory deprivation and 25% have a physical impairment. These

percentages are important because nationwide, as well as locally in our Kupuna Care program, impairment in 2 or more activities of daily living is often considered to be the criteria by which someone may require assistance to remain in independent living. It should be noted that in the recent State of Hawai'i Caregivers Survey over 50% of the sample receiving care was found to be deficient in the ability to perform their own personal care, the most demanding level of help needed when assessing ADL impairments.

Other indicators that eldercare is becoming an in of increasing concern in Hawai`i are that caregivers experience moderate levels of financial hardship, physical strain, and emotional stress from the experience. In the recent caregiver survey, measuring hardship on a 5 point scale (with 1 being no strain and 5 a great deal), the mean score for financial hardship was 2.12; ranked second was physical strain (2.36) with the highest ranked item being emotional stress (2.80). In addition, the income level for family caregivers was well under the median income range for Hawai`i averaging approximately $35,000 annually and over half of the care was provided by caregivers who were themselves already employed. Employed caregivers are of particular concern. In the State of Hawai`i Eldercare Survey completed in the fall of 2007, it was found that few employers provided any eldercare benefits to their employers other than those required by law under the State's Family and Medical Leave Act. This was true even though 38% noticed an increase in the past years of employees providing eldercare and 45% said that workers had adjusted their work schedules to accommodate caregiving responsibilities.

Unpaid family caregivers provide the bulk of care in Hawaii as elsewhere. In a recently released study by AARP in Hawai`i (July, 2007) it was noted that family caregivers play a vital role and are the backbone of long-term care in our state. Even though the value of their caregiving tasks was estimated at over $1 billion (if shifted to the public

arena) the care provided by family caregivers often goes unnoticed. In addition, the supply of nursing home beds in Hawai`i will be far from sufficient to meet increasing demands as baby boomers begin to stress the resources of the long term care system. The State of Hawai`i Caregivers' Survey also found that almost 40% of the caregivers said they had unmet needs, not a surprising result given the other findings already cited. An additional 44% indicated that the reason they didn't use available services was that the cost was too high, a response that was frequently reiterated in the qualitative portion of the study. Other comments indicated there is high level of need for trained and affordable personal care providers and respite care, with a particular emphasis for this service to be specially adapted for people with Alzheimer's disease (Arnsberger and Lum, 2007).

Disability Estimates

In addition to the elderly, Cash and Counseling programs often include services to individuals with disabilities, including those with developmental disabilities. It is difficult to estimate the number of those under age 60 with disabilities in Hawai`i; estimates vary widely from 108,000 (Centers for Disease Control, 2006) to 199,000 (U.S. Census Bureau, 2006). However there are difficulties with both estimates. The first includes older adults and the second includes children age 5 and over. Recalculating the CDC percentages of disabilities by age group (7.2% for the 18-44 age group and 13.4% for the 45- 64 age group), it appears as though we have a maximum of 120,000 adults with disabilities in Hawaii between the ages of 18 and 65 (Note: There is still overlap for those in the 60-65 age group, a large number of individuals). Of these, the highest percentages with disabilities are the Hispanic (14.7%) and the white (14.1%) populations with the lowest rates being among the Asian and Pacific Islander population (9.1%). However, unlike other recent statistical data, these data still group together Asian and Pacific Islander

populations. It is likely that disability rates vary greatly among these populations in Hawai`i. The adult disabled population in Hawai`i as elsewhere is characterized by having a lower level of education and a higher poverty level than their age matched peers (Steinmetz, 2006). Like the elderly, those with disabilities also have high levels of unmet need and a heavy reliance on unpaid caregivers. In 2004, nationwide close to 15 million people with disabilities needed personal assistance services to help with bathing, dressing, eating, and toileting, as well as cooking, shopping, and housekeeping. Of this group, only 4 million used paid, formal services, and only 1-1.5 million received these services through Medicaid (Mathematica, 2007).

Taken together these estimates suggest that we have perhaps 350,000 aged and disabled individuals in Hawai`i. If national data estimates of unmet need are correct for both these populations, this would result in over 150,000 individuals being potentially eligible for Cash and Counseling services in Hawaii. Of these, 3,300 individuals in these categories are currently being served under Medicaid waiver programs in the community (Center for Personal Assistance services; Hawai`i Medicaid 1915C waivers) and an additional 3,845 are in nursing homes (Kaiser Family Foundation, 2007) leaving the huge majority relying on the limited efforts of unpaid caregivers or their own resources to purchase care. (Note: For the purpose of program planning, 'service uptake' is likely to result in far lower numbers of actual enrollees. See discussion below). Interestingly, for those with developmental disabilities, the State has recently taken action to implement a variety of programs and services designed to further individual choice and self-determination in community-based services. One of these services is consumer-directed personal assistance, where individuals with DD/MR have more control over the direction of funding for their personal assistance services offered through the DD/MR Medicaid waiver.

Thus a model for a Cash and Counseling type intervention already exists for this population.

Given these findings, the State, through the auspices of the Executive Office on Aging, is proposing a demonstration project designed to improve the way in which services are delivered to elderly and disabled consumers. It should be stressed that this program is provided to augment, but not replace the care currently being offered for free by family caregivers. In addition, the program outlined below is designed to increase the level of consumer choice and participation in the service selection process through the provision of a flexible cash benefit designed to allow consumers and their caregivers to select and purchase the care they feel they need, within certain budgetary limitations and with the assistance of a professional counselor. These types of programs are already available in various forms in 15 states throughout the country and are often referred to as Consumer Directed Care or Cash and Counseling programs.

Background of Cash and Counseling

Cash and Counseling is a promising program that ensures consumer-directed home- and community-based care for elders and persons with disabilities. It provides elders and persons with disabilities an opportunity to have a voice in their care through a highly-collaborative approach. Consumers participate in every stage of the process of obtaining and maintaining services and products that are necessary for an optimal quality of life. Initially a successful three-state Medicaid waiver demonstration program, Cash and Counseling has been replicated in 12 additional states. In addition, nearly half the states (22) have or are actively planning programs for the frail elderly using the individual budget model. Twelve states have individual budget programs in various stages of development, 11 of which are recognized as having program designs consistent with Cash and

Counseling. Fourteen states and the District of Columbia have or are planning programs with some degree of participant direction that include the elderly, although these programs are generally limited to personal assistance services and only in some cases include a budget for those services. For example, Delaware, Georgia, Ohio, Oklahoma, and Texas allow a beneficiary budget or allowance, but the budget authority applies only to personal care services. Maine, New Hampshire, New York, Nebraska, Kansas, and Virginia allow elderly participants to hire their workers and use a fiscal agent to handle payments, but there is no individual budget (Spillman, Black and Ormond, 2006).

In order to explore the possibility of implementing such a program in Hawai`i, the National Program Office Director, along with contact personnel from the various state Cash and Counseling programs were contacted in an effort to explore their programs. Additionally, interviews with the Department of Human Services-Adult and Community Care Services (DHS-ACS) and the Department of Health-Developmental Disabilities Division (DHS-DDD) were conducted in order to ascertain the availability of services to elders and persons with disabilities in the state of Hawai`i. Finally, evaluation research data from Mathematica Policy Inc. was collected from the Cash and Counseling web site.

The evaluation research data strongly indicate that Cash and Counseling is a consumer-directed approach that promises positive results for elders and persons with disabilities. Based on the evaluation data from the three-state demonstration project, both consumers and caregivers who participated in Cash and Counseling reported higher levels of satisfaction than consumers and caregivers who received traditional program services. Consumers used the counseling and fiscal services widely and were very satisfied with them (Mathematica, 2007). In addition, program counselors reported very few cases of abuse and neglect of the consumers and little fraud, in terms of the use of allowance

(Mathematica, 2007). Under the Cash and Counseling program, caregivers reported much lower rates of adverse effects on their social lives, work lives, and physical and emotional health than caregivers who did not fall under this model. Consequently, the Cash and Counseling caregivers reported much greater satisfaction with life. Increased costs for Cash and Counseling resulted primarily from consumers who were previously eligible for services but did not receive them under the Medicaid waiver.

In considering the adoption of Cash and Counseling for the state of Hawai`i, it is important to consider recommendations that stem from the "lessons learned" from past implementations. As the number of those in need of assistance continues to grow in our state, attention to the availability of consumer-directed home- and community-based services must increase as well. Cash and Counseling is a viable option that has been successful in many states. While several states are considering the inclusion of non-Medicaid eligible consumers in the near future (Minnesota, Vermont, Michigan and possibly New Jersey and Massachusetts), only one state, Illinois, is currently attempting to implement a Cash and Counseling program with a non-Medicaid population as Hawai`i is considering.

Lessons Learned from Other Demonstrations

As noted, Illinois is the only state with a current demonstration for Cash and Counseling for non Medicaid recipients. It is, however, closely linked not only to their current community based Medicaid waiver program but also to consumer directed services previously provided under other funding sources, such as Older Americans Act programs. This last point is a crucial one for Hawai'i and affects our choice for a program design.

Certain lessons can be learned from Illinois. One lesson identified early in the consumer-directed respite models was the potential for administrative responsibilities to

increase, which would be especially true here as an electronic infrastructure is not already established to accommodate a consumer-directed model (e.g., billing, provider enrollment, verification of services, balancing monthly and annual funding availability for each individual customer, and developing formal agreements with a number of different type of providers).

Other lessons were the importance of maintaining flexibility in the delivery of service and the potential increase in utilization of respite services when transitioning to a consumer-directed model. For example, one specific geographic area of Illinois experienced a triple digit percent increase in utilization within six months of transitioning to a consumer-directed model. Consequently, a number of other geographic areas have indicated that it can be difficult to maintain and/or estimate the required funding needed for the entire year. They noted that is most evident when working with a variety of caregivers who possess a variety of needs (e.g., caregivers requiring more intensive up-front respite, caregivers who may only need respite service in the evenings or Sunday mornings, caregivers who attempt to preserve some of their funds for a “rainy day,” and those caregivers who may need a variety of respite options in a short period of time such as personal care assistants, temporary nursing home care or an adult day service).

Although Illinois provides the only non-Medicaid model for Hawaii to emulate evaluations of other demonstrations also provide us with some useful tips on how to best implement a program here. Among the most consistent findings are:

1. It has been found that the appointment of representative payee is a necessary first step in implementing the program. Evaluations of other state programs have found that users of the consumer directed option tended to be the more frail and impaired. They often required assistance in managing and expending the

monthly allowance provided by the program.

2. Stakeholder involvement and participation of current agencies offering service to elders and individuals with disabilities was crucial. Many states have noted that there is a great deal of initial opposition to Cash and Counseling programs from these agencies due to a lack of understanding of the program and differing philosophies. Early involvement of these stakeholders should increase their participation in the program as well as their utility as referral sources.

3. Although the program is designed to meet unmet needs, almost every state has put a limit on the amount of the monthly allowance as one way to control costs (from a median allowance of $313 a month in Arkansas to $1,097 a month in New Jersey).

4. Many states have programs that are implemented through their State Unit on Aging and have relied heavily on Area Agencies on Aging to help implement the program cooperating closely with the National Family Caregiver Resource projects, the Aging and Disability Resource Program and other Older Americans Act programs that serve the elderly without requiring eligibility determinations or income or resource limitations. Those that do have income or asset eligibility criteria rely on self report mechanisms such as those that are used in programs designed to serve the “working poor” that are non-Medicaid eligible but are nonetheless uninsured or underinsured.

5. Assessment tools in most states utilize ADL impairments to determine program eligibility. However in certain states, caregiver characteristics (such as being employed or suffering from chronic illnesses) are also taken into account. In the Medicare Alzheimer’s Disease Demonstration, caregiver criteria (including

measures of depression and burden) were also considered when determining program eligibility.

6. Most programs have implemented measures to prevent either consumer or worker abuse, although neither has proven to be much of an issue in program evaluations.

7. Most programs have had to implement a public education or marketing program to give consumers time to understand the difference between the services they are currently receiving and the service delivery model under the new program. Often the difference that needs to be emphasized is the ability to hire a family member as the service provider.

8. At least in the initial stages, all programs had in place some sort of evaluation mechanism designed to provide feedback on the process of implementing the program, as well as program impact on the consumer and caregiver, and cost effectiveness for the state.

9. Counselors must be trained in order to ensure that advocacy for the program and for the consumers occurs. Additionally, counselors must be trained to ensure that spending occurs shortly after consumer enrollment.

10. Most states found a shortage of available personal care workers to be a problem. Consideration should be given to establishing a worker/ service registry that offers consumers lists of current or former hired workers who would like to work for additional consumers. Studies also suggest that individuals who are “trained and certified” be paid more than minimum wage.

Implementation of the Program in Hawai`i

Hawai`i is in the unique position of being the first state to attempt to implement a Cash and Counseling Program without first administering a comparable Medicaid waiver program. Although this provides certain latitude in the way the program can be designed to meet the unique needs of Hawaii's older and disabled populations, it may be difficult to set up a brand new administrative structure for the purpose of implementing this intervention. Furthermore, because it is a new program and has not yet been developed this way in other states, it is best to begin as a time and target group limited intervention with costs and outcomes to be assessed after a fixed period of time (3 years). After examining the situation, the University of Hawai`i contract team has concluded that there are three possible sites for such a demonstration: (1) Kupuna Care in Honolulu, (2) Kauai County, or (3) One of the health care plan providers for DHS.

EAD Kupuna Care Program

In some ways the Kupuna care program is an ideal setting in which to test the consumer choice option. The EAD Kupuna care program in Honolulu is the only place that on its own will provide sufficient numbers for a true test (200 each in treatment and comparison groups). It will be more cost effective in administration costs and will allow for the integration of the ADRC. Since 1999 Kupuna Care has provided a range of services including transportation, housekeeping and chore services, home delivered meals, case management, adult day care, personal (attendant) care which includes bathing services, and respite care to relieve caregiver burden. Of particular importance for the purposes of the Cash and Counseling demonstrations is that the services are available to those who cannot afford to purchase them elsewhere and who are not eligible for Medicaid. The

relatively flexible eligibility guidelines do require that individuals have impairments in two or more ADL's or IADL's or have a mental impairment.

However, community based input (see below) indicated that there are serious problems in trying to implement the program through the Kupuna Care program. Most counties were not interested in being the site for the demonstration. They had many concerns from the philosophy of the program to who would be the fiscal agent to quality of service and service monitoring. They also had staffing and budget concerns. Therefore, although from a theoretical point of view this would be a good place to begin, realistically it appears unlikely.

A Coalition of Agencies on Kauai

The only AAA that expressed willingness in being the site for demonstration was Kauai Agency on Elderly Affairs (KAEA). They could see that flexible support for families would be a plus for their consumers and could envision how it could be implemented. In addition, Kauai has provider agencies who have implemented consumer directed interventions for individuals with developmental disabilities in the past. These providers feel that they have the experience to overcome many of the objections regarding being the fiscal agent and employer of record. Furthermore, these providers are enthusiastic about the concept and are interested in working together with the elder community to implement the program. This provides Kauai an opportunity for true "lifespan" approach to implementing Cash and Counseling. Finally, community input suggested that a rural area would be the most likely setting where the real benefits of a consumer directed program would be realized. The lack of providers in rural areas is a huge problem that the Cash and Counseling program might be able to resolve. The down side of this option is whether there would be sufficient numbers to do a true experiment. It is estimated that there may

be as few as 2,000 potential users of such a program on the Island and it is unclear how many have unmet needs.

For either of these two options, we are fortunate to have a program that already provides community based long term care services to elders in Hawaii that is not Medicaid waiver based and that provides a natural home for a site to sponsor the demonstration. This option is also timely because under Act 11, Special Session 2008 (S.B. No. 2830, C.D. 1), the scope of Kupuna Care service provision was increased. This measure, among other charges, includes the charge to develop the Cash and Counseling program for Hawai`i, expands the current Kupuna Care program to include overnight, weekend and emergency respite, and appropriates additional funds to the Kupuna care program to increase other unspecified services. In addition, Act 204, SLH 2007, has already appropriated an additional $525,000 to EOA for Kupuna Care this year. It is therefore suggested that some portion of these funds, could be diverted to fund at least the benefit portion of a Cash and Counseling demonstrations. We note, however, that at the time of this publication, the additional $525,000 has not been released for the Kupuna Care program.

Department of Human Services Quest Expanded Access Health Plan Providers

The MedQuest Division of the Department of Human services in developing its new expanded access program has established two new contracts with health plan providers. One is Evercare, an affiliate of UnitedHealth Group, and the second is Ohana Health Plan, a subsidiary of Well Care Health Plans. They are now beginning to implement this health care program for the elderly and disabled. In meetings with the MedQuest division it was found that at least one of the providers is planning to implement a consumer choice option as part of their services. A plan developed in other states to administer this program to

Medicaid recipients is already in place. In a conversation with the DHS Director it was suggested that it could be possible to expand this program, with additional funding, to non-Medicaid eligible disabled and elderly clients. Family members would be eligible to be care providers under this service. Additional administrative costs to do this might be minimal and again it would resolve the issue of management of fiscal services and employer based issues (if DHS is the employer). It would also be the only way for the program to begin statewide.

Target Population for Demonstration and Program Eligibility Guidelines

The target population for the demonstration would be those adults over the age of 18 who have unmet personal care needs and are without the income to meet those needs on their own due to age, a mental impairment, or physical limitation. A recent article (LaPlante, Kaye and Harrington, 2007) on assessing the cost of care under the Medicaid Waiver program suggested that despite including adults with disabilities in the eligible population for a program such as Cash and Counseling, far fewer people may access the program than originally thought. The cost calculations were based on: (1) Requiring assistance with two or more ADL's, or (2) Having a mental impairment; (3) Having an income no more than 300% of SSI guidelines; and (4) Meeting the asset limits of Medicaid ($2,000). It was also suggested that approximately 55% of the people eligible for the benefit would apply and actually utilize it, the rest relying on unpaid informal care to meet their needs.

Using these guidelines it was found that an estimated one million people would be eligible for the benefit translating into three in every 1,000 people. In Hawai`i, given the lack of restrictive income eligibility, this would translate into a minimum of 3,780 to a maximum of 17,180 individuals, some of whom would already be receiving services from

the existing Medicaid Waiver and Kupuna Care Programs. However, it is suggested that these more restrictive guidelines would be an appropriate way to estimate only minimum enrollment as well as the most conservative estimate for future program costs (see below).

Eligibility

Eligibility for the program should be determined by four criteria: (1) Requiring assistance with two or more ADL's (note: not IADL's), or (2) Having a cognitive impairment; (3) Not being Medicaid eligible but being uninsured or underinsured; and (4) Not eligible for similar benefits under Medicare (including the disability benefit), the Veteran's Administration or other similar programs.

Many states have established additional or alternative criteria for their personal care benefit programs. The most common among these is a recognition that those living alone, especially those living alone in poverty, are at the greatest risk of institutionalization and should be prioritized. Additionally, the "one hour" rule (e.g. caregivers who report that the care recipient cannot be left alone for more than one hour) is often suggested as a good proxy measure for identifying those in greatest need of care.

However it is suggested that a self-report mechanism be used for establishing eligibility. Given the time and expense of establishing program eligibility, many recent programs designed to serve those slightly over the poverty level (programs as diverse as the Title IV-E Child Welfare Programs and the Breast and Cervical Cancer Control project) have shown that the expense of eligibility checking far outweighs the savings that might conceivably occur from uncovering fraud. In nationwide Cash and Counseling demonstrations it was also cited as one of the major reasons for delayed program participation.

Service Provision

It is planned that all available services that are considered as necessary to maintain independence should be included under the benefit. Generally, it has been recognized that personal care services (assistance with ADL's) provided in the home are perhaps the most essential service for maintaining independence (utilized by up to70% of those in the demonstrations nationwide). However for the purpose of guiding the development of the program in Hawai`i it is useful to refer to the results of the services utilized or mentioned as needed by caregiver and older adults. These are ranked in the following two tables:

Services Utilized Caregiver Needs Assessment Fall 2007	
Nursing services	25.2%
Training services	24.6%
Case management	22.0%
Transportation	19.8%
Legal services	19.1%
End of life care (hospice)	18.9%
Meals on Wheels	16.0%
Health maintenance services	14.7%
Companion services	13.1%
Bathing/personal care services	13.9%
Adult day health service	12.0%
Light housekeeping	8.8%
Heavy cleaning/yardwork	7.2%
Mental health services	7.0%
Financial services	5.6%
Other types of assistance that would be helpful (N=141)	
Better Medical	3.5%
Respite care	3.5%
Handivan/Wheelchair transport	2.2%
Companion Services	1.8%
Housecleaning	1.8%
Adult or Senior Day Care	1.8%
Transportation	1.3%
Nurses	1.0%
Other (more affordable services, general community services, lower taxes and financial assistance, etc)	7.5%

Older Adults Survey Fall 2007 Service Utilization	
Legal services	15.6%
Transportation	14.4%
End of life care (hospice)	13.0%
Nursing services	12.0%
Health maintenance services	9.7%
Meals on wheels	9.5 %
Light housekeeping	9.0%
Bathing/personal care services	7.0 %
Companion services	6.8%
Financial services	6.3%
Heavy cleaning/yardwork	4.6%
Case management	4.0%
Counseling services	3.1%
Adult day health service	3.0%
Training services	2.3%
Other types of assistance that would be helpful (N=20)	
Better Medical	2.9%
Educational services	1.9%
Affordable Services	1.4%
Physical Therapy	1.4%
Exercise	0.9%
Wheelchair transportation	0.5%

It is notable that a much wider variety of services is suggested in this list. In addition, as noted previously, the needs of adults with disabilities would most certainly include many services not on the list such as employment assistance, education and training funds, perhaps job training assistance, adaptive medical equipment and home modification and perhaps even rental subsidies or housing assistance. Some states have chosen to restrict access to certain services – especially expensive services such as escorted transportation and home modification – under the Medicaid Waiver benefit. However in a consumer directed model such as Cash and Counseling it is considered undesirable to restrict the benefit based on the types of services. In addition to services, some consumers have chosen to purchase supplies and that also seems desirable. In

Hawai`i given the wide variety of needs people have and because those needs do not seem to coincide with national rankings, we would concur with this finding. Instead many states have chosen to limit the amount of the monthly benefit, which under a consumer directed model, seems ultimately the most rational way of doing it (see below). The national evaluation of Cash and Counseling conducted by Boston College under the auspices of the Robert Wood Johnson Foundation Programs suggested a list of goods and services that could be purchased by consumers under the benefit:

Proposed List of Allowed Services Under the Cash and Counseling Benefit
Nursing assistant services (wound care, bladder and bowel care)
Transportation (accessible and escort)
End of life care (hospice)
Skilled nursing services
Respite care (in home)
Overnight and weekend respite care (in home)
Meals on Wheels
Light housekeeping
Bathing/personal care services
Companion services
Handyman or home repair services
Shopping and meal preparation
Counseling or mental health services
Adult day health service or out of home respite
Job Training/Vocational Rehab
Purchase of wheelchair or other accessible equipment
Purchase of medical or home care supplies
Minor home modification (installation of ramps and grab bars)
Therapeutic recreational services
Rehabilitation services (PT, OT, ST)

The other half of the benefit, however, is the “counseling” and fiscal services portions of cash and counseling and it is the role of the counselor to assist the individual and, where appropriate, the caregiver in the purchase of monthly services and to reconcile this to their needs and the amount of the monthly benefit.

Counseling and Fiscal Services

There is a current discussion on the necessity of separating the responsibilities of fiscal control from those of counseling or service provision. While most states have done this in order to avoid potential conflict of interest situations (both establishing eligibility for services and providing the services themselves), New Jersey recently implemented a model in which both of these functions were housed in the same department and found that the increased level of communication meant an increased level of flexibility for clients. New Jersey pointed out that there is an existing and natural overlap between these two functions, in that a counselor already discusses with a client the monthly budgeted amounts that he/she will require to implement the service plan. North Carolina also uses one agency for both purposes due to its experience. Other states have divided the responsibilities. However it still needs to be seen whether it is the right decision for the agency supplying the counselor to also be authorizing and tracking expenditures due to possible conflict of interests. A recent report on the second generation of Cash and Counseling programs reports that as of 2006 only one state used one contractor to provide both services (Kaiser Family Foundation, 2007).

Counselor's Role

The role of the counselor under the Cash and Counseling program is to assist the consumer in writing a care plan (or a plan to manage their care). The focus of this plan is to most effectively use the monthly allowance and to match it to the unmet needs of the care recipient as prioritized by them. As the monthly benefit is flexible, the counselors in most Cash and Counseling programs meet with the care consumer no more than once a month or as little as once a quarter to evaluate the plan and adjust it accordingly. They can also monitor the quality of care received, since the vast majority of the consumers will

likely take advantage of the program option to hire relatives to provide care. The term “counseling” under this benefit refers only to assistance and advice to participants about making and implementing a plan to spend the monthly budget, not mental health services. When the demonstration states began training counselors, they recruited primarily individuals with social services backgrounds (not necessarily MSWs). Counselors in Arkansas and New Jersey did not come from the ranks of traditional "case managers" whereas Florida only permitted current HCBS waiver program case managers to become "counselors”. The original demonstration sites used focus groups of counselors, evaluation surveys of participants and counselors, and process evaluation interviews with state officials to determine how much counseling should be required for purposes of oversight; how much they should pay counselors to ensure that they provide enough, but not too much, assistance, and what types of counselor assistance self-directing program participants and families need or find most useful. Arkansas now requires less counseling, whereas Florida revised counselor training to try to ensure counselors would provide enough. New Jersey determined that counseling would be improved if counselors worked for the same organization that provided the fiscal/employer agent services, something that other states have not necessarily endorsed.

Fiscal Roles and Responsibilities

Fiscal services include serving as consumers' agents for purposes of filing payroll taxes and check writing as well as the overall fiscal management and tracking (Flanagan 1994). Essentially, there are two levels to this service. One is at the level of the authorized representative (if the consumer needs one). This individual, who may serve as representative payee for an individual’s social security or SSI checks, may be legally responsible for the consumer by benefit of family relationship, may have durable power of

attorney, or be a legal guardian or conservator. One protection against fraud is that this individual cannot also be the paid service provider. The authorized representative in some states also had the option to handle paperwork that accompanies the consumer becoming an employer. If this option was chosen it would mean reporting on expenditures and social security information quarterly as well as keeping records of how they spent the allowance each month. The authorized representative also works closely with the counselor. If any planned purchases seem questionable, the counselor would inform the participant that decision by state officials was needed.

In some programs, employer responsibilities are handled at the state level. Most who offer this “support service” as it is termed deduct a (small) percentage from the monthly allowance for management of employer’s responsibilities. For example, South Carolina subtracted $15/month. In some states nearly all consumers use this option (i.e. Wisconsin) and in other states (i.e. Oregon) virtually none of them do.

At the program administrative level another set of fiscal tasks must take place including reviewing program participants' purchasing plans to assure that all intended purchases of goods and services are within state guidelines as well managing the overall program budget so that the goal of a budget neutral intervention is maintained (more is not spent on the treatment group than the control group). The success of the program is based on the fiscal principle of flexibility of fund distribution to meet individual needs and preferences, while preserving necessary accountability to the state and federal governments. If a private individual is not handling payroll reporting, the fiscal/employer agent’s role is then also to manage the payroll tasks for the participant’s employees and to make non-labor related payments for goods and services that have been authorized in the participant’s budget. The fiscal agent’s job is also to generate worker’s payroll checks and

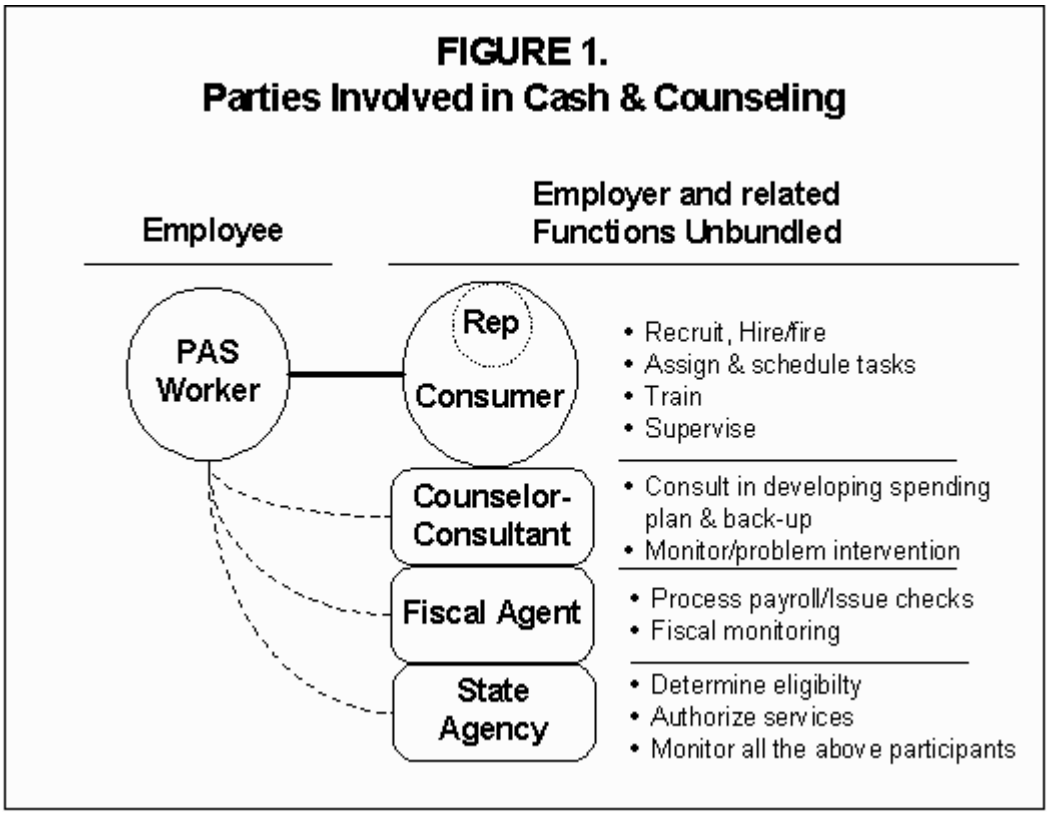
non-labor related invoices in compliance with all federal and state regulations pertaining to domestic/household employees and independent contractors. This contractor would also be responsible for documenting and reporting on all disbursements to the state and participants.

An additional aspect of both levels of fiscal functions is oversight, since for many consumers this is the first time they will become an employer, an essential component of the Cash and Counseling intervention. Original evaluation findings have indicated that consumers said the ability to employ their choice of home care workers was one of the demonstration's most attractive features. Typically, focus group participants and survey respondents were confident they could hire, fire, and supervise their workers and make good decisions about other goods and services that would meet their needs for personal care; however, the rest of the tax reporting procedures were unfamiliar to them. In most states the decision was made to assure prospective participants that counselors would be available to help them with paperwork and track their spending, and that fiscal-service providers would handle their responsibilities as employers by filing tax documents and withholding taxes if they chose to hire workers.

This seems an appropriate choice for Hawai`i. Either a private non profit agency (such as CSI) or possibly the Office of the Public Guardian could expand current service capacity to include these functions. However it may be best to go out for bid for these services. In that case, applicants should be considered that can demonstrate a track record as fiscal agents, a commitment to the principles of consumer direction/self-determination, and experience with Federal Insurance Contribution Act (FICA), Federal Unemployment Tax (FUTA), and State Unemployment Tax (SUTA) taxes in accordance with federal Internal Revenue Service (IRS), Department of Labor (DOL), and State of

Hawai`i Department of Labor rules and regulations. Alternatively, it could be equally feasible for the administrative and service provision functions be housed together in the Executive Office on Aging under the auspices of the Kupuna Care program as in the New Jersey model. The one function that we do recommend being housed in the EOA Director's Office is that of quality assurance and program audits so that there is outside oversight taking place.

The following figure shows how the fiscal agent functions are related.



Monthly Benefit

There are two methods of distributing the monthly benefit once the care plan and the hours and types of services required have been established. One is a direct cash benefit. The only state still using this method is Oregon (Note: Oregon is the only state which has reached its “cap”; in other states the program tends to be underutilized). The disadvantage of this is again the fiscal tracking and accountability that would be required. Under this method, consumers would be allowed to receive their allowance in cash each month from the fiscal-services provider if they agreed to be trained and tested on fiscal responsibilities and submit to a periodic audit (including retaining receipts for all purchases with the allowance). Pay stubs for workers, receipts for goods purchased and any other services or items purchased (or perhaps leased or used) by the consumer would have to be accounted for at the end of each month. In addition, if inappropriate purchases were made (such as using an authorized representative as a paid worker) a payback mechanism would have to be developed. Many sites found this to be cumbersome so in lieu of a direct cash payment, the program could provide participants with a prospectively paid monthly budget that would be managed by a fiscal-services provider at the direction of the beneficiary or a designated representative. This method is now used by all states with the exception of Oregon. Under this method, beneficiaries receive a cash advance each month of up to 10 or 20 percent of the monthly allowance for incidental purchases (e.g. taxi fare) that could not readily be invoiced in advance. Consumers would pay for the bulk of their expenses by submitting invoices (or timesheets for workers' wages) to the fiscal services provider, which would write the checks. They then had all of their eligible expenses paid for directly by the fiscal agent. It is this method which has been proven to be the least cumbersome to implement.

The monthly benefit provided to care recipients varied from state to state ($350 in Arkansas to $1200 in New Jersey). The Arkansas demonstration noted that, on average, people received 47 hours of care per month. In Hawaii, caregivers and older adults both estimated that they had 7-9 hours per week of unmet care needs (or under 40 hours a month); thus this would appear to be an adequate intervention to meet those needs. However, the cost of care in Hawai`i is much higher than Arkansas so a comparable benefit amount might be better suggested by the Florida demonstration where $900 a month was the monthly benefit amount. This roughly agrees with the annual care costs suggested by the Medicaid personal care benefit studies which suggested that it cost just under $11,000 annually to meet the unmet needs of Medicaid eligible consumers nationally (La Plante, M. Kaye, HS and Harrington, 2007). Again it is possible for the benefit to be lower or to be flexibly utilized so that some months might be higher and others lower.

However, the demonstration in Hawaii will not involve Medicaid eligible consumers and the cost to the state will thus not be offset by lowered Medicaid costs. It simply becomes additional money spent and will not be, as other states have found, a 'budget neutral' intervention here in Hawai`i. However if the monthly allowance is limited and a potential 'Medicaid spenddown' population is targeted for this intervention, it is conceivable that there will be long term savings to the State of Hawai`i Medicaid expenditures. Thus we are suggesting that the benefit be limited to $750/mo (see reasoning below) and that low to moderate income consumers be targeted for the initial test of the intervention.

Advisory Group Stakeholders Input Process

All states in the Robert Wood Johnson Demonstration were required to establish a statewide (or at least pilot site) stakeholder advisory group that became involved in the set-

up and monitoring of the Cash and Counseling project(s) in their state. At a minimum stakeholders should come from any one of three possible groups: (1) potential consumers and their caregivers; (2) agencies representing the elderly and individuals with disabilities from the community; and (3) service providers. In Hawai`i initially the advisory committee membership should be established by the Executive Office on Aging with input from community groups. In addition to the obvious advantage of receiving input regarding realistic and effective implementation of the programs, the advisory committee should also be able to assist with the following tasks:

For consumers to provide input regarding:

1. Their preference as to the way in which the cash benefit is administered.
2. Their preference as to the amount of the benefit needed.
3. Their assessment about reimbursement for family (especially spousal) caregivers.
4. Training for caregivers.
5. Needed services that do not currently exist in Hawai`i

For agencies to provide:

1. Advice on program oversight.
2. Assistance with targeting of pilot project(s).
3. Advice on program initiation and publicity.
4. Assistance in reviewing proposal for program's fiscal agency.
5. Enrollment assistance.

For service providers to assist with:

1. Establishing program utilization guidelines.
2. Establishing the interface between their programs and the new one.

3. Creating a two-way referral network.
4. Establishing a pool of personal assistance providers

Enrollment and Recruitment

In spite of the fact that the benefit is perceived as positive and welcomed by the community and consumers, many sites have had a problem with initial under-enrollment of consumers. This increased the cost per client and caused many demonstrations not to be cost effective; high administrative costs serving only a small number of consumers resulted in higher per person costs than for Medicaid programs where consumers were already enrolled. There have been different solutions suggested to deal with this problem; one of the more successful was in Minnesota.

Minnesota contracted out for enrollment assistance locating lead agencies to have "kick-off" meetings for the beginning of the enrollment period in a targeted site. The contractor there worked collaboratively with local lead agencies and other involved parties to simplify and expedite the enrollment process for potential consumers. These regional meetings provided an opportunity for local organizations to meet the contractor, learn more about the enrollment assistance services, and participate in this collaborative effort. Centers for Independent Living were a focal point for this activity in Minnesota. In Hawai`i it is likely that there will be another lead agency involved. The contractors who did this work had enrollment goals for their region and offered regional educational sessions on how to navigate through the enrollment process. Before doing this a referral network was already in place so that as clients enrolled, they could be immediately referred to the appropriate counselor (case manager). The contractors were also to provide technical assistance to any and all parties involved including the consumer, family caregivers, and agencies serving as access points with the overall object being to educate consumers

about the option and help them discover how Cash and Counseling can work for them personally.

In Hawai`i, the best lead agency for assisting with enrollment would be the newly established Aging and Disability Resource Centers (ADRC). In other states, ADRC offices or pilot sites have also been used as sites to enroll in Cash and Counseling programs. This seems like a reasonable approach as it is part of the mission of the ADRCs to make consumers aware of services for which they might be eligible to assist them to remain in the community. They are also mandated to serve elders and people with physical disabilities (the same target population as exists for Cash and Counseling) and are not limited to serving only those who are Medicaid eligible. It is also part of their mission to advertise and assist older consumers in getting the assistance they need through streamlining the existing eligibility processes as well as to provide a service called 'options counseling'. This last service is particularly suited to the Cash and Counseling enrollment effort since it is well within the purview of this project to provide consumers with all available options that can be purchased under their benefit.

Evaluation

The evaluation plan developed for the pilot project will be based on the designs developed by other states. A quasi experimental design will be utilized (as there is no random assignment) to determine whether or not consumers and their caregivers in the treatment group have better outcomes than those in the comparison group. This design is similar to the one used by Benjamin et al. (2000) in evaluating California's In-Home Supportive Services program to examine the effects of consumer direction. The project will be evaluated on a regular basis using multiple measurements to ensure consumer and worker satisfaction. Assessing the quality of supportive services involves both objective

and subjective measures (Kunkel et al., 2002; Benjamin, 2001; and Kane et al., 1994) therefore the evaluation will not only measure satisfaction and personal experience, but will also measure system performances and client outcomes. We will also use outcome measures such as sense of security and reduction of consumer expressed unmet needs will be used with activities of daily living, quality of care, ability to pursue desired activities, general satisfaction, and providers' interpersonal manner, consumer health status self care, and health related quality of life to assess program effects.

We will also measure the performance of the personal care workers, using a scale that assesses the degree to which they completed their assigned tasks, times they arrived late, left early or did not come at all, satisfaction with the schedule and scheduling flexibility. We will also assess the quality of the relationship between the consumer and the paid caregiver assessing the consumers' degree of satisfaction with the relationship, whether they felt neglected or not, whether the care provider was rude or disrespectful, whether the paid caregiver had ever removed something from the household, and whether or not they provided unwanted assistance with certain tasks. If a caregiver is available, we will measure the caregiver's level of burden and depression to determine if these were lessened by the intervention.

Examples of some of the areas to be evaluated and outcomes to be assessed are included in two attached documents. First, the Summary of Nine Quality Initiatives developed by the Centers for Medicare and Medicaid Services is attached. Most of the measures suggested are process measures and the evaluation consists merely of being able to find evidence that these events occurred. These include items such as:

- It is possible to obtain services easily and quickly under the demonstration,
- Information provided is timely and correct,

- Personal goals of the consumer are met (including personal health outcomes),
- Access to services is continuous (unbroken), and
- Providers possess the required skills to maintain high quality services.

This guide also suggests that the intervention also obtain assessments of the providers, cultural competency and an assessment for continuous, ongoing data collection. Financial integrity of the intervention should be assessed as well as risk and safety planning, critical incident management and the safety of the home environment. There should be evidence that appropriate behavior and physical restraints are only used as a last effort and appropriate behavioral interventions are used instead (especially in the case of those with cognitive impairments who may be unable to communicate themselves). Finally there should be evidence that participant's rights and choices were respected through the process of the intervention (See Appendix A for full grid).

The second document attached is from the Mathematica evaluation and covers outcomes such as baseline measures for both client and the caregiver on hours of help received prior to the demonstration vs. post demonstration and their satisfaction with these services, whether or not there are ongoing unmet needs, a list of adverse events (including falls, burns and other accidents), general health status, self care knowledge and behavior, ADL functioning levels and health related quality of life. Among the additional health outcomes there are also measures of falls, contractures, bedsores and urinary tract infections, measures that would generally only apply to the very ill.

Finally as noted previously, there is no method by which cost savings can accrue under this program; however comparative program costs are possible to obtain. It has been suggested that switching from an agency based model of service delivery to using

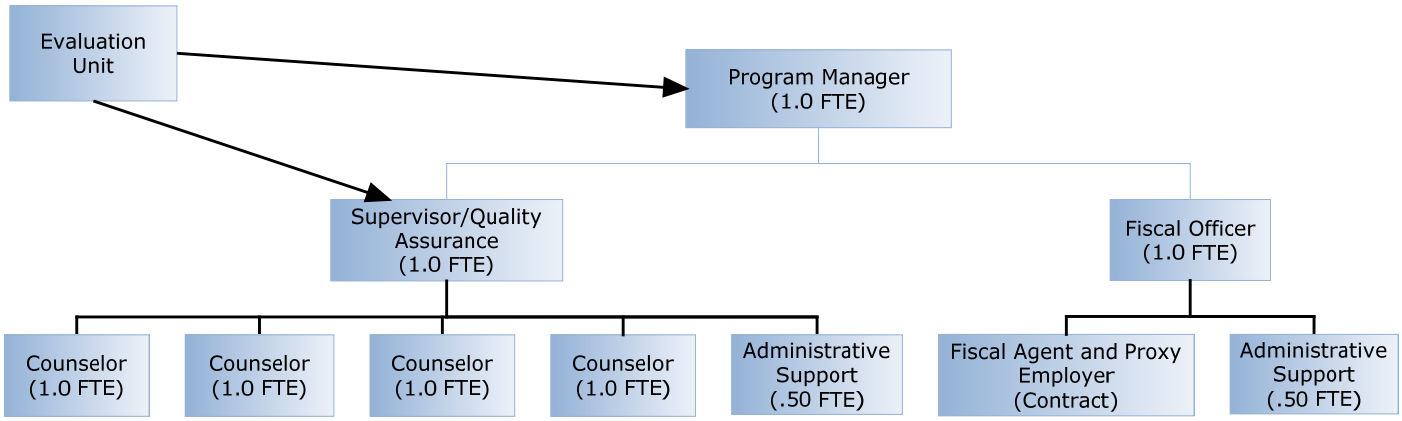
family members to provide substantial amounts of personal care may well reduce program costs; this would be relatively easy to measure.

In addition, cost effectiveness (as measured by amount per month by services received and then compared to program outcomes) is possible to measure. The theory behind such an evaluation is that appropriate use of community based health and social services should offset the costs of more expensive hospital and nursing home care. Thus we would also measure the costs of hospital admissions (especially through emergency rooms) and stays in skilled nursing facilities and the costs associated with them and compare these costs between treatment and comparison groups. It also would be an excellent idea to establish baseline measures as the current number of Medicaid beds in skilled nursing facilities in Hawai`i in order to assess the eventual possibility of a reduced cost for the state engendered by the much lower costs of paying caregiver to meet unmet needs in the community than the entire cost of 24 hour care in a skilled nursing facility.

Proposed Staffing Pattern for the Project

The figure below shows the proposed staffing pattern for the project as eventually implemented for the entire state. One program manager overseeing a supervisor responsible for quality assurance who in turn has oversight over an estimated 4 full time counselors and administrative support are on one side of the organization chart. On the other side is an in-house fiscal office overseeing the fiscal agent and employer proxy functions which we are recommending be fulfilled by a contract agency. Both halves of the project would have an administrative support individual and the evaluation contractor would be an autonomous unit. However for the purposes of the demonstration a reduced model is proposed with only one counselor and additional fiscal oversight responsibilities

assigned to the program manager. Additionally in the demonstration year(s) an enrollment contract is added to facilitate outreach and information about this new project.



Budget for Demonstration

The annual budget for the demonstration portion of the project is projected below. Annual costs are largely accounted for by the monthly benefit, however there are significant overhead costs in the first two years prior to full implementation. Certain tasks will be implemented by individuals; others (i.e. evaluation, enrollment and fiscal services) will go out for contract. At the end of the planning year, RFP's will be issued through the Executive Office on Aging for fiscal services and evaluation. Responses to the RFP will be evaluated by the program manager for a history of similar service provision as well as cost effectiveness.

It should be noted that these costs are approximations only and would vary based on a number of factors.

Budget Item and Description	% Time	Annual Cost Yr 1 2008-2009	Annual Cost Yr 2 2009-2010	Annual Cost Yr 3 2010-2011
UH Planning Grant ~ To develop plan for implementation, set up advisory board, issue RFP for fiscal and service provision functions, establish interagency coordination, develop funding strategy, grant writing. ~ Evaluation (2nd and 3rd yr only).	(Contract)	$100,000	 $20,000	 $35,000
Demonstration Staff ~ Project Director – responsible for program implementation staffing, contract and budget oversight, quality assurance. ~ Counselors (3-4) – manages caseload, establishes program eligibility, develops and monitors care plan, ~ Fiscal agent/proxy employer - responsible for payroll deductions, employer tax reporting requirements. ~ Participant outreach and enrollment by ADRC's. ~ Administrative Support.	 100% 100% (Contract) (Contract) 100%		 $90,000 $180,000 $100,000 $40,000 $45,000	 $90,000 $180,000 $100,000 $20,000 $45,000
Total Program development, administrative, and support costs.		$100,000	$475,000	$470,000
Flexible monthly allowance @ $750/mo x 12 mo's x 200 people (1/2 enrolled in yr 2 ;1/2 enrolled in year 3).			$900,000	$900,000
Total By Year		Year 1 $100,000	Year 2 $1,375,000	Year 3 $1,550,000

Although grant funding is possible to offset some of the program costs and will be applied for, the actual cost of providing the allowance will need to be funded by the State. It was felt that the originally suggested amount of $500/mo. was probably too low to see any effect from the demonstration. Only the State of Arkansas offered a lower benefit. This estimate for Hawai`i was originally based on the average level of unmet need being approximately 8 hours per week or 32 hours a month. It is estimated that the cost of care will range from a low of $10/hr (personal care assistance) to $20 hr (for escort services/ transportation, home modification, etc). An average of $15/hr was used to estimate an average monthly cost of $ 480 per month. An additional $20/mo was added to include the need for supplies (incontinence supplies, grab bars, etc). However, after receiving community input on the hourly costs of care in the state for personal care services and supplies, it was felt by most providers that $500/month would be insufficient to meet needs and cover employer related costs, therefore, the monthly benefit was changed to $750. Similarly the number of individuals (250) receiving the allowance was reduced to 200, the statistical minimum for the ability to evaluate a program effect. With 200 people in a treatment group and 200 in a control group, this will provide 85% power to detect a medium effect (d_c=.30) from the intervention. Increasing the amount of the benefit however will also hopefully increase the effect size.

Issues to be Considered

The remaining issues to be considered as the plan is developed are many. First, there will need to be 'buy in' from the aging and disability communities for the work to even begin. This original caveat has turned out to be true. To some extent this is a reflection of current workloads and the efforts to implement the ADRC intervention. But some were at least initially uncomfortable philosophically with the demonstration and worried about

substituting paid for unpaid care, especially for spouses. As mentioned previously, the aging and disability communities also have differing needs and it is likely that the disability community may prioritize completely differing service needs from the elderly community. Needs may be different but so far this has not been an issue. If anything the DD providers in particular understand and wish to implement the consumer directed option. As noted previously, service providers, care homes for the elderly and skilled nursing facilities may be, at least initially, unwilling to participate, seeing this project as a threat to the supply of "private pay" consumers. Staff, both fiscal and counseling, will need to be hired and trained. Final decisions will have to be made about where to house both of these functions. Funding will need to be obtained. Additional smaller issues that will need to be resolved include an undersupply of personal care workers, underpayment of these same workers, health and safety issues for both consumer and workers, monitoring the quality of service, and fraud and abuse issues. There are also no models to follow in implementing a Non-Medicaid program and addressing the special issues that are certain to occur in Hawai`i. We will be using the planning year and the demonstration project itself to resolve these issues prior to the implementation of the statewide project if that is determined to be the direction that is taken by the State.

Timeline

A possible timeline for the planning year and the proposed demonstration project is displayed below.

Activity	Planning Year	Year 1 Demonstration				Year 2 Demonstration			
	Thru 6/30/09	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Convene and hold meetings with the Stakeholder Group									
Initial planning - research other states, participate teleconferences									
Finalize project policies, tracking and assessment procedures									
Complete planning process; present report to Legislature									
Develop training materials									
Establish MIS needs									
Secure Project Director and finalize areas of responsibility									
Train staff, C&C counselors, fiscal intermediaries									
Outreach to consumers/project publicity									
Interagency coordination for referrals									
Select outcome measures									
Enrollment of consumers									
Begin quality assurance monitoring									
Collect/review and analyze data									
Assess project impact									
Prepare and submit project evaluation									

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Appendix 1

Fiscal/Employer Agent (F/EA) Responsibilities

Customer Service. The F/EA must be able to communicate effectively with participants who have a wide variety of disabilities. The F/EA must have a Customer Service System that includes:

A. A toll-free number, or reasonable accommodation in place
B. TTY line
C. Internet/e-mail communication
D. Availability of foreign language and American Sign Language interpretation if requested
E. The capability to make materials available in alternative formats needed by participants such as, but not limited to, large print
F. For the services that it provides, develop a method for receiving, responding to and tracking complaints from participants and participant's employees within 48 hours

Information and Orientation for New Participants. The F/EA must provide new participants and participant's employees with standard information and an orientation to F/EA services that includes, but is not limited to:

A. F/EA services brochure
B. A participant enrollment packet which includes, but is not limited to:
    1. Introductory letter;
    2. A description of F/EA services, hours of business and key contact information;
    3. Participant contact information including emergency contact information;
    4. Semi-completed IRS Form SS-4, Application for Employment Identification Number, for signature;
    5. Semi-completed IRS Form 8821, Tax Information Authorization Form, to obtain tax information on behalf of participants;
    6. Semi-completed IRS Form 2678, Appointment of Agent, for signature;
    7. Semi-completed state tax and unemployment insurance registration form:
    8. Semi-completed State Unemployment Insurance Form granting F/EA authority to act as an employer agent of the participant (if required);
    9. Semi-completed state New Hires Form;
    10. An agreement to be signed by the participant that lists the rights, roles and responsibilities of the participant, representative or guardian, participant's employee, F/EA and state program agency; states that the participant understands each party's role and responsibilities, and states that the participant agrees to abide by the policies and procedures of the F/EA and the state program agency
    11. An Authorized Representative Designation Form signed by the participant's representative that lists the role and responsibilities of the representative related to the participant and the F/EA and any limitations, states that the person agrees to be the participant's representative and

will abide by the policies and procedures of the F/EA and state program agency

12. An agreement to be signed by the participant and the participant's employee stating that the participant is the employee's employer, the employee has the necessary knowledge, skills and experience to meet the participant's support service needs and has received orientation and training sufficient to meet the participant's needs
13. An agreement to be signed by the participant's back-up employee that lists the back-up worker's role and responsibilities, times available and any limitations, and states that the person agrees to be the participant's back-up employee
14. Instructions for the completion of all forms

C. An employee employment packet which includes, but is not limited to:

1. Introductory letter;
2. An employment application;
3. Bureau of Citizenship and Immigration Services (BCIS) Form I-9, Verification of Citizenship and Alien Status;
4. IRS Form W-4, Employee's Withholding Allowance Certificate with instructions and completed example;
5. IRS Form W-5, Earned Income Credit Advance Payment Certificate with instructions;
6. A confidentiality policy;
7. Grievance procedure for disputes between participants and their employees
8. Payroll schedule indicating the days when worker timesheets are due at the F/EA and the days when the F/EA will issue employees' paychecks;
9. Payroll time sheet with instructions;
10. Instructions for the completion of all forms;
11. An agreement to be signed by the employee that lists the role and responsibilities of the participant, employee, F/EA and state program agency; states that the employee understands the roles and program's responsibilities; and understands and agrees to abide by the F/EA's and state policies and procedures
12. A release form to conduct a statewide Criminal Background Check; and
13. A release form to conduct Department of Health Abuse Registry screening.

Payroll Services

The F/EA acts as a fiscal agent for each participant in accordance with Section 3504 of the IRS code and IRS Revenue Procedure 70-6. The F/EA must:

A. Obtain IRS and state approval to be an Employer Agent;
B. Obtain authorization from the state unemployment insurance agency for the limited purpose of managing unemployment taxes for each participant;
C. Prepare and file IRS Form SS-4, Application for Employer Identification Number, and obtain separate FEIN for thesole purpose of filing IRS forms 941, Employer's Quarterly Federal Tax Return, W-2, Wage and Tax Statement, and W-3, Transmittal of Wage and Tax Statement, as an Employer Agent;
D. Prepare and file IRS Form SS-4, Application for Employer Identification Number (FEIN), and obtain an FEIN for each participant;
E. Assist participants in verifying employees' citizenship/legal alien status by verifying social security number with the Social Security Administration and completing the Bureau of Citizenship and Immigration Services (BCIS) Form I-9;
F. Ensure that wages paid to employees are in compliance with federal and state labor laws;
G. Compute, withhold, file and deposit federal Medicare and Social Security (FICA) and federal income tax as required by law. In carrying out this function, the F/EA must:

    1. Use IRS Form 941 or its successor forms;
    2. File quarterly in the aggregate for all participants represented using the employer agent's separate FEIN; and
    3. Deposit FICA and federal income tax withholding in accordance with IRS depositing rules.

H. It is recommended that the F/EA withhold, file and deposit federal and state income taxes for workers even when federal and state tax rules make this optional for domestic service workers.
I. Refund over-collected FICA withholding to employees and employers (or state) when employees do not earn the FICA wage threshold for a particular calendar year;
J. Compute, withhold, file and deposit federal unemployment taxes (FUTA) individually for each participant annually using the participant's FEIN to match state unemployment tax (SUTA) filing process. The F/EA must:
    a. Use IRS Form 940, 940 EZ or successor forms;
    b. File annual IRS IRS Form 940, 940 EZ or successor form for each participant the F/EA represents; and
    c. Deposit FUTA in accordance with IRS rules.
K. Refund over-collected FUTA withholding to employers (or state) when employer's employees in the aggregate do not earn the FUTA wage threshold for a particular calendar quarter in the current or previous calendar year, as necessary;
L. Manage Federal Advance Earned Income Credit;
M. Compute, withhold, file and deposit state income taxes individually;
N. Compute, withhold, file and deposit state unemployment insurance taxes (SUTA) individually and refund over-collected SUTA to employers or State as necessary;
O. Apply judgments, garnishments and levies to workers' paychecks, as applicable;
P. Prepare and file IRS Form W-2, Wage and Tax Statement in accordance with current IRS instructions for agents;
Q. Prepare and file IRS Form W-3, Transmittal of Wage and Tax Statements, annually in the aggregate in accordance with current IRS instructions for agents;

R. Retire a participant's IRS Form 2678 and IRS Form 8821 when the participant is no longer an employer represented by the F/EA;
S. Retire a participant's FEIN and state tax registration number(s), and terminate federal and state tax filings when the participant is no longer an employer;
T. Carry out any other payroll and tax function necessary to ensure compliance with federal and state laws and program rules (i.e. RI Temporary Disability Insurance);
U. Process payroll from timesheets signed and submitted by employees and participants and ensure payment within two weeks of the end of each payroll period, with payroll issued at least every two weeks;
V. Provide participants and employees with timesheet forms and pre-addressed, pre-stamped envelopes for signature and submission; and
W. Provide the option of Direct Deposit for participants employees, if requested.

Workers' Compensation Insurance Coverage. The F/EA must inform participants about their obligations for compensating employees in the event of a work injury and the need for mandatory Workers Compensation Insurance Coverage. In carrying out this provision, the F/EA must:

A. Explain coverage available through individual standard workers' compensation insurance policies and home owners' or tenants' insurance policies; and
B. Broker worker's compensation insurance coverage in some form on behalf of participants and assure payment of worker's compensation insurance premiums. The F/EA must attempt to negotiate volume discounts with insurers to make individual policies as affordable as possible to participants.

Invoices. The F/EA must process and pay authorized invoices within 2 weeks of the F/EA's receipt of the invoice; and

Criminal Background Checks. The F/EA must ensure that Cash and counseling program rules regarding criminal background checks for employees and representatives are met. The F/EA must conduct Hawaii criminal background checks for all participants paid caregivers as well as any appointed participant Representatives.

Management of Participant's Budget Funds The F/EA ensures the following in regards to managing participant's budget funds:

A. Funds must be kept in a non-interest bearing account separate from all other bank accounts managed by the agency.
B. F/EA must enter into a Memorandum of Understanding (MOU) with deposit bank regarding ownership of program funds and provide the Department with copies of said MOU.
C. F/EA must provide a monthly budget statement to participants detailing budget funds expended, budget funds remaining and other information needed to assist the participant in managing their own budget, in an agreed upon format.

D. F/EA must develop (in conjunction with DHS) a method to obtain from the Department the participants monthly Cost of Care (if applicable), and to ensure that the participant's monthly Cost of Care is collected and documented.
E. F/EA must have a system to receive, process and pay all non-labor related invoices, including payment to vendors as specified in the participants spending plan and to ensure that all payments correspond to the plan.

Information Technology/Record Keeping. The F/EA must demonstrate the following capabilities:

A. Have a Disaster Recovery Plan in place for restoring software and master files and hardware backup for all computerized records associated with Cash and counseling participants.
B. Have a system in place for the storage of all records and files associated with Cash and counseling participants, their employees and vendors as required by federal and state regulations.
C. The ability to transmit data and information between the F/EA and the Department electronically.

Keeping Up to Date with Federal and State Rules and Regulations regarding F/EA's and Household Employers. The F/EA must demonstrate the system that they utilize to review all IRS and State forms, instructions, notices and publications related to the role of F/EAs in performing their duties, and to update forms and procedures as needed.

Worker Registry: In order for participants in the Cash and counseling to have access to the widest range of potential caregivers, a worker registry will be established. The F/EA should give every paid caregiver who passes initial Criminal Background, Abuse Registry and citizenship screening the option to be listed on that registry and provide to the registry basic identifying information for each caregiver who requests placement on the registry.

Independent Choices
Self-Assessment of Personal Care Needs

Name:_____

PERSONAL CARE NEEDS

Activity	Needs Assistance YES/NO	Weekly Frequency	Will Use Cash Check If Applicable
Bathing			
Showering			
Shampoo			
Hair Care			
Oral Care			
Toileting			
Foot Care			
Shaving			
Skin Care			
Nail Care			
Dressing			
Grooming			

SOURCE
Check If Applicable)
( ) HIRING EMPLOYEE(S)
( ) ASSISTIVE DEVICE
( ) AGENCY SERVICE
( ) HOME MODIFICATION
( ) EQUIPMENT/SUPPLIES
( ) OTHER

NUTRITIONAL NEEDS

Activity	Needs Assistance YES/NO	Weekly Frequency	Will Use Cash Check If Applicable
Meal Preparation			
Meal Serving			
Eating/Feeding			
Clean Up			
Shopping			
Encourage Fluids			

SOURCE
Check If Applicable

( ) HIRING EMPLOYEE(S) ( ) HOME MODIFICATION ( ) OTHER
( ) ASSISTIVE DEVICE ( ) DELIVERY SERVICE
( ) AGENCY SERVICE ( ) PUBLIC TRANSPORTATION

MOBILITY

Activity	Needs Assistance YES/NO	Weekly Frequency	Will Use Cash Check If Applicable
Walking			
Transfers			
Wheeling			
Stair Climbing			
Change Positions			
Assist with Equipment			
ROM			
Transportation For Errands			

SOURCE

Check If Applicable
( ) HIRING EMPLOYEE(S)
( ) ASSISTIVE DEVICE
( ) AGENCY SERVICE
( ) HOME MODIFICATION
( ) OTHER

OTHER RELATED SERVICE/EXPENSES

Activity	Needs Assistance YES/NO	Weekly Frequency	Will Use Cash Check If Applicable
Adult Day Care			
Caregiver Training			
Chore Services			
Cleaning Service			
Laundry Service			
Respite for Adult Caregivers			
Home Modifications			

SOURCE
Check If Applicable
( ) HIRING EMPLOYEE(S) ( ) HOME MODIFICATIONS ( ) PUBLIC TRANSPORTATION
( ) ASSISTIVE DEVICE ( ) EQUIPMENT/SUPPLIES ( ) OTHER
( ) AGENCY SERVICE ( ) DELIVERY SERVICE

Estimated Weekly Time Assistance is Required:_____

OUTCOME: Any ACTIVITY checked must be listed on the Expenditure Plan.

Appendix 3

Independent Choices
Participant Self-Assessment

I. YOU DECIDE WHAT SERVICES AND PURCHASES WILL HELP YOU MEET YOUR PERSONAL CARE NEEDS.

1. What services do you want and need?

2. What purchases will help you?

II. YOU SELECT THE PEOPLE YOU WANT TO HELP YOU OR WHAT THING YOU NEED TO BUY TO HELP YOU LIVE IN THE COMMUNITY.

1. How will you find and select people to help you in your home?

2. How do you shop for the purchases you need to make?

3. How do you plan to train and supervise the people who work in your home?

4. How will you tell your workers what you like or don't like about their work?

5. If you are not happy with the work of the worker you hire, how will you handle the situation?

III. A COUNSELOR CAN HELP YOU LEARN HOW TO FIND YOUR WORKERS, HOW MUCH TO PAY YOUR WORKERS, HOW TO TRAIN YOUR WORKERS AND MANY OTHER THINGS.

1. Are you willing to ask for help if you need it?

_____ Yes

_____ No

IV. FAMILY OR FRIENDS CAN HELP YOU MAKE DECISIONS IF YOU WANT.

1. Do you have someone you want to appoint as your representative decision maker?

_____ Yes

_____ No

Appendix 4

Community Input

From August through October 2008 a series of meetings were held with agencies, providers, and individuals to discuss the draft document *Report on the Feasibility of Providing Consumer Directed services for Non-Medicaid Eligible Older Adults and Persons with Disabilities in the State of Hawai`i*. Meetings were held with the Elderly Affairs Division in Honolulu, the Maui County Office on Aging, the Kauai County Agency on Elderly Affairs, the Aging and Disability Resource Center staff for Hawai'i County, and Board of Directors of the Hawaii Waiver Providers Association (HWPA). The HWPA group included representatives from Easter Seals Hawaii, Goodwill Industries, ARC of Kauai, ARC of Hilo, ARC of Maui County, Catholic Charities Hawaii, SECOH and Full Life. Several meetings were also held with various representatives of the Department of Human Services Adult and Community Care Services Branch. In addition a community advisory board was formed composed of representatives from the aging and disability communities. This group met in September of 2008 and again in November, 2008. The following is a summary of the input from all of these meetings.

Each session was introduced with an agenda that included opportunities for invitees to address: the philosophy underlying the current push for consumer directed care options, level of funding, expected outcomes, staffing patterns, the amount of the monthly benefit, monitoring and quality assurance, budget, the role of the fiscal agent, the design of the demonstration, the best site for the demonstration and any other issues the agencies wished to address. The following is a summary of their comments.

1. Proposed Benefit Amount

In three of the meetings it was felt that the proposed amount of the benefit for recipients ($500 on average per month) seemed minimal; some counties felt that anything less than $2,000/month would not truly be helpful. A typical comment from Maui was "Well, I would say at least twice that, at least a $1,000 a month if you are going to meet people's needs. Or if you are only going to meet their needs half way then maybe $500 would do it but it is really not much money." However Kauai Agency on Elderly Affairs and the ARC of Kauai both felt that it would be sufficient to assist families. One comment from Kauai was, "Well, $500 per month right now under the Kupuna Care Program would purchase about 5 hours of personal care [weekly], that's about the average, some people want 4 hours, some people want 6 hours so that is about right. Now homemaker services, it would be a lot less, so that might make it more flexible." In the meeting with the disability providers, the $500 amount was considered sufficient. In a similar consumer directed program they had administered, the funder (RWJ) authorized funds up to $7,000 a year which would roughly equal the amount of funds to be expended under this benefit.

Other providers assessed the sufficiency of the amount based on the calculation of what agency costs were. One comment from Maui was "Personal Care Home Health Care is about $18/hr for CNAs. We pay $33/hr for personal care. For a regular agency, CNA is about $17.50" but then noted that if you hired privately it would be less: "If you hire privately, it is about $14/hr". Other providers noted that "Personal care ranges from $14-$17/hr, not including bathing; $33/hr includes bathing." And again they noted "If a family member is hired, it may not cost $33/hr." They also felt that $20 for supplies was low. Another issue around the monthly benefit amount was whether or not it needed to be

completely spent each month. A respondent from Maui said "For example you get your money but if you do not want to spend it all now you can save it until the following month."

Other issues and comments about the monthly benefit amount included:

- Would the $500 monthly benefit be considered taxable income?
- Is the amount the same for everyone?
- Would the State take care of taxes and workman's comp?
- Can the money be rolled over and/or saved up?
- How flexible is the monthly amount?
- Should we take a case by case approach to authorization?
- Idea of a spending account makes sense. It is going to be easier to administer.

2. Program Fraud/Misuse of Funds

There were also concerns about possible misuse of funds. Vouchers and direct worker reimbursement were suggested as other possible methods of service delivery. EAD made a suggestion to put in a caregiver's supplemental services program where the care manager works out the care plan with the family. They noted that "Ohana Care at Child and Family Service has it and works with the family and allows payment on almost anything that assists family and caregiver. Cash is not given directly to anyone but instead the person is reimbursed the amount due to a finite amount for supplemental services."

From Maui the comment was "So would you consider a reimbursement instead of giving them the cash up front? Do you think that would be a preferred option? It would eliminate the need for workers comp and employee/employer type relations. [The consumer] would present some type of receipt or invoice for services and get reimbursed

up to a certain amount a month and whatever they did not use that month they would carry on to the next."

There were few issues/concerns about fraud/misuse from the disability providers. Again, based on experience with two other consumer directed programs, providers could only recall one incident where funds had been misused. The simple mechanism they used to track funds was to set up an account (checking) for each consumer. Deposits were made by the agency and funds were spent as needed by the family/consumer/caregiver; however receipts had to be turned in for items purchased and the agency paid the workers directly.

3. Role of the Counselor

There were also many discussions about the role of the counselor. It was universally agreed that the caseload was too high and that if the demonstration was going to be statewide, each island would need to have at least one assigned counselor, even if that position was not full time. It was also suggested as an alternative model that the entry point into the system could be through existing case management programs of the AAA's. In this way it could be a program that supplements rather than replaces current options. AAA's were also concerned about a family's ability to select services without the ongoing guidance of a case manager.

4. Contractor/Agency Model of Service Delivery

There were difficulties with completely abandoning the contractor model or agency model of service delivery. Agencies did not want to be in charge of a pool of workers and responsible for paying them, monitoring their hours and checking on the quality of service delivery. One comment was, "As you move to another system that is consumer directed, then the role of whoever is to educate and train clients and caregivers. You have the

clients and caregivers who are adept and savvy and know how to search the internet and make phone calls and feel confident and that do not have language issues. Then you have others that do not have a clue." However as noted above most programs felt that this model could be more cost effective. In addition the disability providers approved of the non agency approach in rural areas as a way to meet unmet needs; they felt it would be easier to find providers if the consumer could choose whoever they wanted (family member, friend, etc) as a provider.

5. Need for Program Monitoring

While providers agreed that it was "Nice that we are moving to choice" they also suggested it would not be the best for care monitoring concerns. One comment was, "Registries will need to be kept on those who provide care; especially personal care but also those who do other sorts of services (e.g. home renovations) to make sure they are legitimate." Quality of care was a concern if family members are used. Maui staff noted that "Even if family members should undergo training such as the KCC training program, [someone will] need to undertake this responsibility from Maui. That would be a huge burden on the office because as it is we are already burdened." Another comment was, "What about handling disputes? Especially with employee/employer relationships, you get an immense amount of labor law issues. Employee/employer is just an idea. What would be our responsibility? Say, we do this as far as gave them a list of people, what is our responsibility to make sure that these people we gave them the list of are okay? Do we have to do background checks on them? Do we have to make sure they are established agencies? How much investigation do we have to do to provide a list for people who may not know somebody that they want to give them a choice? It should be the agency's responsibility. The next question is if you make a list and give it out and they take that

person and something goes wrong, who is liable?" KAEA also talked about the need for quality assurance to be in place and said "We do not get complaints about workers now, but what would we do if we got a complaint say about a daughter?"

6. ADRC as Point of Entry

Most sites agreed that ADRC would be a good point of entry as it is set up to serve the same population that is designed to be served by Cash and Counseling (e.g. a non Medicaid, elders and people with disabilities). Audrey Suga-Nakagawa, statewide director for the ADRC program, agreed that it was an ideal function for the ADRC, but noted that "neither Kauai and Maui have one yet; it will be a year coming at least. In addition, it will not be a physical site on either island."

There were not many concerns about tasking ADRC with enrollment and recruitment other than that the physical site would be easier than on line or web based ADRC's such as Oahu. On Kauai they said not currently having the ADRC was not a problem, as long as it was up and running by the time the demonstration began. However in another comment from Maui "I know I asked the question about entry through the ADRC, I know we did not quite talk about that but with the development on Maui with the ADRC, is the timeline we are proposing realistic in accordance with the development of the ADRC or is it going to be separate from the ADRC?" It was agreed that the easiest place would be on the Big Island where it is a physical place but will need to have trained people available for phone/website inquiries. EAD mentioned that in Honolulu stationing someone at Child and Family Service might be desirable, for instance, so that there would be a place to go.

7. Kupuna Care as Site for Comparison

There was some discussion about the program being embedded in the Kupuna Care program. In general people could see the fit. An example of this was a comment from Kauai "It makes sense and seems logical to have entry into Cash and Counseling start with the Kupuna Care Program. Front line is our intake assessment. Information and Referral does front line assessment and identifies clients' needs, therefore, it would be logical to have Cash and Counseling start there." But there were definitely funding concerns about stretching existing Kupuna Care funds. One comment was "To do this, we need a separate pot of money so that you do not impact those already in the Kupuna Care system. Unless you can divert those already there into this, there is no admin money within the $525,000 so you would need another pot of money."

Another comment was that it would be hard for Kupuna care to be a true control group in the experiment. First of all, people could not be randomly assigned so this would be a weak design. It was noted that the selection of participants would be difficult. If they were allowed to make their own decision which program to choose, it was likely that the more "difficult" clients would end up in Kupuna Care. It was noted that you would "need to make sure sample is similar, with the same number of really frail people", so you would have a balanced sample and costs could be comparable. They said "…Kupuna Care has difficulty with clients that need a lot of hand holding and take more time. For this to be an accurate comparison, there needs to be oversight on who this Cash and Counseling program takes. The tendency to take in people who are easy is highly likely since they can make decisions on their own. Immigrants, non-English speaking, low educated people may go to an agency like Kupuna Care."

EAD noted that the targeted numbers for treatment and comparison (250 each) might be too high; there are only about 600 in case management that receive service in a year in Honolulu. Another similar comment from Kauai, “Well, the thing about it is, here on Kauai I don’t see that we have that much volume. In fact, and this is off the top of my head, I would think 10 people at the beginning of the demonstration. Because I don’t know if the people who are currently receiving services or the people who are coming in for services would be appropriate for this program. So, I don’t think that our volume is enough.”

8. Who is the Real Employer?

Many concerns were voiced about who is the actual employer. Questions asked included: Do the taxes come out of the monthly funded amount? Who pays employer’s quarterly taxes? Who is the “employer of record?” Many noted that elders might not be able to act as their own employers and that a fiscal intermediary might work better (note: this was suggested in the proposal). From Maui one comment was “One other thing brought up was if the consumer hires someone, does that person have to be an employee? Do they have to do all the federal withholding and workers compensation, or can they be an independent contractor? That was not clear in the proposal whether the person they hire can just be an independent contractor. Like they want to hire their sister to do the house cleaning, does the consumer have to start thinking about withholding and workman’s comp?” Another comment from Maui was that if the elder had to withhold taxes, pay workers comp etc that the program would be costly. “They are getting $500 to pay for services and yet they have to pay for workman’s comp or payroll taxes and it defeats a lot of the purpose of Cash and Counseling.”

This issue was one that needed to be addressed immediately so possible solutions from various agencies were sought. Several ideas came from those programs which had tried consumer directed care and had some solutions/ideas about client as employers. One comment from an agency was "We ran a home program and no one paid the client. It was between the client and if it was a family member and that was it, it went well. The state made payments to the county department and the county paid the clients directly when they qualified. They purchased their own service and there was a monitoring system for employees to spot check and make sure they were spending the money correctly."

There were also tax questions as to whether or not the monthly benefit would count as income to the client and how things would then work with the IRS. Was that income to the client? A member of the advisory board familiar with these issues from the UH Center for Disabilities Studies noted in an e-mail (he was not able to attend the meeting) that this is "a very complicated issue; so much so that Cash and Counseling around the country generated a whole new section of IRS code." In Cash and Counseling the demonstration funds (not the consumer's) were used to pay for payroll taxes etc. In theory the individual consumer was responsible for ensuring that this was paid; however, the consumer was not a pure employer of record because again the IRS didn't quite know how to deal with this. He went on to note that in later more evolved versions of the demonstration the individual is rarely the employer of record. "A Fiscal Employer Agent (FEA) (another term that evolved from the Cash and Counseling demonstrations) is established as the employer of record. This individual (or organization?) is then legally responsible if the IRS want to come after someone. In Hawaii's current consumer directed waiver programs, government agencies are the FEA (in CDPA and Nursing Home Without Walls)." The consumer in this

situation retains several of the areas of authority including hiring or firing, managing the hours and time sheets, sort of like a temp agency.

Other programs had gone to the legislature for support. They noted “We put in a statute that you could not count it as income for other program services.” Others said that this was the method used by DHS where they are able to hire a person to help them provide whatever services, be it transportation, housekeeping, chores, cooking, etc. An EAD meeting participant said “Again, Nursing Home Without Walls does the same thing and takes care of workers comp and employers responsibilities.” Another comment was about a simple personal care program at Hale Mahaolu, “where we use our registry with independent contractors, it could also be family members and they contract directly with that person and we reimburse the client for whatever they are paying. It is based on income through the sliding fee scale. We have been doing it for 20 something years but the people on our registry need to meet certain criteria. They turn in an invoice and they pay the aide then we reimburse them.”

In the four state evaluation conducted by Mathematica, one option after experimenting was, in lieu of a direct cash payment, to provide participants with a prospectively paid monthly budget that was managed by a fiscal-services provider at the direction of the beneficiary or a designated representative. Under this program beneficiaries were offered two options. First, they would be allowed to receive their allowance in cash each month from the fiscal-services provider if they agreed to be trained and tested on fiscal responsibilities and submit to a periodic audit (and retained receipts for all purchases with the allowance). Second, beneficiaries would be able to receive a cash advance each month of up to 10 or 20 percent of the monthly allowance for incidental purchases, such as taxi fare, that could not readily be invoiced in advance. Consumers

would pay for the bulk of their expenses by submitting invoices (or timesheets for workers' wages) to the fiscal services provider, who would write the checks. The first option was decidedly unpopular with beneficiaries—only a handful among thousands chose to manage the allowance themselves. Most chose to receive the modest cash advance, although a sizeable number took none of their allowance in cash and had all of their eligible expenses paid for directly by the fiscal agent (Doty, Mahoney, Simon-Rusinowitz, 2007).

9. Where to Place the Demonstration Project?

There was much discussion as to where to place the first demonstration. Culturally there was more interest in the rural counties than Oahu; even suggestions that rural areas might be better to lower administration costs. One comment from Maui was, "It seems like when you talk about 250 clients statewide, that does not make sense to go statewide on a demonstration project. Maybe just pick a county in the rural areas instead of spreading it out because that is a lot of administrative cost to hire a counselor on Maui, a counselor on Kauai." Another comment was, "Maybe you should just have one area then you do not need four different counselors, maybe one or two because you really want to find out if this project works… I think in some sense a rural demonstration would be good because I think rurally more people would rely on one or a couple of providers as opposed to multiple providers. They would be more likely to hire a family member or a neighbor or a friend or somebody that they knew to do more tasks, service providing, like homemaker and maybe include personal care and transportation for shopping. That is why we are saying the rural demonstration project would work a lot better because the availability of services provided by the agencies is less. That is why like you said the rural areas are a good place to start." Finally, the DD/MR providers felt strongly that the need

was greatest in the rural communities of Kauai, Maui and the Big Island where it was difficult to find providers and being able to use the money flexibly to hire individuals they knew rather than negotiate with an agency who had no workers in their area would prove to be the best benefit.

10. Eligibility Requirements

People questioned the need for any eligibility process. It was stressed, however, that if it existed at all it would only be fair that both income and assets are included. Should there be any at all other than age/need? People noted the difficulty administratively of "verifying financial information/enforcing financial need." Another issue was should eligibility included those who are insured or underinsured? It was noted that it is pretty hard not to get insurance in Hawaii; if that was the criteria few people would be eligible; however also noted that often services such as respite are not covered by insurance. One question from Kauai was, "Why have guidelines on income if no one is monitoring? Is self reported income sufficient? If self reported income is accepted, it will require less work. Verifying income will take a whole lot of research and paper work. That in and of itself will require a lot more time and attention. With the verification process it will take you that much longer to determine eligibility."

11. Involvement of the Disabilities Community

The aging community and their service providers had many questions about how to involve the disabilities community when they were only familiar with providing service to the elderly. From Kauai we heard "And that's a big question. They've given us a lot of responsibilities in areas that we know nothing about. AOA, CMS is coming to the aging network and saying 'okay now serve the disabled no matter what the age', and as much as we would like to, we cannot draw on experience because we have none. We have no

knowledge, no experience of something that got its start because of its mandate, but you know it's not expected to provide you with answers that we don't have."

From the other end, however, there were few problems in the disability community about involving elders and the agencies that served them. Comments from the home and community based disability providers indicated that they should lead the way since they better understood the concept and had already had experience in consumer directed interventions. The provider representative from the ARC of Kauai mentioned that she already had a good relationship with the KAEA and had no problem working with them.

On the other hand a comment from Maui "We were intending this to be for the disability community as well, how does the current process we have written work or not work for people with disabilities?"

12. What are the Expected Outcomes?

There were some statements that the expected outcomes need to be better defined and that consumer satisfaction and reduction of caregiver burden were not enough to switch to another mode of service delivery. The advisory board suggested we should include delay of institutionalization or reduced hospital stays as measures of cost effectiveness or at a minimum, do a cost benefit analysis. Cost measures in general were also considered to be a good addition to the evaluation. The process measures that were considered sufficient for the early days of Cash and Counseling (e.g. were the services delivered satisfactorily? Did the workers do a good job?) were not considered to be sufficient. Instead, targeted outcomes that included health and cost outcomes were seen as necessary. From Maui a comment was, "I understand when you say it is consumer's choice, it is one thing, but if the goal is to prevent people from being institutionalized, then maybe that is one measurement you can look at. Just because it is the consumer's choice

does not mean they are going to choose what is going to prevent them from being institutionalized. When you talk about control group and treatment group, again, what if both are satisfied with what they get? At the same time when you have a control group and a treatment group, your criteria for selection becomes very important and needs to be taken into consideration." Another comment was, "What would the methodology be in determining what the cost is? Possible methodology would be to track reduction in hospital visits and emergency visits as outcome indicators."

13. Monitoring and Quality Control

There were several discussions of how quality control was to be maintained. People asked who does that and how often? There were suggestions that there needs to be some kind of guidelines and qualifications, and someone to monitor "besides that one counselor to provide services for the whole state." Other people noted that "we need to make sure the consumers are getting the type of services they want and need and deserve. There needs to be some type of overseeing." From Maui one provider suggested, "Just an idea. I think the system I use personally works very well and it is part of my health benefit account where I get a credit card for my health spending account and I can spend up to so much a year and it works very well and you have consumer choice. It seems to be you can take these four counselors and convert them to spending account people and build in a security system so you can monitor expenditures through that system and let each client set their choice about what they use it for. You will have a built in mechanism to monitor."

14. How Would This New Program Interface with Medicaid Managed Care for the Aged, Blind, and Disabled Populations?

There was some discussion that DHS might be the best place to launch the program given the Medicaid Quest Expanded Access. This was discussed at the advisory committee meeting and there was not a great deal of support for it. However in conversations with DHS it was determined that it might be possible, as they are implementing a consumer choice option currently as they launch the new program. They have two or three programs now, they noted, that serve non Medicaid consumers and the capacity already in place to assume the role of employer and manage the fiscal responsibilities. From Maui a comment was: “It seems to me for 250 cases it might be an option to have your two health plans pilot test this for the system because it is going to be a lot of administrative work for the aging network at the same time that you are developing ADRC that simultaneous the managed care system can be testing both the Medicaid and non-Medicaid”.

15. Cost Effectiveness

It was noted that Cash and Counseling is likely to be less costly than Kupuna Care or any agency delivered model of service provision because “what the County would pay us or the state would pay the agencies for the services would be a lot more than what we would pay the consumer directly.” The consumer could purchase the services from a family member for much less than they would through a service agency. The providers for those with developmental disabilities also felt that this method of service delivery was likely to cost less than agency services.

16. Expanded Services

Among the Medicaid home and community based providers for those with developmental disabilities, it was enthusiastically pointed out that the nature of the program was to make all types of possibilities open to consumer purchase, including

unusual items such as purchasing transportation and buying a washing machine. In Kauai (KAEA) there was a less enthusiastic discussion about the expanded services available under Cash and Counseling. This was one of the comments "So theoretically, someone coming in to this program would have triple the amount of services available to them. Kupuna Care only has 8 services. I believe that Nursing Assistance, Skilled Nursing, Occupational Therapy, Physical Therapy, those would be or could be covered under home health as a Medicare benefit. I'm not sure how frequently those services would be utilized. The Job Training/Vocational Rehab, I would assume this is more for individuals with disabilities. Most of our folks wouldn't be looking for job training."

Another provider went on to say "Are we willing to go into other services that are beyond the Kupuna Care? The services that are with Kupuna Care we know the providers, we know the scope of services, we would just be using a different payment method, right, with Cash and Counseling? Because we have everything else in place. So we could start with Kupuna Care services, it would be easier for us to introduce this new system. If we did it with personal care and we did it with homemaker and whatever we are already using instead of going into vocational rehab which we know nothing about. But you know the overnight and weekend respite care we do offer that under Kupuna Care but having it under a program like this would give us more flexibility."

17. Other Comments

a. Type of client - some types of clients might not be appropriate for consumer directed … others not. People hoped that options would remain for a choice of each.

b. Evaluation – finding sufficient sample size, (from especially Maui and Kauai) matching amounts of cash people get from each project would be difficult, what

are outcomes should not they be more than just client satisfaction? What about delay of institutionalization (from Kauai and Advisory committee).

c. The program design was questioned. It is a quasi-experimental design and people felt that without random assignment the design lacked sufficient power to see differences between treatment and control groups.
d. In general, Area Agencies on Aging were concerned about adequate funding support to take on an additional project. They are clearly concerned about being asked to implement a new model of service delivery without sufficient funds to implement it.
e. Education and training for caregivers will be crucial.