Nursing Home Diversion Modernization Program Final Evaluation Report

Philip McCallion, Ph.D. & Lisa A. Ferretti, LMSW

Center for Excellence in Aging & Community Wellness, University at Albany

www.albany.edu/ceacw

Submitted: January 18th 2011

Nursing Home Diversion & Modernization Project (NHDMF)
Fund by the U.S. Administration on Aging and the State of New York

Participating Counties: Broome, Oneida & Onondaga

Project Director: Gail Koser
Assistant Director, Division of Policy, Research and Legislative Affairs
New York State Office for the Aging
2 Empire State Plaza
Albany NY 12223-1251
Gail.Koser@ofa.state.ny.us
Summary

The New York State Office for the Aging received a 2008 Nursing Home Diversion Modernization (NHDM) 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 18 month grant period one hundred and thirty-three individuals from Broome, Oneida and Onondaga Counties were served, exceeding the project target of 100. The ‘typical’ consumer participating in the NHDM was aged 80 and over, had three or more ADL needs and five or more IADL needs. Of the participants in the program, 32% chose to direct their services themselves, and all others appointed a consumer representative.

The consumers admitted to the NHDM actively worked with case managers/care coordinators to craft their own care plan and budget. Through those plans, 68% of participants accessed assistive technology and home renovations and purchased goods and services; 26% 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 developed procedures and training modules to identify eligible participants for the program and support the delivery of consumer-directed care. The New York State Office for the Aging has also initiated regulatory changes designed to support the extension of these 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 NHDM was at an objectively established risk for nursing home placement and Medicaid spend-down. However, of the 93 participants who were in the program for at least 90 days and who were then served for an average of 8.34 months of program enrollment, 81% of participants did NOT enter a nursing home and for the same group 83% did not spend down to Medicaid. The total monthly savings realized were $89,157 (compared to State average Medicaid funded in-home care) or $410,780(compared to State average nursing home care costs).

Over a relatively short period of time considerable success was demonstrated in modernizing services to include 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 2008 Nursing Home Diversion Modernization (NHDMAP) grant from the U.S. Administration on Aging (AoA). The grant began on September 30, 2008 and was funded for 18 months with a no-cost extension for six months, ending September 30, 2010. 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 NHDMAP grant was implemented in three counties in New York - Oneida, Broome, and Onondaga - 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).

**Broome County**

Broome County, with a population of approximately 200,000, is located in the Southern Tier of New York State. With one large city, Binghamton, the county comprises small towns, villages and rural areas stretching along the Pennsylvania border. Persons aged 60 and older comprise 21.7% of the population and the oldest old (those over 75) are the only growing population group in the county, increasing in numbers by 3% over the last decade. The Broome County Office for Aging assists seniors and caregivers by providing the services and benefits that elders need to live independently, offering those services both in the community and in people’s own homes. During 2009, the Office for Aging provided services and benefits to 11,103 identified seniors and caregivers, with 51% of those served aged 75 or older.

**Oneida County**

Oneida County is a mix of small towns and cities and rural communities in central New York with a population of approximately 235,000, of whom 21.5% are over the age of 60. The Oneida County Office for the Aging and Continuing Care serves as the lead planning, funding and advocacy agency for older adults and also for persons of any age with disabilities, their families and caregivers with a goal of maintaining maximum independence through service provision. In 2009, this Office for the Aging served a total of 12,049 unduplicated consumers with a variety of services including information, assistance, and community based in-home services. On-going case management and in-home services were provided to approximately 3,000 individuals.

**Onondaga County**

Onondaga County, in the west central area of New York State, has a population of approximately 454,000 people, of whom approximately 18.6% are over age 60. The county comprises one large city, Syracuse, several suburban communities, small towns, villages, and rural areas. The Department of Aging and Youth (Onondaga County’s AAA) offers a full range of programs and services for the approximately 84,000 county residents aged 60 and older. In 2009, meals programs reached over 6,000 older adults, and over 80,000 hours of in-home non-medical care and social adult programs were provided.
The three counties were chosen as pilots based on the following criteria:

- Each has a long history of local innovation and a readiness for taking on this new initiative.
- Each has a well-established NY Connects program (New York’s ADRC).
- Each provides all the core functions required by the federal government for the purposes of this grant, such as the provision of information and assistance on long term care options.

Based on data provided by AoA, there were a total of 16,583 seniors eligible for nursing home diversion in New York State; the project was intended to serve 100 participants, or 12% of eligible older adults in the three pilot counties.

**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 monthly, structured visits to each county, technical assistance conference calls, and on-site technical assistance on an as-needed basis throughout the NHDMP. 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 prepare for the successful implementation of consumer-directed services and of changes in operations/procedures/practices that would support both project specific delivery and any future 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 NHDMP from reviews of care plan documents, assessment instruments and interviews with case managers/care coordinators
• Tracking of consumer progress in NHDMF 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
• 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 SPSS16. 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 significant collaboration between the New York State Office for the Aging, staff from the three participating AAAs, and the Center for Excellence in Aging & Community Wellness. 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 for NHDM 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 NHDM. 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 NHDM. An addendum was developed that permitted supplementing the DMS-1 score with points for IADLS, informal supports, and health events.

**Standards for Who Can Provide In-Home Services**: The standards that were adopted for the NHDM 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 able 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 NHDM, the New York State Office for the Aging and partners 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 Nursing Home Diversion Modernization 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 NHDM.

**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 NHDM. The model includes instruments and forms such as the NHDM 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 NHDM, 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.

**Training:** Staff from the Center for Excellence in Aging and Community Wellness provided online, phone conference, and in-person trainings for all three 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 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.

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 the pilot 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 either underway or being discussed 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 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. Subsequently, delivery of the NHDMAP model was monitored during the monthly technical assistance visits to ensure that it was being delivered as intended.

Included in the monthly 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 NHDMAP 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 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, helping consumers (or consumer representatives) through the process of arriving at a decision and avoiding the presentation of information on services in certain 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) **Pre-screening**

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

1) **Different Auspices:** for one county (Oneida) NY Connects was embedded in the AAA, for another (Broome) they were separate but co-located and for the third (Onondaga) 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 three 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 the three counties, local targeting requirements for current 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 NHDM among the more than 1,000 potential enrollees identified for the project. A review of the screening records indicated that over 85% met income and asset ranges for the project, demonstrating that both NY Connects and the AAAs moved quickly and decisively to identify appropriate consumers. Meeting other screening/assessment criteria and consumer choice then reduced the final numbers to 133 participants.

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 cases (19) – see Table 1 - a DMS-1 supplement score was added so that persons with IADL as opposed to ADL needs were included, as were 17 who exceeded the 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 NHDM. A majority of those who scored above 180 were from Oneida County. 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>
<thead>
<tr>
<th>DMS-1 Scores</th>
<th>Number of Consumers</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;59</td>
<td>19</td>
</tr>
<tr>
<td>60-119</td>
<td>47</td>
</tr>
<tr>
<td>120-179</td>
<td>50</td>
</tr>
<tr>
<td>&gt;180</td>
<td>17</td>
</tr>
</tbody>
</table>

**Functional Eligibility - Who Was Served**

DMS-1 Scores - Combined (n=133)

There were also some persons who were accepted with lower (4) or higher (7) income, or lower assets (28) because it was believed they would otherwise benefit from the program. A majority of those with higher income and assets were from Onondaga County and those with lower incomes and assets were mostly from Broome and Oneida Counties. 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).

(3) **Consumer-directed Implementation**

The three NHDMP counties began serving participants in the fourth quarter of the first project year. Oneida served its first participant beginning June 1, 2009. By August 1, 2009 all three pilot counties were serving participants. As of March 31, 2010, the project goal to enroll 100 participants (Oneida - 37, Broome - 30, Onondaga - 33) was achieved. Enrollment continued throughout the six month no cost extension period and by September 30, there were 133 participants enrolled in the NHDMP (Oneida – 55, Broome – 32, Onondaga – 46).

**Demographics:** Approximately 76% of participating consumers were over age 80 with many (24%) aged 90 and older (see Table 2); less than 38% lived with a spouse; almost 50% lived alone; and twice as many females as males were served.

Table 2

<table>
<thead>
<tr>
<th>NHDMNP Participant Age Groups (n=133)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Individuals</td>
</tr>
<tr>
<td>60-64</td>
</tr>
<tr>
<td>65-69</td>
</tr>
<tr>
<td>70-74</td>
</tr>
<tr>
<td>75-79</td>
</tr>
<tr>
<td>80-84</td>
</tr>
</tbody>
</table>

**Personal Finances:** Most 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**

**Financial Eligibility (Income) - Who Was Served**

Monthly Income - Combined (n=133)

![Bar chart showing distribution of monthly income among consumers](chart1)

**Table 4**

**Financial Eligibility (Assets) - Who Was Served**

Assets - Combined (n=133)

![Bar chart showing distribution of assets among consumers](chart2)

**Identified Levels of Need:** Approximately 69% of participants (see Table 5) had 3 or more ADL impairments such as assistance with 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 (59% had 5 or more IADL impairments).
**Table 5**

Number of ADLs for which NHDMMP
Participants Needed Assistance (n=133)

<table>
<thead>
<tr>
<th>Number of ADLs</th>
<th>Number of Individuals</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>1</td>
<td>16</td>
</tr>
<tr>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>3</td>
<td>26</td>
</tr>
<tr>
<td>4</td>
<td>28</td>
</tr>
<tr>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>7</td>
<td>7</td>
</tr>
</tbody>
</table>

**Table 6**

Number of IADLs for which NHDMMP
Participants Needed Assistance (n=133)

<table>
<thead>
<tr>
<th>Number of IADLs</th>
<th>Number of Individuals</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>7</td>
<td>20</td>
</tr>
<tr>
<td>8+</td>
<td>28</td>
</tr>
</tbody>
</table>

**Self-direction**: Approximately one third of participants 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 many consumer representatives who lived separately and some
consumers with live-in family members remained self-directing. An important distinction was that consumers with cognitive difficulties all used a consumer representative. During monthly 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 NHDMF 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; in one case an initially self-directing consumer decided to rely on a family member as a representative instead, in two cases the consumer representative came to realize that the responsibilities were beyond their time availability and it was transferred to another family member, and in four cases the consumer decided not to proceed with consumer-directed services because they did not want this level of responsibility.

**Care planning:** Care planning was guided by the NYS NHDMF 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 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 particularly in the initial stages, case managers/care coordinators did not always have the information they needed to advance the process, and consumers (or consumer representatives) were not always ready to make decisions, thereby delaying the completion 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 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.

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

**Case Description 1**

*Consumer #1 was an 87 year old, widowed female, living alone. 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.*

At the time, she was already receiving home delivered meals, and was on a waiting list for a personal care aide to help with housekeeping. However, she expressed she was most interested in a social outlet, a way to get out of the home. Current informal supporters were not willing to transport but did help her by running errands very infrequently. The consumer’s home was also excessively cluttered, resulting in narrow passageways, making maneuvering somewhat difficult. Because the consumer lived alone, met the financial requirements, and largely managed her own care with minimal involvement from her informal support network, she was considered to
be eligible for consumer-directed care. The consumer made the decision to be self-directing, not believing she needed a representative.

The case manager/care coordinator recognized the consumer’s primary wish: opportunities to socialize with others, but also raised that the amount of clutter in the consumer’s home meant that navigation was difficult and raised some concern for her safety.

The consumer had a daughter-in-law who did what she could to help, but was becoming very overwhelmed with this and other responsibilities. Given this, the consumer either wanted her daughter-in-law to be reimbursed for her assistance, or to receive supplemental services to remove the burden of care. Although the consumer did not think addressing the clutter in her home was important and thought that it was not a safety issue, she did eventually decide to make efforts to lessen the clutter in her home, as part of her care plan.

The case manager/care coordinator provided and explained to the consumer a general list of services and goods likely to be helpful, encouraged the consumer to add to the list and then encouraged discussion of options. For instance, the idea of a chair lift, though ultimately not chosen, was discussed as a means to help the consumer get down the stairs more easily to do laundry. Additionally, heavy cleaning services suggested by the consumer were considered; something not normally done by the Office of Aging but available under this program. Consumer-directed in-home services were also discussed, at which point the daughter-in-law requested not to be a paid aide. This discussion ultimately led to utilizing the services of an agency provided companion with the daughter in law continuing to help with ADLs and IADLS as she was able. To get out of the house more, the consumer chose to attend a congregate meal site three days a week with associated transportation in lieu of home delivered meals.

Case Description 2
Consumers #2 was 87 years old, and living with her spouse. All IADLs required assistance, and ADL needs included assistance with bathing, dressing, hygiene, and walking.

This consumer was referred because she was refusing care from licensed home care provider agencies. She had a history of receiving personal care assistance, but with her Alzheimer’s disease progressing, the aide needed to cue her to take a bath, which upset the consumer and caused her to dismiss the aide.

The consumer was eligible for consumer-directed care because her husband was already very involved in her care by supervising her all day, keeping their schedule, and managing every day activities and because, when the role was explained, he was willing to be her consumer representative. The husband also had needs; he was becoming overwhelmed, was looking for additional help with supervising his wife and he needed someone to assist her with ADL care.

The case manager/care coordinator worked with the spouse to gain a sense of what the consumer was like and what her preferences would have been. Contact with a previous case manager/care coordinator was also helpful. The husband’s difficulty hearing over the phone, discomfort with phones, and hesitancy in admitting the need for help encouraged the case manager/care coordinator to visit several times in the initial stages in order to build rapport and really understand the wishes and needs.
In the initial plan the husband decided he preferred to have companion services two days a week to help with supervision and he and a daughter who visits occasionally would address ADL needs themselves. Then he himself experienced a fall and reluctantly recognized that he needed additional help. When the case manager/care coordinator discussed the possibility of recruiting an in-home services worker, the husband declined, not wanting the hassle of advertising and going through an interview process. He did agree to try an aide from a different home care agency and discussed his need to interview the aide and observe the aide with his wife so that he could see if she was comfortable before he agreed to on-going services. This approach worked and the plan included two hours of agency provided personal care, twice a week.

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.** 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 NHMDP for EISEP and for any Older Americans Act programs accessed to support NHMDP. Cost share levels varied greatly for participants. Almost 50% of consumers were at a no cost share level, but there were approximately 21% of participants who were at 40% or higher cost share (see Table 7).

**Table 7**

<table>
<thead>
<tr>
<th>Initial Cost Share (n=133)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Consumers</td>
</tr>
<tr>
<td>0%</td>
</tr>
<tr>
<td>65</td>
</tr>
</tbody>
</table>

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. 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, working with an FMS, and providing
consumers (or consumer representatives) with financial reports. 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 one county 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
- 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 three 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 $833 per month over
approximately 8 months. For about 25% of cases there was a need for a budget modification to raise
the amount available (in 60% of cases because of increased needs, but for 40% because progress was
not made on a large one-time expense such as a renovation and budget dollars were reallocated to
more personal care hours and to other goods and services). That said, in a majority of cases less money
was actually spent than was allocated in the budget; again there were delays in implementing large one-
time purchases and consumers changed their minds about expenditures.

There were other reasons for both budget modification and budget under-spending. In reviewing
budget documents and in discussions with case managers/care coordinators a picture emerged of
consumers and consumer representatives who were interested in the cost of items and who proved
frugal in their use of public dollars to support their care. A prime example was a consumer for whom a
stair-glide was to be purchased who was dissatisfied with the lowest of the three bids initially obtained
and independently found an additional bidder able to supply a refurbished model at 50% of the cost presented by the prior lowest bidder.

**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, hospital beds, adaptive equipment, stair lift/glide)
- Home modifications (e.g., wheelchair ramps, plumbing to move washer/dryer, driveway surface for wheelchair vehicle, stair and bathtub rails and grab bars)
- Small appliances

**Table 8**

<table>
<thead>
<tr>
<th>Services Received by NHDMP Participants (n=133)</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-Home Services Worker</td>
</tr>
<tr>
<td>Respite/Companion Care</td>
</tr>
<tr>
<td>Traditional Personal Care</td>
</tr>
<tr>
<td>Home Modifications</td>
</tr>
<tr>
<td>Assistive Technology &amp; Other Goods</td>
</tr>
<tr>
<td>Transportation</td>
</tr>
<tr>
<td>Meals (Congregate &amp; Home Delivered)</td>
</tr>
</tbody>
</table>

From interviews with case managers/care coordinators, approximately 40% of participants considered hiring an in-home services worker but ultimately only 26% 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 the four 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.

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 approximately 40% of cases where an in-home services worker was used, there was also past history of difficulty in locating aides in the area where they lived (often rural but sometimes suburban, not on a bus line). In home services workers were usually already known to the consumer (or consumer representative). As one consumer said .... I always wanted to have my granddaughter as the aide... but some were hired after the consumer (or consumer representative) interviewed several candidates found on lists maintained by the FMS. Both approaches were found to result in successful in-home services worker placements.

**Quality Assurance:** There was great concern to ensure timeliness and “completeness” in the consumer-directed experience. The project adapted the CMS Quality framework and developed standards with 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 but one 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:

“The Community Living Program completely changed the tenor of all our lives. My mom has repeatedly said she would "die" if she ever had to go to a nursing home. Thanks to your support, each day she is transported and attends the day program she gets stronger emotionally and physically.” ~Sam C.

“Thanks to the stair glide we were able to purchase through the program, my father was able to go upstairs to sleep comfortably in his own bed for the first time in over a year.” ~Mary C.

“Since we got the stair glide, my husband and I are both able to go downstairs. Getting outside is much easier now with the ramp we’ve had installed, and we are much happier and much more independent.” ~Virginia W.

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 to effective and timely delivery were encountered.

Much was learned in the quality assurance process about the challenges for consumers who were not used to being a full partner in both decision-making and in taking responsibility for their care plan and budget. As a result, the explanation of the program was refined for new cases, timeframes were established for revisiting care plan components when consumers or consumer representatives were hesitant to proceed (happened particularly with large item purchases and renovations) and criteria was formulated for deciding when a level of services was beyond the means of the program.

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 the training modules and the overall project procedures for the three NHDMC counties, as well as for the seven counties who later joined the Community Living Program. These procedures will be included in consumer-directed services in statewide implementation of EISEP.

Included in technical assistance was support for the three counties to adopt local quality assurance standards and procedures and such adoption was successfully achieved and implemented in all three counties.

(4) Systems Change
In their pursuit of the NHDMC opportunity, the New York State Office for the Aging was interested in understanding the policy, procedure, and administrative changes necessary to incorporate and sustain consumer-directed approaches, particularly through 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 both provide information to inform this process and observe related outcomes.

NHDMC proved a catalyst for significant reform in New York State’s long term care system. Throughout the project the New York State Office for the Aging engaged in a process to modify EISEP regulations. The revisions expanded the definition of ancillary services and increased the percentage of EISEP funding that an AAA may use for ancillary services from 10% to 33%. This provides increased flexibility and options for addressing client needs. Additionally, emergency regulations were adopted on
September 22, 2010 to support the greater flexibility needed by counties participating in NHDMF and in the Community Living Program. These emergency regulations were subsequently resubmitted using the regular rule-making process and are expected to become final early in 2011. This will allow AAAs throughout NYS to incorporate consumer directed in their EISEP program.

(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 93 persons all of whom had been enrolled for a minimum of 90 days and who had an average enrollment of 8.34 months.

Nursing Home Placement: Over an average of 8.34 months of program enrollment, 81% of 93 participants, all at measured risk for nursing placement, did NOT enter a nursing home. During the course of the project 18 participants (19%) were admitted to a nursing home.

Medicaid Spend-Down: Over an average of 8.34 months of enrollment, 83% of 93 participants did not spend down to Medicaid. Where spend-down did occur, it appeared to be less about the levels of income and assets at the start of the program and more about rapidly changing and demanding care needs. This latter point is important given that some individuals were admitted into the program (through a waiver process) who did not meet the initial income and asset criteria.

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 $6,916.67 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., $3,458.34 per month)
- Actual consumer-directed costs for 93 individuals who participated for at least three months in NHDMF and for whom complete consumer-directed cost data was available (an average monthly cost of approximately $833.00 for consumer directed services and approximately $1,666.67 for associated case management/administrative supports per person served was derived from an average of 8.34 months of actual service delivery to the group).

If the NHDMF participants were to spend-down to Medicaid and had to receive Medicaid-supported home care, the monthly costs of these 93 participants would be approximately $321,626. Alternatively, if these same 93 participants were to enter into a nursing home, their costs would reach approximately $643,250 per month. Since NHDMF was successful in helping participants to avoid Medicaid spend-down and nursing home placement, NHDMF at minimum saved the public $89,157 per month (Medicaid-supported home care costs of approximately $321,626 minus NHDMF costs of approximately $232,469) and may have saved the public as much as $410,780 per month (Medicaid nursing home costs of approximately $643,249 minus NHDMF costs of approximately $232,469) – see figure 1.
The NHDMGP cost comprised a monthly total of approximately $77,469 of costs attributable to each care plan and budget and approximately $74,250 in monthly case management/care coordination costs and approximately $80,750 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.

Summary

Implementation of NHDMGP was a success with recruitment targets exceeded, consumer satisfaction exceptionally high and savings realized as compared to nursing home and Medicaid-supported home care costs. An effective and easily administered training program for case managers/care coordinators was established, model policies and procedures developed, 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 NHDMGP was seen to successfully extend the efforts of AAA programs and NYConnects to reach individuals and families at risk before risk becomes a crisis. Most importantly, 81% of participants enrolled for at least three months were diverted from nursing home placement and 83% of those same participants were diverted from Medicaid spend-down.

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 undertaken to support implementation of NHDMGP and 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.

**Next Steps**

Given the successes of the initiative in the three Broome, Oneida and Onondaga counties individuals who participated in the NHDM will be followed for another 12 months post grant initiative to track, review, and assess the extent to which the expectation of additional savings over time in Medicaid and nursing home costs holds true for NHDM participants.