Community Living Program Program Final Evaluation Report

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Community Living Program (CLP)
Funded by the U.S. Administration on Aging and the State of New York

Participating Counties: Albany, Cayuga, Dutchess, Orange, Otsego, Tompkins, Washington.

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Summary

The New York State Office for the Aging received a Community Living program (CLP) grant from the U.S. Administration on Aging (AoA). This AoA funding was targeted at reaching individuals not eligible for Medicaid, but who were at high risk of nursing home placement and of spending down their income and assets to the Medicaid level. The project used consumer-directed models of care to help individuals determined at risk for nursing home placement and/or Medicaid spend-down to maintain their independence and remain in their communities.

During the grant period, one hundred and fifty individuals were recruited and one hundred and fourteen participated in CLP for at least 90 days from Albany, Cayuga, Dutchess, Orange, Otsego, Tompkins, and Washington Counties. The 'typical' consumer participating in the CLP was aged 80 and over, had four or more ADL needs and seven or more IADL needs. Of the participants in the program, approximately 50% chose to direct their services themselves, and all others appointed a consumer representative.

The consumers admitted to the CLP actively worked with case managers/care coordinators to craft their own care plan and budget. Through those plans, 67% of participants accessed assistive technology and home renovations and purchased goods and services; 22% hired and supervised their own in-home services worker and most also accessed traditional Older Americans Act (OAA) and state funded services administered by the Area Agency on Aging (AAA), such as home delivered meals, transportation and agency provided personal care to address ADL needs such as bathing and dressing. Participants reported they were very satisfied with the program and that the approach helped them to remain in the community and to avoid nursing home placement and Medicaid spend-down.

The New York State Office for the Aging and its partners utilized previously developed procedures and training modules to identify eligible participants for the program and support the delivery of consumer(self/participant)-directed care (NOTE: In New York these approaches for both Medicaid and non-Medicaid populations are collectively characterized as consumer-directed and this term will be used here).

The New York State Office for the Aging also began implementation of regulatory changes designed to support the extension of consumer-directed approaches to its state funded Expanded In- home Services for the Elderly Program (EISEP) in the participating counties and throughout the state. EISEP funds personal care services, in addition to case management, non-institutional respite and other services for older adults served by AAAs.

Every individual who was admitted to CLP was at an objectively established risk for nursing home placement and Medicaid spend-down. However, of the 114 participants who were in the program for at least 90 days and who were then served for an average of 12.6 months of program enrollment, 90% of participants did NOT enter a nursing home or spend down to Medicaid. The total monthly savings realized ranged from $140,562 (compared to State average Medicaid funded in-home care) to $534,774 (compared to State average nursing home care costs).

Over a relatively short period of time considerable success was demonstrated in implementing consumer-directed care; facilitating case managers moving into the role of care coordinators who collaborate with the consumer; supporting persons at risk of nursing home placement and spend down to remain at home in their community using approaches with which they reported high satisfaction; and producing savings as compared to Medicaid funded services.

Introduction and Background

The New York State Office for the Aging received a Community Living Program (CLP) grant from the U.S. Administration on Aging (AoA). The grant began on September 30, 2009 and, with an extension, ended September 30, 2012. This AoA funding was targeted at individuals not eligible for Medicaid, but who were at high risk of nursing home placement and of spending down their income and assets to the Medicaid level. Consistent with AoA goals, the project used consumer-directed models of care to help individuals determined at risk for nursing home placement and/or Medicaid spend-down to maintain their independence and remain in their communities. The model used was designed to offer individuals more involvement and control over the types of services, goods, supports, and benefits they received, and the manner in which their services were delivered.

The CLP grant was implemented in seven counties in New York - Albany, Cayuga, Dutchess, Orange, Otsego, Tompkins, and Washington - with the Area Agency on Aging (AAA) in each county serving as lead agency. All of these counties have a strong and innovative AAA as well as a well-developed NY Connects (New York's Aging and Disability Resource Center).

The ***Albany County Department for the Aging*** is dedicated to advocating for the needs of all seniors, committed to working collaboratively with the local aging network and fighting as a united force for more services for seniors and their families. The majority of their services are delivered through contracted not-for-profits and case management services are provided collaboratively with the Department of Social Services. ***Albany County — NY Connects*** operated in collaboration with the Department of Social Services is a trusted program where anyone who needs long term care information and services (i.e., a child or adult with a disability, an older adult), their family members and helping professionals can get the information they need to make informed decisions about long term care as well as the assistance needed in linking with services.

The ***Cayuga County Office for the Aging*** works with local and state government and with community agencies to coordinate services and ensure access to services for all seniors and their families. ***Cayuga NY Connects*** located within the Cayuga County Long Term Care Office, cooperates with the Cayuga County Department of Health & Human Services and the Cayuga County Office for the Aging to be a one-stop place to find cost-effective, high quality Long Term Care.

The ***Dutchess County Division of Aging Services*** plans, coordinates and provides an array of community based services to the elderly and persons who require assistance in the long term care system, in an effort to promote independence, dignity and quality of life. Through its distinctive role of committed advocate and community partner, the agency strives to ensure clients' needs will continue to be met now and in the future. ***DUTCHESS NY Connects***, is the long term care services division of the Dutchess County Division of Aging Services. DUTCHESS NY Connects provides information, referral, assessment, and case management for people, regardless of age, who need help to remain at home, or who are thinking about or require residential health care facility services or other alternative living assistance. They provide an unbiased assessment of a client's total needs.

The ***Orange County Office for the Aging*** is committed to meeting the special service needs of Orange County's senior population, their families and friends who care for them. Orange County Office for the Aging offers services, either directly or through sub-contracts, designed to maintain the quality of life of

those aged 60 and over. The primary goal of the Office for the Aging is maintaining the dignity, wellbeing and independence of senior citizens through the Office's distinctive role as advocate and community partner. Within the Office for the Aging, Orange County NY Connects is a point of entry program that provides comprehensive and objective information and assistance on long term care. This information and assistance is provided to consumers of all ages and their caregivers who are exploring available options for home, community based and institutional long term care services.

The ***Otsego County Office for the Aging*** is the primary resource for leadership in identifying emerging trends and future directions as defined by the aging population. The Office for the Aging provides direct assistance and services to the aging community of Otsego County including Heating and Energy Assistance (HEAP), help with Medicare and Medicaid, and Home Delivered Meals (HDM). ***NY Connects of Otsego County*** helps to provide living assistance to eligible individuals living within Otsego County. NY Connects provides information on Home care and other long term care options.

The ***Tompkins County Office for the Aging*** is the point of entry into aging services in Tompkins County providing objective and unbiased information regarding the array of services available for older adults and their caregivers. Established in 1975, their mission is to assist the senior population of Tompkins County to remain independent in their homes as long as is possible and appropriate, and with a decent quality of life and human dignity. ***Tompkins County NY Connects*** is a cooperative project between the Tompkins County Office for the Aging and Long Term Care Services to provide information and referral about the many long term care services available in Tompkins County and to improve access to these services.

The ***Washington County Office for the Aging*** is committed to Service, Education and Advocacy to meet the needs of Washington County Seniors. As the entry point for information and access to a comprehensive system of client based service for senior citizens and their families, the Office for the Aging pays particular attention to the socially, physically and economically isolated, such that they can remain successfully independent, in their homes and communities with dignity***. NY Connects in Washington County*** is the locally based point of entry system that provides one stop access to free, objective and comprehensive Information and Assistance on long term care. Trained NY Connects Information and Assistance Specialists provide individualized information and assistance and links individuals of all ages needing long term care, as well as their caregivers, to the services and supports they need to maintain independence to the extent possible, regardless of payment source. It is a trusted community resource that links individuals to the most appropriate services of their choice.

Technical Assistance and Evaluation

As was specified in the original proposal, the Center for Excellence in Aging & Community Wellness (CEACW) at the University at Albany provided technical assistance through bi-monthly, structured visits to each county, technical assistance conference calls, and on-site technical assistance on an as-needed basis throughout the CLP project. CEACW was also responsible for program evaluation, gathering data on the operations of the project and evaluating the outcomes and consumer satisfaction of the initiative using a combination of quantitative and qualitative approaches.

The CEACW is a translational research center that develops, tests, and implements innovative practices and policies. CEACW's diverse research, training, education, planning and services activities synergistically work to improve the creation, delivery and sustainability of evidence-based practice models. CEACW is dedicated to improving the quality of life for older adults, their families and caregivers, and the communities they live in, and is frequently a partner with the New York State Office for the Aging in implementing and evaluating innovative programming and service system change for older adults.

Evaluation Methodology

A mixed methods approach was used in data collection to understand:

1. Who was served
2. Processes, successes and challenges in selecting participants, developing care plans and budgets and tracking activities, expenditures and outcomes
3. What were the outcomes in terms of diversion from nursing home placement and Medicaid spend-down

There was also interest in understanding and describing the activities at both a county and state level to expand the successful implementation of consumer-directed services and of changes in operations/procedures/practices that would support both project specific delivery and continued embedding of consumer-directed approaches in New York State and county supported services to older adults.

In pursuit of these evaluation objectives, data collection activities included:

- Gathering demographic data on persons who were pre-screened and building a data base incorporating data on all completed pre-screen instruments
- Gathering demographic, service level, and budget data on consumers enrolled in CLP from reviews of care plan documents, assessment instruments and interviews with case managers/care coordinators
- Tracking of consumer progress in CLP from monthly reviews of care plan documentation, interviews with case managers/care coordinators and interviews at six month intervals with samples of consumers
- Training needs assessments gathered in interviews with county administrators, case managers/care coordinators, New York State Office for the Aging staff and reviews of issues and concerns raised in monthly project telephone conferences
- Assessing the outcomes of trainings, including trainee satisfaction, intended learning and desired additional instruction
- Participation in project director initiated monthly project telephone conference calls and quarterly in-person meetings with notes taken on major issues, items for follow-up and training needs
- Interviews with consumers/consumer representatives, case managers/care coordinators and local administrators
- Bi-monthly reviews of records to identify project and individual care plan and budget progress, implementation of consumer-directed principles, maintenance of identified quality assurance targets and implementation of quality improvement recommendations
- Development of a database to capture all consumer demographics, goals budget amounts and services received
- Review of procedures, contracts, billing documentation and care plan and budget tracking systems, including how recommendations for improvement were implemented

- Development of illustrative case descriptions

Analysis. All quantitative data was entered into an SPSS dataset and descriptive statistics and graphs were generated using SPSS20. Notes from interviews, attendance at monthly telephone conference and from in person project wide meetings and case record reviews were systematically reviewed with confirmation from a second reviewer. The reviewers used a cross comparative method designed to highlight emerging themes which subsequently led to additional interviews as necessary and triangulation with the quantitative data to confirm or further illustrate those themes. Summary paragraphs were then generated and representative case studies were developed, targeting the processes of implementation and change.

Findings

The findings generated are reported under the following headings: (1) Preparation and Training; (2) Pre-screening; (3) Consumer-directed Implementation; (4) Systems Change, and (5) Outcomes Data.

(1) Preparation and Training

Developing Consumer-directed Services for New York. The launch of the project benefited from the prior significant collaboration between the New York State Office for the Aging, and staff from the three participating AAAs (Broome, Oneida, and Onondaga) and the Center for Excellence in Aging & Community Wellness who worked together on the prior Nursing Home Diversion Modernization Grant (NHDMG). With significant leadership and staff support from the New York State Office for the Aging, the partners jointly developed:

- ***Targeting Criteria Regarding Assets*****:** The asset level was set at $17,250 to $41,400 for an individual and $25,125 to $116,220 for a couple. The asset range for an individual was set at 125% to 300% of the 2009 Medicaid asset level for an individual ($13,800). The lower range for a couple was set at 125% of the 2009 Medicaid asset level for a couple ($20,100). The ceiling was calculated using the upper limit for an individual ($41,400) plus $74,820, the co-owned assets that a community spouse in New York State may retain if their spouse goes into a nursing home. Subsequently, due to difficulty in finding participants who met the asset requirement early in the project period, a single person asset waiver process was established.

- ***Targeting Criteria Regarding Income*****:** The income range was set at 125% to 300% of Supplemental Security Income. The "floor" and "ceiling" for an individual was $11,415 - $27,396 and $16,725 - $40,140 for a couple.

- ***Functional Criteria*****:** Functional eligibility criteria included:
  - Self-directing or having a consumer representative available
  - Either "totally dependent" in at least *one* of the following Activities of Daily Living (ADLs): Eating/Feeding, Bed Mobility, Transferring, or Toileting, or at minimum "need some assistance" in at least *two* of any of the following ADLs/Instrumental Activities of Daily Living (IADLs): Bathing, Dressing, Walking/ Wheeling/Mobility, Taking Medication, Cooking Meals/Reheating Meals, or Using the Phone.

  Once these requirements were met, priority was given to consumers who were/who in the past had been difficult to serve through traditional approaches because of their location and/or needs

for which there were not sufficient resources in current programs, or because of their dissatisfaction with available services.

The Long Term Care Placement Form - Medical Assessment Abstract DMS-1 was modified and used to determine functional eligibility for CLP. This form assesses need for nursing care and therapy, functional and mental status, cognitive issues and impairments. Scores between 60 and 180 were considered at risk for nursing home placement and eligible for CLP. An addendum was developed that permitted supplementing the DMS-1 score with points for IADLS, informal supports, and health events.

For CLP implementation in the seven new counties the same criteria were implemented. In addition, a number of standards developed under NDDMG were also utilized:

- ***Standards for Who Can Provide In-Home Services*: The standards that were adopted for the CLP included the following:** In-home Services Workers must be 18 years of age and older, be able to satisfactorily meet background and health screening criteria, not be legally or financially responsible for the consumer (e.g. spouse or legal guardian), and not be the consumer representative.

- ***Standards for Who Can Be a Consumer Representative*:** A consumer may choose to have another person assume the role of consumer representative ale to work with them to develop and manage the care plan and budget on their behalf. In order to be considered capable of designating a representative, the potential participant must be able to positively identify the representative and affirmatively indicate that he/she wants the representative to coordinate part of or all of his/her care.

- ***Approved Diversion Services*:** The range of services provided to the consumers included personal care, consumer-directed personal care, housekeeping, chore, and companion services, social and medical adult day care, home delivered meals, congregate meals, nutrition education and nutrition counseling, caregiver supports, health promotion, transportation, and medication management. Consumers could also receive goods and ancillary services, such as home modifications, assistive devices and assistive technology, durable medical equipment, home maintenance, and appliances such as microwave ovens.

To fully structure CLP, the New York State Office for the Aging and partners had also developed an Operations Manual containing a series of six Modules and all the necessary forms and tools to be used by case managers/care coordinators and consumers/consumer representatives. The Modules include:

- ***Module 1 - Consumer-directed Care and the Community Living Program*:** The purpose of Module 1 is to describe and define concepts and terms related to consumer-directed care as a key concept vital to CLP.
- ***Module 2 - Targeting & Pre-Screening*:** Module 2 describes the process to be used to identify potential participants for the program and provides a prescreen instrument to be used by NY Connects workers as well as care coordinators and a program brochure for use with consumers and possible referral sources.
- ***Module 3 - Screening/Assessment and Eligibility Determination*:** Module 3 discusses in detail the screening/assessment and eligibility determination for CLP. The model includes instruments

and forms such as the CLP Financial Information and Consumer Agreement and the modified DMS-1 forms used for eligibility determination.

- ***Module 4-Care Planning and Budget Development*:** Module 4 is a step-by-step overview of the process of developing individual care plans and budgets within CLP, consistent with principles of consumer-directed approaches, person-centered planning and strengths-based approaches. Tools and forms that are included are goals and options worksheets, consumer goals and needs, backup plans and emergency contact information, cost sharing threshold and schedule, care plan, budget, consumer rights, consumer agreement to participate, consumer/ consumer representative agreement of tasks and responsibilities.
- ***Module 5-Using a Financial Management Services Agency*:** This module describes the specific role of the financial management services agency in the management of consumer-directed in-home services workers and in some cases, of other consumer-directed care plan expenses under an approved care plan and budget.
- ***Module 6-Quality Assurance and Data Collection*:** Module 6 provides detail about quality assurance and discusses inclusion of quality improvement strategies into all phases of the program. It also outlines quality indicators and data collection needed within the project. Participant-related, provider-related, and system-related components are covered.

Again the approach taken was to utilize the same procedures, manuals and modules. In addition the three NHDMG counties, Broome, Oneida, and Onondaga were contracted to be available as consultants to the new counties.

Training: Staff from CEACW provided online, phone conference, and in-person trainings for all seven counties on person-centered planning, strengths based approaches, consumer-directed options, screening and assessment, care planning and documentation, and quality assurance. In addition, on a bi-monthly basis, Center staff visited each county and reviewed records, assisted with procedure and contract development, problem solved case issues and provided targeted and county specific trainings and supports. CEACW also operated an online learning community and resources developed under NHDMG, copies of sample procedures and contracts and all training materials were available there. In addition, there were opportunities for blog posts and discussions to further facilitate interaction between the new counties and the NHDMG counties and with CEACW staff to further development of relationships, training and understanding. In a number of cases technical assistance telephone calls also occurred between NHDMG mentors and CLP partners.

At baseline there were a number of case managers and administrative staff who believed that consumer-directed principles were already embedded in their day to day operations. Also, in all counties there were already Medicaid funded consumer-directed programs through the County Department of Social Services that focus on the provision of personal care, and staff were also aware of Money Follows the Person Initiatives that were underway in the State. A particular concern was that some of the NY Connects staff who were responsible for screening for this program also screened for the Medicaid Consumer-Directed Personal Assistance Program (CDPAP) and initially thought the two programs were the same. A critical task during technical assistance and training was to review existing efforts, delivery philosophies and co-occurring initiatives and to clarify where there were differences and similarities. In particular, differences in eligibility criteria, the inclusion of goods and services in the service mix, addressing concerns about paying family members as in-home services workers, protecting rather than spending down income and assets, and moving from case management to a care coordination orientation were addressed.

Note: A particular challenge was that several counties were already experiencing the need to waitlist requests for personal care assistance and in others it did not seem possible during the grant period to implement county level legislative and procedural changes to implement the purchase of goods or payment for renovations. Training and technical assistance focused upon finding innovative ways to implement consumer-directed strategies with limited options.

Delivery of the CLP model was monitored during the bi-monthly technical assistance visits to ensure that it was being delivered as intended.

In technical assistance meetings with case managers/care coordinators and with AAA administrators were a series of open-ended questions designed to elicit responses that helped check/verify that CLP approaches were being followed. Examples include:

> (1)…. Where a neighbor was being considered for an in-home services worker… *who did the consumer (or consumer representative) consider for in-home services worker before making their choice?* - to establish if the consumer (or consumer representative) was discouraged by the case manager/care coordinator from hiring a family member.
>
> (2) …. Where personal care was the primary component of the plan*…. In your discussion with the consumer (or consumer representative) what were the consumer's ideas about how their goals or needs might be met?* - to establish if traditional personal care approaches were encouraged or if brainstorming of alternative approaches were discouraged by the case manager/care coordinator.

A review of notes from the bi-monthly CEACW visits confirmed that throughout the project that case managers/care coordinators encouraged consumers (or consumer representatives) to consider a broad range of alternatives to achieving goals and meeting needs. There were also many times during technical assistance visits when case managers/care coordinators appropriately sought advice and additional training/modeling on encouraging consideration of a broader range of services than had been their prior experience, thereby helping consumers (or consumer representatives) through the process of arriving at a decision and avoiding the presentation of information on services in ways that appeared to encourage selection of those services. There were also instances where case managers/care coordinators remarked that care plans that emerged were not only successful but reflected ideas from consumers (or consumer representatives) that the case manager/care coordinator would not have thought of.

(2) <u>Pre-screening</u>

There were several challenges to be addressed in the pre-screening component of the project:

1) ***Different Auspices***: For some counties NY Connects was embedded in the AAA, for others (Dutchess) they were separate with shared case management and for still others NY Connects was separately located and was largely a source of referrals rather than an active collaborative partner. There was considerable work on refining the processes of the NY Connects and AAA offices related to this project. In all counties staff in both units reported an improved working relationship and greater success in reaching and serving older adults before they are in crisis.

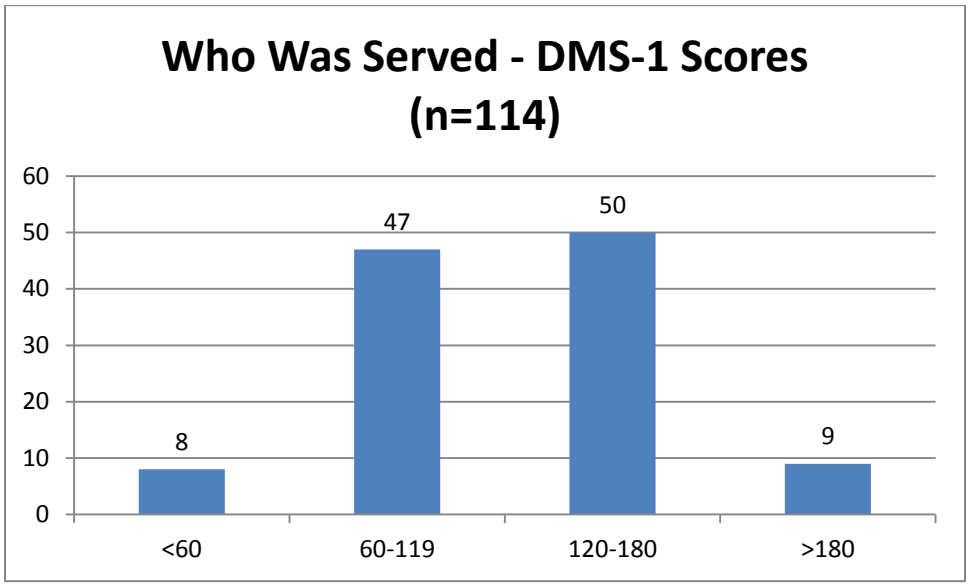
2) ***Financial Need*:** Previously, in many counties, local targeting requirements for programs such as EISEP meant that people not in immediate crisis and/or who held moderate to substantial assets and income tended not to be represented among those receiving usual AAA services. This profile changed in CLP. Among the more than 800 potential enrollees identified for the project, a review of the screening records indicated that over 80% met income and asset ranges for the project.

   There were a number of individuals who were accepted with lower or higher income or assets than planned because it was believed they would otherwise benefit from the program. In the cases of persons or couples with higher incomes, a review found that they usually met asset requirements and similarly those with high assets often met income requirements. Again there was no evidence (as measured by cost share rates over time) of increased rates of spend-down for these individuals.

   A majority of participants were already known to NY Connects and to the AAAs (i.e., they currently or previously received services).In several counties there was new engagement with potential participants with monthly income over $3,000 and/or assets over $40,000 with recognition that helping these individuals to make better decisions about the use of their own resources in supporting care will mean that they will be less likely to precipitously spend down those resources.

3) ***Meeting Screening/Assessment Criteria***: The vast majority of the people served met all income, asset and DMS-1 score (60-180) criteria. In a small number of final cases (8) – see Table 1 - a DMS-1 supplemental score was added so that some persons who had IADL as opposed to ADL needs were included. Nine people exceeded the recommended score; in these cases, provided they met all other criteria and with approval from the State Office for the Aging, the individuals were deemed eligible for the CLP. Persons admitted with a score higher than 180 tended to have very active family caregivers and although their needs were great, their care needs had stabilized and case managers/care coordinators felt those needs were manageable within the program. A post-hoc review of nursing home placement rates did not find that either group was significantly more or less likely to enter a nursing home.

Table 1

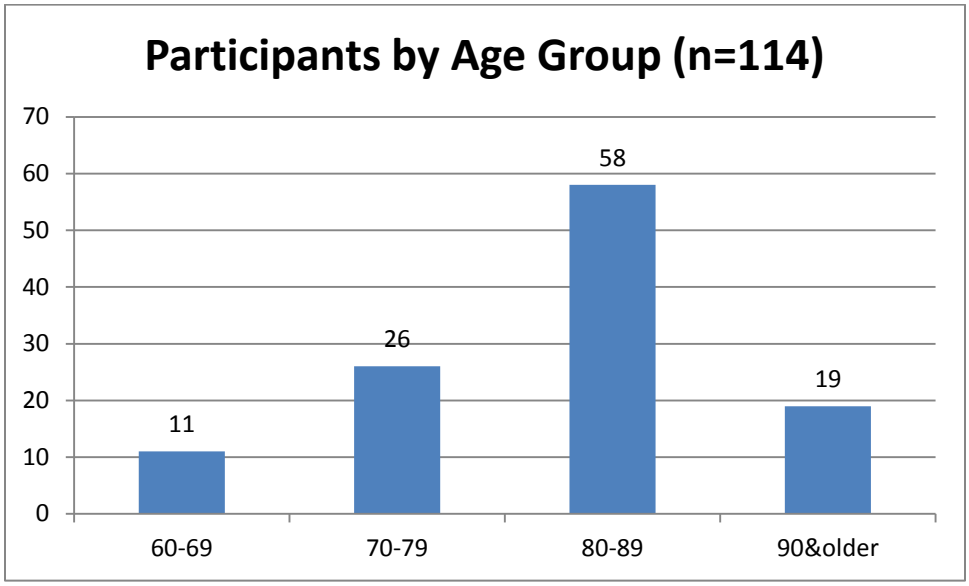


(3) Consumer-directed Implementation

Most counties experienced challenges in reaching their targeted numbers. This reflected time taken to complete contracting with financial management agencies, securing approval for procedural changes to permit use of in-home services workers, and to purchase goods and non-traditional services, overall county budget challenges that led to holds on enrollment and waitlists, as well as, other county specific challenges (e.g., an unwillingness by desired in-home services workers to accept the permitted rate of pay).

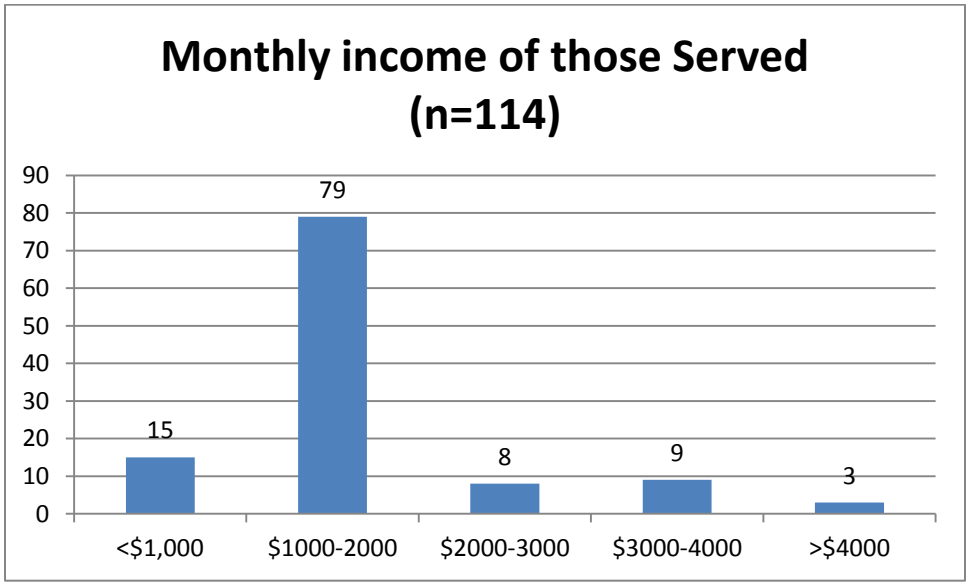
Demographics: Approximately 67.5% of participating consumers were over age 80 with many (16.7%) aged 90 and older (see Table 2); less than 40% lived with a spouse; almost 50% lived alone; and four times as many females as males were served.

Table 2



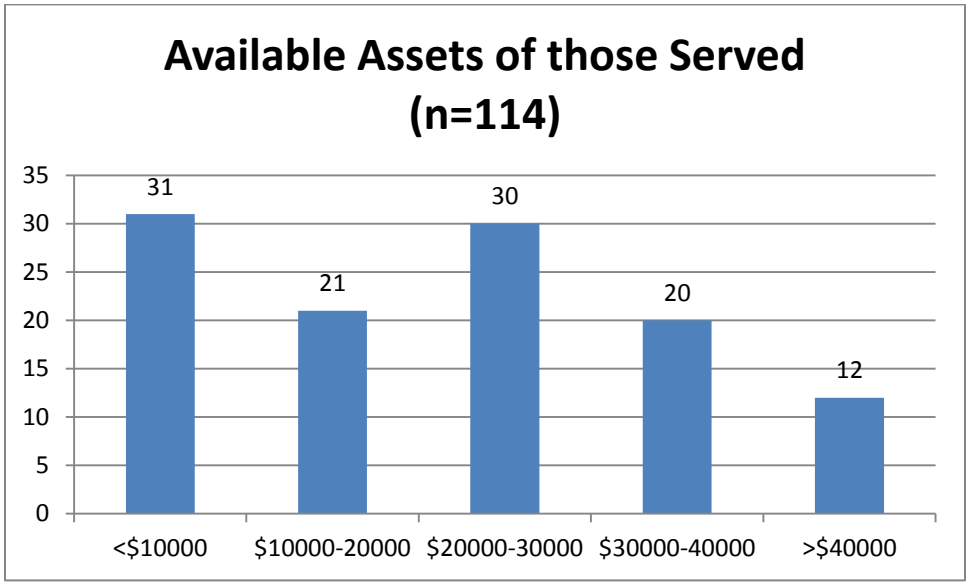
Personal Finances: Almost 90% participants had incomes of between $1,000 and $3,000 per month (see Table 3) and assets between $10,000 and $40,000 (see Table 4).

Table 3



NOTE: Income eligibility for CLP was Individual-$951.25 to $2,283.00 (monthly); Couple-$1,393.75 to $3,345.00 (monthly).

Table 4



NOTE: Assets eligibility for CLP was Individual-$17,250 to $41,400; Couple-$25,125 to $116,220.

Identified Levels of Need: Over 60% of participants (see Table 5) had 3 or more ADL impairments needing assistance with activities such as bathing and dressing and (see Table 6) the need for assistance with instrumental activities of daily living such as shopping, cooking and transportation was considerable for many consumers (almost 90% had 5 or more IADL impairments).

Table 5

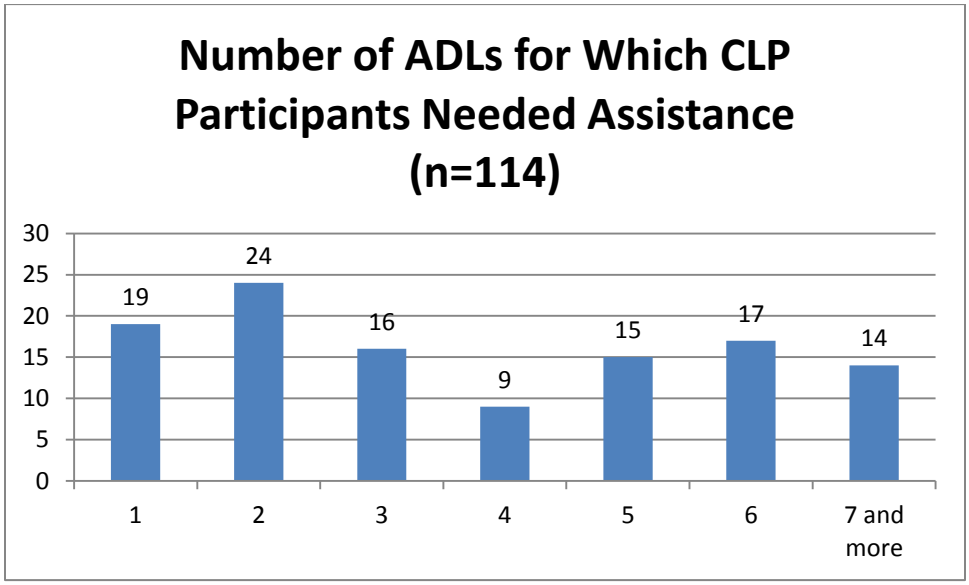
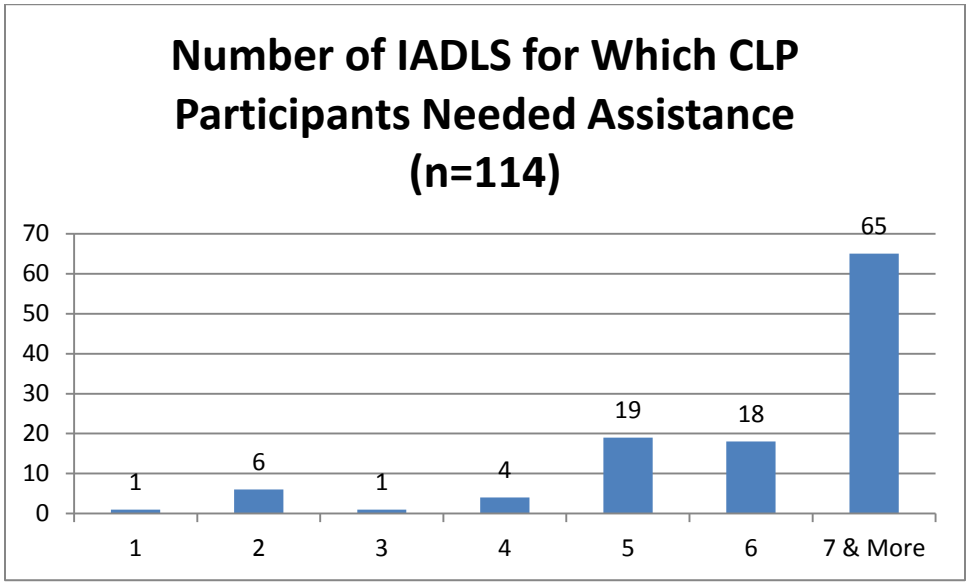


Table 6



Self-direction: Almost one third of participants (32%) chose to be self-directing, but many who did choose a consumer representative were still involved and influential in the design of their care plan. It appeared that those with a live-in family member were more likely to involve them as a consumer representative, but there were some consumer representatives who lived separately and some consumers with live-in family members who remained self-directing. An important distinction was that consumers with cognitive difficulties *all* used a consumer representative.

During bi-monthly technical assistance visits to the counties, the process of choosing to be self-directing or choosing a consumer representative was discussed with the case managers/care coordinators. As the CLP progressed, the case managers/care coordinators found that their explanation of both the responsibilities and the opportunities of consumer direction benefited from using the clear descriptions developed in the project training modules and from the description of roles and responsibilities that all parties review and sign during care planning. There were several cases where roles had to be renegotiated by either involving a consumer representative, or, if one was already designated by finding a new family member to assume this role.

Care planning*:* Care planning was guided by the NYS CLP training modules and by a set of care planning forms that were developed specifically for the project. The modules and forms were designed to guide consumers (or consumer representatives) and case managers/care coordinators through a process of beginning with the consumer's goals, wishes, desires and needs, the consideration and costing of alternatives, decisions on priorities and preferred ways to meet those priorities, and the finalization of a plan. Regular reviews of the case records, interviews with case managers/care coordinators and periodic telephone calls with randomly selected consumers and consumer representatives established that the care planning process was implemented as envisioned. Some challenges identified were that the process took longer than traditional case management in the initial stages, case managers/care coordinators did not always have the information they needed to advance the process, and in many cases consumers (or consumer representatives) were not always ready to make decisions, thereby

delaying the completion and implementation of care plans. Solutions included realizing that additional investment of time in developing the care plan meant that case managers/care coordinators spent less time in day to day management (this was now largely managed by consumers or consumer representatives).

With practice, case managers/care coordinators reported that they came better prepared to meetings and were more comfortable in involving consumers and consumer representatives in gathering information. This resulted in greater ownership by the consumers and consumer representatives, and increased likelihood that decisions among options would be made. Case managers/care coordinators also reported that once a care plan was established the on-going monitoring was often less that for traditional cases.

Several illustrative case descriptions were developed to document how the care planning process was being implemented.

Case Description 1

Consumer #1 was an 83 year old, widowed female, living alone but with an involved and concerned daughter. Her ADL needs included the need for assistance with bathing, hygiene, and dressing, while her IADL needs included housekeeping, shopping, laundry, transportation, and meal preparation.

Referral was made by daughter and both consumer and daughter were present when the care coordinator visited. The consumer was already receiving home delivered meals and was on a waiting list for a personal care aide to help with personal care. She also expressed an interest in a social outlet, a way to get out of the home. Because the consumer lived alone, met the financial requirements, and largely managed her own care with minimal involvement from her daughter, she was considered to be eligible for consumer-directed care. The consumer made the decision to have her daughter be her representative but wanted to be involved in decisions.

The case manager/care coordinator recognized the consumer's primary wish: opportunities to socialize with others and the daughter's concern that her mother needed help with personal care.

Identifying an in-home services worker was discussed as was utilizing the county companion program but neither appears to meet needs and wishes. An alternative of attendance three days a week at a social day program (where there would be opportunities to socialize and to address personal care needs) was agreed upon and the number of home delivered meals reduced given the lunch meal served there. The daughter also committed to continue to help with ADLs and IADLS as she was able on the other days.

Case Description 2

Consumer #2 was 92 years old, and living with his spouse. All IADLs required assistance, and ADL needs included assistance with bathing, dressing, hygiene, and walking.

This consumer was referred by his son who was concerned for both his father and mother.

The consumer was eligible for consumer-directed care because his wife and son were already very involved in his care and managing every day activities and because, when consumer-

directed services were explained he was interested in finding his wife some help with his care. He designated his son as his representative.

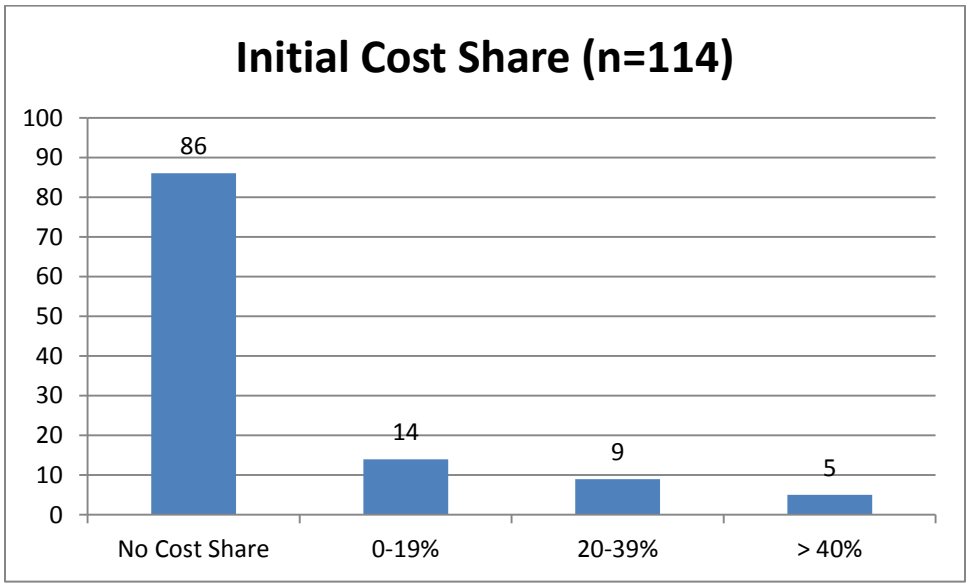
The case manager/care coordinator worked with the consumer, the spouse and son to gain a sense of the consumer's preferences.

In the initial plan all three decided that they would hire an in-home services worker, agreed a number of hours of assistance with the care coordinator and contacted the FMS for suggestions as the FMS maintained a list of people available to work with consumers. After interviewing several candidates they were not satisfied and re-contacted the care coordinator. They revised the plan to utilize an aide from a traditional agency. However, they asked to interview 2-3 aides from the traditional agency so they could feel comfortable with the person assigned. The agency agreed to sending two aides for interview and one was chosen.

The case descriptions illustrate that case managers/care coordinators worked effectively with both self-directed consumers and consumer representatives, considered wishes as well as assessed needs, helped participants consider options and were open to consumer-directed and hybrid models of service delivery.

Cost share. Most counties accessed EISEP funds to pay for traditional personal care services when chosen by consumers or consumer representatives and some utilized these funds for in-home services workers. Cost share based upon income is a feature of the New York State Expanded In-home Services for the Elderly Program (EISEP), and was included with AoA approval in CLP for EISEP and for any Older Americans Act programs accessed to support CLP. Cost share levels varied greatly for participants. Over 75% of consumers were at a no cost share level, but there were several participants who were at 40% or higher cost share (see Table 7).

Table 7



Case managers/care coordinators reported that it was unusual to have high cost share persons in their programs, but those that had high cost shares appeared willing to be in this program because they

valued both the care coordination and other supports they were provided, and the ability to be actively involved in managing services and in-home workers they selected. Some had already experienced significant reductions in their available resources and wanted to both understand options and take steps to manage remaining resources more effectively. There were a number of screened high cost share individuals who were already privately paying in-home services workers who did not follow up on their initial interest in the program. A primary reason for this was that the worker they currently were using was not interested in being employed by a Financial Management Services Agency (FMS) and the consumer was not willing to lose a worker they knew and trusted.

Budgeting. Creating individual budgets was a new process for most case managers/care coordinators. The AAAs were not familiar with tracking individual budgets and working with an FMS. This was a work in progress throughout the project. However, by project's end each county had:

- Entered into contracts with at least one FMS (in two counties for both in-home services workers and for goods and other services)
- Developed and successfully implemented procedures for purchasing, paying for and collecting cost share on goods and services (not all counties)
- Prepared a cost sheet for case managers/care coordinators so that they could easily cost out options being considered in the care plan
- Trained case managers/care coordinators and supervisors in the use of excel spreadsheets to track individual budgets and the overall program costs
- Worked with their accounting departments on the tracking of expenses, timely processing of vouchers and reimbursements and, in the later stages of the project, the inclusion of service cost information in electronic tracking systems

In addition, during technical assistance visits, Center staff discussed with case managers/care coordinators how they presented cost and budget information, handled budget adjustments and reported back to consumers on the expenditures to date. These questions were designed to elicit the extent to which consumers (or consumer representatives) were facilitated in weighing options, making decisions and bearing responsibility for the management of their budget.

A review of the discussions and notes made during these site visits established that, for all counties, there was strong commitment and improving practice over time in engaging consumers (or consumer representatives) in weighing costs and preferences and making final decisions about the shape of their care plan and budget but involvement in taking responsibility in managing budgets was less well developed. It took some time to shape administrative systems to generate timely reports and in formats easily understood by consumers and consumer representatives. However, by project's end this was achieved.

A review of budget documents found that budgets ranged greatly in size from a low of $135 in total costs (a one-time purchase) to monthly costs of $1,500 that extended for multiple months (paying primarily for hours of care by an in-home services worker), with an average of $461 per month over approximately 12.6 months. For about 25% of cases there was a need for a budget modification to raise the amount available (usually because of increased needs and in a small number of cases because a one-time purchase such as a lift chair was identified that would reduce the need to increase personal care hours). That said, in approximately one third of cases less money was actually spent than was allocated in the budget; usually because of delays in identifying an in-home services worker or in moving forward with renovations.

Services received: Participants chose a wide range of traditional and consumer-directed services (see Table 8) including:

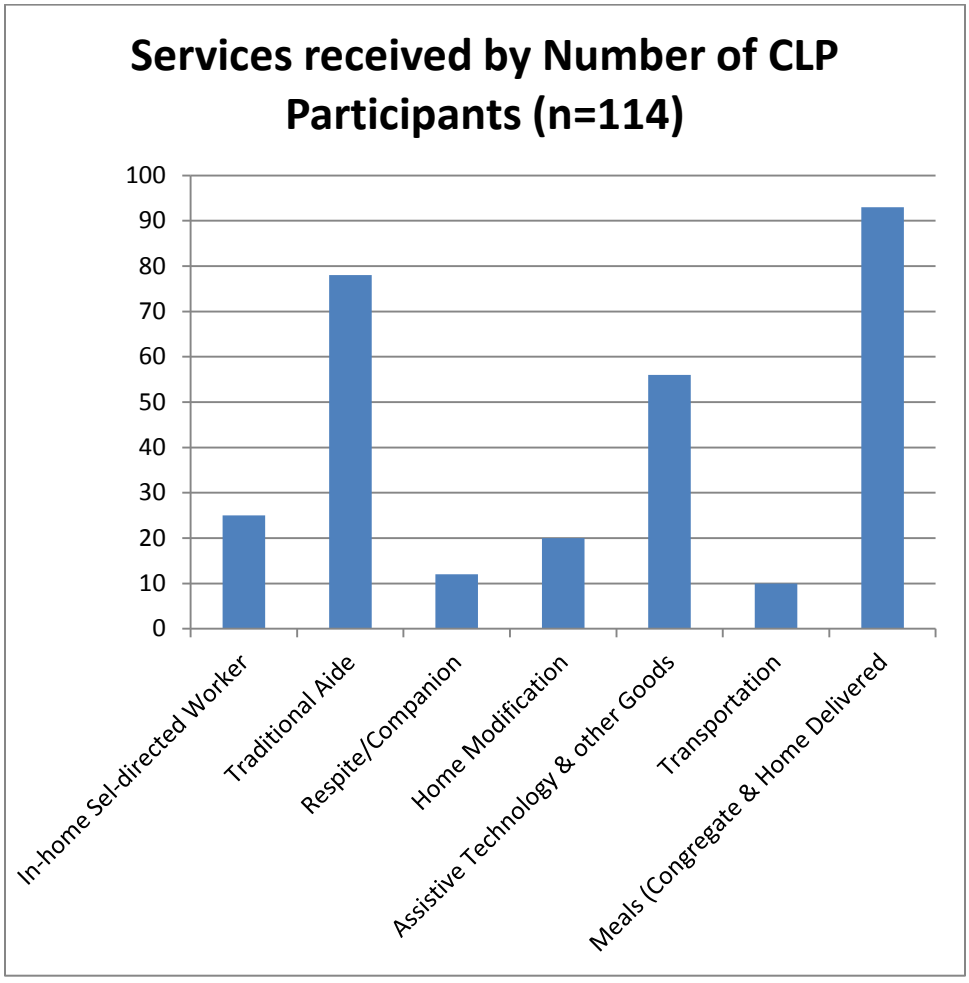
- Personal care (consumer-directed and traditional)
- Companion services (consumer-directed or traditional agency)
- Respite
- Purchase or repair of equipment and assistive technology (e.g., lift chairs, monitoring systems)
- Home modifications (e.g., wheelchair ramps, plumbing to move washer/dryer, bathtub rails and grab bars)
- Transportation (to appointments, day program and/or social engagement)
- Meals (both home delivered and the opportunity to attend a congregate meal site)
- Small appliances (microwaves)

From interviews with case managers/care coordinators, approximately 40% of participants considered hiring an in-home services worker but ultimately only 20% did. As discussed earlier, some participants were already paying privately for personal care and considered transferring this responsibility to the FMS. In most cases this did not occur; however even in those cases, case managers/care coordinators were often successful in helping the consumer (or consumer representative) to better manage their use of their own resources through:

- Improved scheduling
- Help reducing the number of personal care hours consumers were purchasing by supporting the development and successful implementation of a one-time purchase such as a home modification which reduced the needed hours of care

In cases where employment was either transferred to an FMS or a private pay worker was replaced, there were reports by the consumers/consumer representatives of better supervision of employees through this approach.

Table 8



The majority of in-home services worker hires occurred because the consumer (or consumer representative) was interested in having greater consistency in the worker assigned than they were currently experiencing or had previously experienced through a traditional home care agency. In several counties where there was ready availability of traditional agency aides many participants reported being satisfied with current aides and chose not to choose an in-home services worker.

Quality Assurance: There was great concern to ensure timeliness and "completeness" in the consumer-directed experience. The project utilized the CMS Quality framework with standards and associated timeframes and activities to measure seven dimensions of quality: participant access; participant-centered planning & delivery; provider capacity and capabilities; participant safeguards; participant rights & responsibilities; participant outcomes & satisfaction; and system performance. Records and procedure reviews and interviews with key staff were used in the discovery phase to understand what was happening day to day and was shared with counties to support any needed remediation to support continuous quality improvement in delivery. In addition, every six months four to six consumers or consumer representatives were randomly selected and independently interviewed by telephone to

assess how well and how timely protocols were being followed. The calls also assessed consumer satisfaction with the program.

Specific findings from the consumer calls included:

- Everyone reported that participation in the program helped (all said that the program helped a lot)
- Consumer and consumer representative perceptions of the likelihood of going into nursing home without the program ranged from somewhat likely to almost certain with a majority saying very likely or almost certain
- Every consumer reported feeling safe in their home
- All consumers and consumer representatives reported satisfaction with the level of case manager/care coordinator contact they received
- No problems were identified with timeliness of program delivery

Some examples of comments provided by consumers included:

"We really needed help. My mother didn't want to go to a nursing home and the whole family has worked hard to make sure that didn't happen,… we were getting exhausted and just needed some help,… I think she got to stay home those last few months before she died because of this program,...." *Bill H.*

"I really appreciate the home delivered meals, I always wear the PERS now and that microwave they bought is so easy to use,…" *Mary G*.

In the spirit of continuous improvement, the approach in all quality assurance activities was not to be fault finding but to inform improvement with technical assistance offered and changes in procedures considered where barriers to effective and timely delivery were encountered.

Many of the quality and implementation issues were also discussed in the monthly multi-county teleconferences sponsored by the New York State Office for the Aging. This process helped to refine overall project implementation and to inform the development of procedures for statewide consumer-directed services implementation in EISEP.

(4) Systems Change

As previously noted, the New York State Office for the Aging has been working on including consumer-directed approaches in the state funded Expanded In-home Services for the Elderly Program (EISEP), which funds personal care services, in addition to case management, non-institutional respite and other services for older adults served by AAAs. Evaluation staff had the opportunity to provide information to inform this process.

(5) Outcomes Data

There were two outcomes established for the project, divert persons from nursing home placement and divert from Medicaid spend-down. To assess these outcomes it was decided to examine the status of enrolled participants who had care plans and budgets established and who were in receipt of services

under the plan. This resulted in a sample of 114 persons all of whom had been enrolled for a minimum of 90 days and who had an average enrollment of 12.6 months.

Nursing Home Placement: Over an average of 12.6 months of program enrollment, 89% of 114 participants, all at measured risk for nursing placement, did NOT enter a nursing home. During the course of the project 12 participants (11%) were admitted to a nursing home.

Medicaid Spend-Down: Over an average of 12.6 months of enrollment, only one of 114 participants entered Medicaid supported home care.

NOTE: Nine participants died and three moved out-of-state during the course of the project.

At the request of the New York State Office for the Aging, a basic cost analysis was also undertaken. Given that all participants were judged at risk both for nursing home placement and Medicaid Spend-down, costs were compared for:

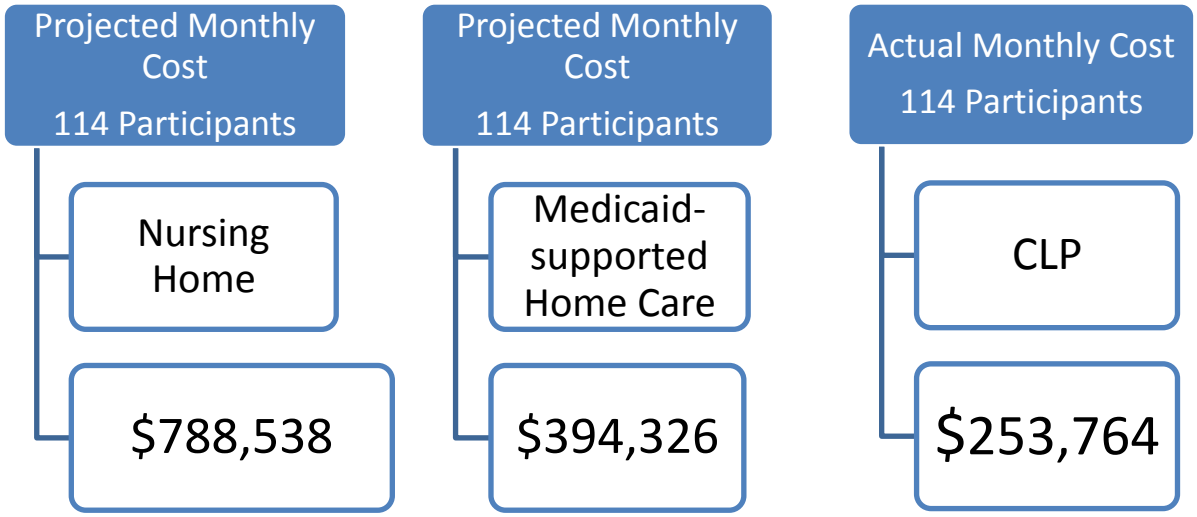
- Nursing home placement (calculated at approximately $6,917 per month based upon an annual nursing home cost to Medicaid of $83,000)
- Enrollment in Medicaid-supported home care programs (estimated for Central New York as half the nursing home cost to Medicaid, i.e., approximately $3,459 per month))
- Actual consumer-directed costs for 114 individuals who participated for at least three months in CLP and for whom complete consumer-directed cost data was available (an average monthly cost of approximately $461 for consumer directed services and approximately $1,765 for associated case management/administrative supports per person served was derived from an average of 12.6 months of actual service delivery to the group).

If the CLP participants (all of whom were at risk) were to spend-down to Medicaid and had to receive Medicaid-supported home care, the monthly costs of these 114 participants would be approximately $394,269 per month. Alternatively, if these same 114 participants were to enter into a nursing home, their costs would reach approximately $788,538 per month.

The CLP cost comprised a monthly total of approximately $52,554 of costs attributable to each care plan and budget and approximately $113,772 in monthly case management/care coordination costs and approximately $87,438 in monthly supervisory and administrative costs. Interviews with county administrators indicated that there were higher than usual supervision and other administrative cost to support start-up of this project; such costs would therefore be expected to decline as use of consumer-directed approaches progresses. It would also be expected that as consumers are able to continue to stay at home and in the community and to maintain their resources, that there may be additional savings over time as compared to nursing home and Medicaid-supported home care costs.

With the CLP costs for all 114 people included, CLP at minimum saved the public $140,562 per month (Medicaid-supported home care costs of approximately $394,326 minus CLP costs of approximately $253,764) and may have saved the public as much as $534,774 per month (Medicaid nursing home costs of approximately $788,538 minus CLP costs of approximately $253,764) – see figure 1.

Figure 1 Cost Comparison: CLP, Nursing Home and Medicaid-supported Home Care



Summary

Implementation of CLP was a success with consumer satisfaction exceptionally high and savings realized as compared to nursing home and Medicaid-supported home care costs. Challenges were experienced in recruitment, in funding care plans and in extending a full range of services in some counties. Nevertheless an effective and easily administered training program for case managers/care coordinators was established, model policies and procedures implemented, effective and successful linkages between NY Connects and county AAA staff in coordinating screening and assessment functions demonstrated, and utilization of existing State and Federal funding streams modeled. Consumer-directed approaches appeared to work well with prevalent service philosophies in county AAAs, and CLP was seen to successfully extend the efforts of AAA programs and NY Connects to reach individuals and families at risk before risk becomes a crisis. Most importantly, almost 90% of participants enrolled for at least three months were diverted from nursing home placement.

On a system-level, the success experienced and cost savings realized should encourage New York State to further expand use of consumer-directed approaches. The policy and regulatory work now being extended to EISEP will position services offered through AAAs to further advance the inclusion of consumer-directed approaches and the successful maintenance of greater numbers of older adults in the community.