

Rebalancing Initiative Pilot Project Executive Summary

Prepared by:
William Lamb, Associate Director for Public Service
Judie Svihula, Research Scientist
UNC Institute on Aging

September 26, 2008

On August 1, 2007, the North Carolina Department of Health and Human Services (DHHS) amended its CAP/Choice waiver program to encompass the Rebalancing Initiative Pilot Project (Pilot). CAP/Choice is a consumer directed waiver that allows Medicaid recipients to take responsibility for managing and making decisions about their care. The Pilot allowed 30 Medicaid recipients to access self-directed community-based services and support options in Forsyth and Surry Counties. To be eligible for the Pilot, participants had to have a significant physical disability and be an adult in the age group 18 through 64; Medicaid eligible, discharged from an acute care setting, and at risk of nursing facility placement.

Through the Pilot, the Rebalancing Initiative Local Leadership Team planned to examine various issues with the current long term care system, including premature nursing facility placements, the dismantling of individuals' homes, loss of informal support system, greater cost to taxpayers, and compliance with the Olmstead decision. The Institute on Aging, University of North Carolina at Chapel Hill (IOA) was contracted to conduct an evaluation of the Pilot.

There were few referrals to the Pilot in both Surry and Forsyth Counties, resulting in three participants. To evaluate the Pilot, IOA researchers conducted pre- and post-test interviews with key informants who were involved in implementing the Pilot; conducted interviews with the Pilot participants as well as three CAP/DA waiting list participants, and compared the experiences of the Pilot key informants with the experiences of care advisors who have been involved with the CAP/Choice program in Duplin and Cabarrus Counties for more than three years.

The challenges faced by the key informants who were involved in the Pilot fell into five major categories: a) pilot implementation, b) planning process, c) discharge process, d) financial management, and e) eligibility criteria. Key issues are discussed in the following paragraphs.

Implementation was a challenge because the Pilot embodied a different philosophy and a largely unfamiliar population to serve. Moreover, the scope of work was unknown. Although communication with Cabarrus and Duplin Counties about their implementation of CAP/Choice was helpful, Forsyth and Surry Counties were dissimilar enough from these counties that they were unable to replicate Cabarrus' and Duplin's start-up

processes. Uncompensated time and effort involved in setting up the Pilot, including the unrecompensed expense of the fiscal intermediary, created much greater administrative burden than was anticipated.

Comments by many of the key informants about the planning process portrayed a discomfort with the participatory planning method and taking charge of the Pilot implementation. Due to shifts in management, disconnects in State-level communication regarding the Pilot created barriers to implementation and exacerbated the already high level of discomfort with taking control of the Pilot start-up.

Key informants stated that the discrepancy between the eligibility criteria and the ideal population for the Pilot made it difficult to obtain appropriate referrals. The acute care discharge requirement as well as the lengthy Medicaid eligibility process posed challenges in identifying individuals with the capacity and willingness to take on the responsibility for their care. The following paragraphs list the lessons learned from the challenges the key informants faced during the Pilot.

Lesson 1: Including all stakeholders in planning a pilot project requires a detailed explanation and frequent reiteration of: a) the overall goals and objectives of the project; b) the planning process, including the planning method; and c) the degree of control stakeholders should take in project implementation.

Lesson 2: Changes in stakeholder roles, program philosophy, and populations served requires advanced planning and education. This may include: a) an interim period between planning and implementation to review and reflect on the approaches and possibilities; b) identifying and negotiating systemic barriers; c) contracting with another group to collect, analyze, prepare and provide information and training to stakeholders; and d) engaging consumers of other pilot projects to share their experiences.

Lesson 3: It is critical to settle financial and administrative issues before pilot implementation, including state-level communication regarding the pilot and account codes as well as administrative and staff time involved in start-up, and fiscal intermediaries.

Lesson 4: To obtain successful referrals there needs to be an appropriate fit between the eligibility requirements and possible consumers.

Recommendations key informants made for implementing CAP/Choice, included:

- Provide advance planning to consumers and their families before a crisis occurs
- Provide potential consumers and their families with a choice in personal care options when they enter an acute care facility
- Establish a “presumptive Medicaid” eligibility process to speed up access to services
- Establish a state consultant and fiscal intermediary

The key informants added that it is necessary to have a good working relationship and collaboration among all community services agencies and that expanding existing services and case management as well as adding transportation options are essential components to the success of CAP/Choice.

Interviews with six consumers, three Pilot participants and three CAP/DA waiting list participants, provided additional insight into key components for individuals' success in self-directing their care. The main reason given by Pilot participants for participating in the project were the flexibility and increase in in-home aide hours, as well as the ability to obtain non-traditional services and supplies. After hospitalization, Pilot participants as well as CAP/DA waiting list participants required higher levels of care and had greater need for assistance from family members. Both groups of participants stated that their greatest care requirement was to have in-home care assistance, in particular assistants "who care". In addition, it was important to obtain medical equipment and supplies. Both groups also expressed a desire to remain independent. In contrast with the Pilot participants, the CAP/DA waiting list participants identified a need for transportation.

It appears that the cost of providing CAP/Choice services to the Pilot participants was less expensive than either CAP/DA or nursing facility placement. The participants responded positively to the Pilot and experienced positive results. All three participants received services much quicker than they would have otherwise; one avoided nursing facility placement, one achieved greater independence through the ability to transfer from bed to wheelchair; and one is increasing muscle strength and coordination at home by supplementing out patient rehab with a *Wii* exercise software video.

In conclusion, many states are adopting some form of consumer-directed care. The evaluation research reported here demonstrates the value of monitoring a pilot as it is implemented. The evaluation findings do not permit unequivocal policy recommendations. Instead, a policy judgment about consumer-directed care depends on weighing the benefits to consumers and their families against increases in job pressures for agency workers and in unconventional Medicaid expenditures.

**Evaluation Report
Rebalancing Initiative Pilot Project**

**Prepared by:
William Lamb, Associate Director for Public Service
Judie Svihula, Research Scientist
UNC Institute on Aging**

September 26, 2008

The Rebalancing Initiative Pilot Project (Pilot) was originally designed to allow 30 participants to obtain a CAP/DA slot and have immediate access to services and supports upon discharge from a hospital or acute rehabilitation facility. However, the design for the pilot had to be modified because it was only possible to amend the CAP/Choice waiver. As a result, the North Carolina Department of Health and Human Services (DHHS) CAP/Choice program expanded its community-based service and support options for Medicaid recipients to include Surry and Forsyth Counties on August 1, 2007.

The Pilot was introduced through a kick-off event on August 15 in both Surry and Forsyth Counties. The eligibility criteria for the Pilot included adults ages 18 through 64; Medicaid eligible, discharge from an acute care setting, at risk of nursing facility placement, and having a significant physical disability. Through the Pilot, the Rebalancing Local Leadership Team (Team) planned to examine issues with the current long term care system, including premature nursing facility placements, the dismantling of individuals' homes, loss of informal support system, greater cost to taxpayers, and compliance with the Olmstead decision.

CAP/DA and CAP/Choice are Home and Community Based waiver programs that provide an array of services which promote community living for Medicaid beneficiaries who would otherwise be at risk for nursing facility placement. Waiver services complement and/or supplement the supports that families and communities provide as well as the services provided through the Medicaid State Plan and other public programs. Services are provided to recipients living in private residences.

CAP/DA is a "traditional" waiver in which providers take the lead role in directing client services. CAP/Choice is a consumer directed waiver in which the waiver participant leads the development of the plan of care and has the authority and responsibility to manage and make decisions about waiver services. CAP/DA is available statewide while CAP/Choice is currently available only in four North Carolina counties. In both programs, recipients must be deemed able to remain safely in their homes.

CAP/Choice is a Medicaid waiver program that provides some services in common with CAP/DA as well as additional services for individuals electing to self direct their care. Services common to both programs include adult day health care, in-home aides, waiver supplies, home mobility aids, preparation and delivery of meals, telephone alert,

in-home respite, institutional respite and case management (care advice in CAP/Choice). In addition, the CAP/Choice program provides financial management, personal assistant services, and consumer directed goods and services. CAP/Choice participants have the option to hire their personal care assistants or use a home health agency. During the Pilot project there was a delay in processing the home health agencies' paperwork in order for them to obtain provider approval; however, this delay did not appear to impact the Pilot process.

The Institute on Aging, University of North Carolina at Chapel Hill (IOA) was contracted to conduct an evaluation of the Pilot project. Following is a brief summary of county activities related to participant screening and referrals across the Pilot period in Surry and Forsyth Counties.

Surry County

Over the pilot period, Surry County received three referrals, two were pre-screened and found to be inappropriate, and one did not wish services. There were four other inquiries, which did not meet the pilot criteria for the following reasons: not a hospital discharge, not in the target age group, and/or not Medicaid eligible.

Forsyth

Forsyth County had ten referrals, and three were deemed appropriate for the Pilot project. Six referrals did not meet the Pilot criteria for the following reasons: three were over age 64, one lived outside the service area (Stokes County), one was admitted to a nursing facility before a pre-screen could be done, and one was an Adult Protective Services case with "questionable" caregiver backup status. One referral was received July 18, but the county had stopped taking referrals in June because Senior Services, Inc. decided their staff could not handle any more Pilot participants due to the administrative burden involved.

Challenges Forsyth experienced and reported at the Local Leadership Team meetings included: coordination with a separate agency to do the education regarding the Pilot project; eligibility criteria for the Pilot participants versus the eligibility criteria for the community-based Medicaid program; lack of appropriate referrals; tremendous amount of time expended with a delay in reimbursement; and the self-directed component of CAP/Choice involving a financial intermediary was extremely costly.

Positive outcomes experienced and reported by Forsyth included: prescreens provided the necessary information to determine if the consumers were eligible, and were reimbursed; one participant would have been placed in a facility without the Pilot option; and two participants obtained services in place much sooner than if they were on the CAP/DA waiting list.

Because there were few Pilot participants, information was collected from Cabarrus and Duplin Counties, each of which have had three years of experience with CAP/Choice.

The experiences of these two counties were compared with the experiences of Forsyth and Surry Counties.

The remainder of this report comprises: a) an outline of the objectives of the Pilot project evaluation; b) themes developed from pre- and post-test interviews with key informants on their experience with the Pilot project, c) Cabarrus and Duplin Counties' experience with CAP/Choice, d) the initial roll-out of CAP/Choice in Forsyth County, e) participants' experiences based on interviews with three CAP/Choice Pilot participants and three CAP/DA waiting list participants, and f) a discussion of the Pilot outcomes and recommendations based on our observations of Team meetings as well as key informants' and participants' interviews.

Institution on Aging Evaluation Objectives

The Institute on Aging researchers planned to outline, using a comparative case approach, the participant and comparison group outcomes, the lessons that were learned, and key informant and participant suggestions for improving CAP/Choice. Three methods for collecting and analyzing data were anticipated, and two were utilized:

1. Work with the Division of Medical Assistance in order to describe trends in both expenditures and aggregated individual trajectories through services. The intention was that the data would allow the IOA researchers to assess whether the project had an impact on these trends when compared to other similar counties. Due to only three participants, the researchers could not assess whether the project had an impact on these trends thus did not collect such data. However, information was collected from Cabarrus and Duplin Counties, each of which have had three years of experience with CAP/Choice. The experiences of these two counties were compared with the experiences of Forsyth and Surry Counties.
2. The IOA researchers collected data from eleven Team members (key informants) at two points in time. The first survey (pre-test) asked these experts: a) which services are critical for individuals with disabilities to remain in their home or community as well as to transition individuals out of nursing facilities and back into their communities; b) what are the barriers and facilitating factors in individual circumstances that are important in stopping or reversing placement into a nursing facility; and c) what resources sustain and/or are needed to improve existing services and/or programs. The second survey (post-test) compared the experts' pre-test answers and the consumer data to ask questions that allowed the experts to evaluate the efficacy of the project overall. Data was requested of certain individuals in addition to the pre- and post-tests.
3. The researchers collected data from six participants: three Pilot participants and three CAP/DA waiting list participants. The data collected from the participants is anecdotal.

Key Informant Pre- and Post-test Interview Themes

The essential components of the Rebalancing Initiative Pilot Project (Pilot) identified by the key informants remained relatively unchanged between pre- and post-test. About two-thirds stated that community service provision to Medicaid recipients with disabilities to remain in their homes was the key component. About a quarter indicated that service awareness was an essential component.

Pre-test expectations of key informants regarding how participants would respond to the availability of services through the Pilot were positive overall. Key informants based this assessment on the idea that people want to remain in their homes. At post-test, about a third of the key informants noted that the three participants seemed pleased.

When asked at pre-test “What do you feel will motivate people to participate in the Pilot project?” almost half said the availability of consumer directed, individualized care and about a quarter said avoiding “placement.” At post-test, key-informants stated that the low participation was not as much due to motivation issues as it was to other factors. The major areas mentioned were the: a) inclusion criteria; b) implementation process; and c) discharge process. These areas will be discussed in the section on challenges.

Over half of the key informants at pre-test felt participants would respond positively overall if the Pilot was a good fit and if they understood what is involved; others mentioned there may be barriers such as understanding what is involved and/or reluctance to take on the responsibility. These predilections appear to have found relevance in the three participants who joined the Pilot. At post-test, the care advisor observed that two of the three participants seemed confused and concluded that it might be because the participants did not read and understand the manual. These two participants have been problematic in following essential instructions such as regarding payroll. They appeared not to understand the seriousness of being the employer of record, and dealing with institutions such as the IRS and the Employment Security Commission. One example provided was the participant ignoring mail coming to their house because they did not think it was important. These two participants did not proactively communicate questions or concerns to the care advisor. When there was a break down in the process the care advisor would contact the participants to remind them of their responsibility. It has taken several months to get these two participants to mail in timesheets regularly. Sometimes the participants did not answer the door when the care advisor knew they were home. A third participant appears to be a perfect fit for the Pilot project. Both participant and caregiver have read and understood the manual and have communicated effectively with the care advisor.

At pre-test, about a third of key informants anticipated that participants would expect to receive in-home aide assistance from the Pilot and a quarter felt they would expect to receive a choice in support and services. At post-test, the care advisor noted that two participants expected help in a broad sense, mostly assistance in the home. For these two participants it was not the expectation of what the Pilot could provide that was the impetus for participation, it was their response to the discharge planners’ suggestion in attempting to obtain services for them. The third participant had read the manual beforehand and was a good fit with the Pilot criteria. As a result it was easy to explain

what services and supports were appropriate and would be covered under the Pilot.

About half of the key informants at pre-test felt that Pilot participants would hope to benefit from a better quality of life and dignity as a result of the Pilot. About a quarter stated participants would expect more control and freedom of independence. The care advisor noted at post-test that the participants did not hope to stay out of a nursing facility because of the Pilot. The underlying reason was that the Pilot families most likely would not have placed the person in the nursing facility for different reasons, such as family interdependence and support, and the age of the participant making a nursing facility an inappropriate setting. The care advisor noted that admission to a nursing facility carries with it a lot of guilt for the caregiver of a young person. Also, a younger person may not participate as much in his or her care management and goal achievements if admitted to a nursing facility due to the restrictive environment. Two of the participants have been in and out of the hospital several times; one has not. One caregiver received respite services.

When asked at pre-test “How do you think Pilot participants actually will benefit from the Pilot project?” about two-thirds of the key informants anticipated the participants would benefit from more choice and control that would help them achieve increased independence; about a third stated they might benefit from a better quality of life, self concept, and leading a more normal life. At post-test the care advisor reported on the status of the participants. One had transitioned from skilled to intermediate level of care, one had been able to transfer to a wheelchair from a new bed and independently use the toilet facilities, and one had supplemented outpatient PT/OT with a *Wii* exercise software video in the home and hopes to pursue employment. In summarizing how the participants actually benefited from the Pilot, the care advisor said that the participants received assistance in the home quicker than they would have otherwise. Another key informant stated that care advisors are beneficial in terms of making participants more aware of resources and the different service organizations that are able to assist them. While the participants may not initially take advantage of the available resource possibilities, they have learned about their options.

Pre-test responses from key informants to the question “What services do you feel are essential to the participants’ success in avoiding nursing facility placement?” showed that 100% felt that appropriate and adequate in-home aide, including flexible hours and choice in what services are provided, would be essential. About a third stated that care advisor assistance would be essential. Post-test responses were more varied, with just over half suggesting that in-home aides/personal care services and about a third stating care advisor assistance were essential. About a quarter of key informants mentioned both medical supplies/equipment and family support; about a fifth mentioned transportation, housing, and home modification. The reasoning behind the responses included: a) the availability of most home and community based services, like CAP/DA, have a waiting list. Provision of interim in-home services is essential while more permanent arrangements are being made. Flexible hours and services provide respite to family caregivers and allow them to be employed and carry out their own responsibilities; b) there needs to be an evaluation of the individual’s needs and goals

by a care advisor in order to identify the services and supports necessary for a participant to live independently. The availability of a care advisor to assist with questions and to help a participant understand the Pilot requirements and provide adequate follow-up was critical to the participant's success in the Pilot; and c) the ability for participants to use Medicaid funds for non-traditional services enhances participants' therapy and provides the ability to budget more effectively. There need to be sufficient financial assets, in addition to what the Pilot provided, to be able to continue to live independently in the community.

Key informants were asked "What challenges might arise from the Pilot project?" at pre-test. Responses included about half of the key informants stating that adapting to role changes during planning process would be challenging; although about a third expected the process would get easier over time. About a quarter each said having a system that focuses on hospital discharge, monitoring for fraud and abuse, and consumers would not have enough education to understand and carry out their responsibilities. Key informants were asked to retrospectively identify the actual challenges that arose from the Pilot. These responses fell into five major categories: a) pilot implementation, b) planning process, c) discharge process, d) financial management, and e) eligibility criteria. There was some mention of participant capacity or motivation. Responses within these categories are described in the next several paragraphs.

Implementation

Over two-thirds of the key informants recalled that the implementation of the Pilot was a challenge. Because this was a pilot project, no one knew exactly what would be involved with implementing it in either county. The effort entailed refining and redefining the CAP/DA program. It was extremely helpful to contact Cabarrus and Duplin Counties. These counties let the lead agencies review and use whatever was needed of the materials that they had developed. However because each county is different, for example in resources and hospital discharge planners, Forsyth and Surry could not pick up what was done in Cabarrus and Duplin and replicate it. The Pilot had different rules and a different philosophy than CAP/DA. Moreover, Senior Services expressed some concern about serving younger individuals with disabilities because it has more experience serving an older population.

Initial marketing of the program to providers and discharge planners seemed to be a major issue. This arose, in part, from the difficulty in identifying and clarifying the scope of work. Additionally, trying to get into the hospitals to present the Pilot was a challenge. Further, obtaining discharge planner buy-in was difficult. One example given was explaining the Pilot to discharge planners who appeared to perceive only the additional time and effort it would take on their part and not see the benefit of the program.

Another key challenge for the agencies was the work involved with the participants both in familiarizing them with the CAP/Choice program and in selecting their caregiver, which has been outside the scope of what the agencies had performed in

the past. A concern expressed was helping the participant find providers of services who were not going to abuse the system with the participant as the employer of record. There are fewer opportunities for monitoring in the Pilot than in the in-home care agency system.

Another challenge was the length of time it takes to get the services started. One key informant explained, "The timing of setting up the services depends on how much advance notice the [care advisor] gets, whether the FL2 paperwork is completed correctly and given to the [care advisor], and EDS approves it." In addition to the FL2 process, there are assessments to be performed, and various employer paperwork to complete and get approved.

Planning Process

About two-thirds stated the Pilot could have been planned better before attempting to implement it. A few questioned the initial identification of Forsyth and Surry counties on the basis that they had Aging & Disability Resource Centers (ADRCs). Forsyth and Surry counties were chosen as the Pilot counties for the Rebalancing Initiative because the involvement with ADRC was considered an asset. By having both Senior Services and ADRCs in the same area, it was felt they would be able to enhance each others' efforts, and duplication would be avoided.

Many key informants appeared uncomfortable with the participatory method of planning, which was deemed by some as "a lack of organization". One key informant stated, "For our first several meetings there was not a lot of explanation. There was not a lot of direction -- it was kind of haphazard and that didn't get a whole lot better as time went on." Because of the participatory method of planning, the guidelines and scope of work changed several times. Moreover, there was no specificity on how the Pilot was to be set up, which was viewed both positively and negatively. It allowed Senior Services, Inc. and Surry County Senior Services to take control of implementing the Pilot and its parameters. At the same time, it hindered the accurate identification of appropriate participants. For example, key informants expressed confusion over the exact definition of "a significant physical disability" which made it difficult to explain the concept to the discharge planners.

Another challenge that arose when the counties attempted to set up the Pilot was having their CAP/Choice paperwork returned to them. Shifts in state management had created gaps in communications about the pilot.

Discharge Process

Over half of key informants said the acute care discharge process posed challenges. The ability to get into the hospitals to present the Pilot information to the discharge planners was a challenge. Based on the key informant responses, information on the Pilot was sent and multiple attempts were made to talk to the four hospital groups; Hugh Chatham Memorial Hospital, WFU Baptist Medical Center, Northern Hospital

of Surry, and Forsyth Medical Center; but these efforts did not have much affect. The discharge planners seemed to hear the information and process it, but the care advisors received mostly inappropriate referrals. It seemed as if the discharge planners were trying to get services for people whom they could not send to a nursing facility.

Financial Management

Financial management became a major issue with the Pilot. While most key informants were not directly involved with a fiscal intermediary, just under half identified this financial management as a challenge. Forsyth County, which enrolled the three Pilot participants, brought the fiscal intermediary in-house. Financial management continued to be an issue to the extent that the Senior Services, Inc. stopped adding participants. Every participant who was added to the Pilot had presented new financial management challenges; the cost became exorbitant for the agency due to time and fees that had to be paid to the payroll agency.

In addition, there was no reimbursement for time spent learning and starting up the Pilot. It was a tremendous financial strain for ADRC and Senior Services in both counties to fund the personnel and effort involved versus the available reimbursement. It was not only the delays with Medicaid and taking so long to get paid, but also the grant did not provide funding for activities such as writing the CAP/Choice manual and other activities involved in the Pilot start up.

Eligibility Criteria

From the beginning, several key informants identified one eligibility criteria in particular that might present challenges: discharge from an acute care setting. However, it was not until mid-way through the Pilot that other eligibility criteria appeared as barriers to recruitment. At post-test about half of the key informants identified the eligibility criteria in general was a challenge. They felt that if the criteria were less restrictive with regard to age, discharge from an acute care setting, and significant physical disabilities there would have been more referrals. Some felt that it might have been better to have channeled potential participants through the ADRC or through CAP/DA. The reasoning behind these responses included the length of time it takes to process Medicaid eligibility and finding individuals directly from an acute care setting who are have the capacity and are willing to take on the responsibility of being the employer of record. Upon being discharged from an acute care setting, an individual may want someone else to take care of these responsibilities for them. Moreover, potential participants in an acute care setting required more education about CAP/Choice than they would have if they were already familiar with the CAP/DA program.

Participant Capacity or Motivation

There was some mention of participant capacity or motivation as being possible

barriers for the Pilot. A key informant described the reasoning behind this response in this way, "Being able to get all the services in place is difficult for a person who is disabled and who's still in the hospital setting, they may not know how to get candidates to interview." Others indicated that an alternate caregiver may not be in place or there may be unknown family barriers to self directed care.

At pre-test, the key informants were asked how they anticipated the Pilot would change the relationships among community service organizations that provide resources to adults with significant physical disabilities. Close to two-thirds foresaw improvements in collaboration and coordination of services and relationships. At post-test over half of the key informants declared there had been no change in the relationships among providers. Just under half stated that they have an improved understanding of and coordination with the other providers, or have continued the positive collaborative relationships they had at the start of the Pilot. One key informant stated it thus: "There definitely needs to be a good working relationship between aging and disability services in a county to overcome the difficulty in serving this group. Younger and disabled is a different population than elderly and disabled. Although Forsyth ADRC and Senior Services had a working relationship beforehand, it needs to be closer in order to serve the broad adult population of individuals who have disabilities."

Transportation was the one additional community service required by the Pilot population that was identified at pre-test by about a quarter of key informants. Other community services and supports were mentioned at pre-test; however, by less than a fifth of key informants. At post-test about a fifth stated a need for additional services such as case management (perhaps through Center for Independent Living (CIL) or ADRC), transportation, providers of home modification services and the funds to pay them, and community attendant care. One key informant noted that while their county may not need additional community providers, the available services could be expanded to serve more people.

At pre-test, key informants mentioned various areas that might require improvement across the Pilot: a) involvement of providers in planning process, b) improved community awareness (both providers and potential participants), c) the creation of simple to understand brochures, and d) lifting the age criteria. Areas for improvements at post-test fell into two major categories: Pilot implementation and the planning process. Other areas mentioned included consumer capacity, Pilot oversight, and Pilot funds. These are discussed below.

Pilot Implementation

About two-thirds of key informants mentioned that if the Pilot implementation process had been different it may have been more successful. Several felt that running the Pilot through the CAP program was not ideal. This response was based on the rationale that the services could have been delivered better through a new program or through another program, such as CIL. Others stated that because the

pilot had a different philosophy than other CAP programs it required new rules, new paperwork, and additional staff to make it operational. These changes were costly. One key informant seemed to capture an unspoken ideal for the Pilot when stating that there must be “some type of system change where people are looking for this service when they enter the hospital to give [them] enough the time to get this type of program in place.”

Several mentioned that the CAP/DA waiting list would have been a better place to seek Pilot participants and, in the process, reduce the waiting time for some. Bringing participants into the Pilot directly from acute care settings was problematic, as one key informant stated, “If consumers don’t feel well they don’t want to take on any additional responsibilities and [for] family members who provide care to another family member and are trying to arrange services and make sure everything is covered, there’s not enough time.” And, as stated previously, there was a greater need for educating potential participants from an acute care setting than would have been required if they had been referred through CAP/DA.

Another idea mentioned by several key informants was presumptive Medicaid eligibility, which they felt would speed the implementation process.

Planning Process

About a third of key informants reflected that the planning process could have been improved. Suggestions for future pilots included: a) having an interim period between planning and pilot start-up to review and consider different approaches and possibilities; b) doing more research on previous pilot projects (for this project Cabarrus and Duplin) prior to pilot start up. The background research (including collecting, analyzing, creating and providing information and training to provider agencies) could be contracted out to another group so that the provider agencies would not have to bear the administrative burden; c) having consumers involved with the other pilot projects tell their experiences so provider agencies could have an idea of the population they are serving. Having knowledge of the population and seeing the successful outcomes might create a parallel success; and d) seek greater input from providers regarding pilot criteria and populations, which might improve participant referrals and participation.

Consumer Capacity

A few key informants suggested that improvements in consumer capacity would ensure greater success. One key informant stated that for consumer choice to succeed there must be adequate funds through Medicaid or alternate sources for individuals and their support systems to meet their daily financial needs. Another key informant stated that consumer directed care is good, but that consumers must have the capacity to make sure their care is adequate. The concern here is that because participants may hire family members or friends, they may not be comfortable in expressing disapproval with the care they are receiving; or they might fear losing

their aide altogether.

Pilot Oversight

A few key informants expressed concern about the reduction in CAP oversight with consumer directed care and with it the increased possibility for fraud and abuse. The rationale behind this concern is that the participant ends up suffering when appropriate and adequate care is not provided. Having extra check points through the involvement of more organizations lowers the probability of fraud and abuse.

Pilot Funds

It appears that a few informants were not clear about the overall objectives of the Rebalancing Initiative. These few expressed concern over grant money being spent to fund what they perceived as a long planning process versus providing services to consumers. They felt the Pilot accomplished very little. One key informant questioned whether safety and adequate care can be provided in the community at the same or at lower cost than institutional care. Another felt the Rebalancing Initiative money would have been better spent on current programs such as to reduce the CAP/DA waiting list or to serve a greater number of people through the Home and Community Care Block Grant program.

The researchers sought additional information from discharge planners. Only one hospital discharge department responded to inquiries. One manager of case management, after an initial agreement for us to gather information, decided that it was too time consuming. The manager stated that the major barrier of referring patients to the Pilot was that most patients were not independent enough, especially cognitively. More appropriate referrals would be individuals who were physically disabled but had cognitive capacity to direct their care. These might be individuals who would come from acute rehab, such as those with spinal injuries. Another issue was that at the beginning, after they had identified individuals to refer to the program, they were told that the Pilot was not yet in place; as a result, they had to go back to the patients and explain that it was not available yet.

CAP/Choice in Cabarrus and Duplin Counties

Cabarrus County

CAP/Choice has been in place for three years in Cabarrus County and there are currently 19 active consumers. The time from initial approval of CAP/Choice to when the first employee began working on the program was approximately 2 years. Cabarrus County Department of Social Services (DSS) initiated participation in the CAP/Choice pilot in June of 2005. The implementation of CAP/Choice was challenging because there was no precedence to follow or any CAP consultants experienced in consumer directed services to call upon for advice. CAP/Choice was superimposed upon the framework of the existing CAP/DA regulations with some enhancements and

exceptions, the primary difference being that the CAP/Choice consumer is considered to be an “employer of record” who directs his or her own care. Consumers may learn about CAP/Choice from their current CAP/DA case manager, from the DSS Adult Services Intake Screener, from word of mouth by other CAP participants, or during the initial home visit by the CAP intake social worker. Any CAP/DA consumer may request to transition to CAP/Choice. It is not necessary for a consumer to have a representative, if cognitively able to direct his or her own care. Should that ability to self direct care decline significantly, either a representative may be designated or the consumer will be transferred back to CAP/DA. Most of the consumers are younger in age than the CAP/DA population (average age is 49.3 years with the youngest age 22 and the oldest age 96.) Six consumers have quadriplegia, 2 have traumatic brain injuries, and the others have various primary diagnoses. There are 8 females and 11 male consumers. The primary appeal to CAP/Choice is: 1) flexible scheduling; 2) less money is spent on in-home aide that can be redirected to other areas or to purchase more hours of care coverage (traditional in-home aide costs \$14.88/hr in a CAP/DA budget, vs. \$7.18 to \$12.06 /hr. for a personal assistant in a CAP/Choice budget); 3) ability to have the personal assistants perform tasks that wouldn't be allowed if they were working through an in-home aide provider agency (examples include giving injections, transportation to doctor or therapy appointments, etc.).

There have been no signs of fraud or abuse. Many CAP/Choice consumers have medical conditions necessitating complex care (examples include bedfast patients who require frequent turning and repositioning, consumers who need suctioning or wound care, etc.). CAP/Choice consumers are usually very discriminating in whom they hire as personal assistants because quality care is absolutely essential for their health, safety and well-being, and their ability to continue living at home. Many have successfully hired and trained family members as their personal assistants. The 19 CAP/Choice consumers in Cabarrus County have 25 personal assistants; 13 of the personal assistants are immediate family members (3 spouses, 3 mothers, 2 daughters, 1 daughter-in-law, 2 sisters, 1 brother and 1 son).

Personal assistants are typically paid a higher hourly rate by the CAP/Choice consumer than they would receive working through an in-home aide provider agency, although there is trade-offs. Some in-home aide agencies provide health insurance, vacation, holiday and sick leave. On the other hand, the personal assistant may privately purchase health insurance and negotiate with the consumer for time off.

It usually takes three to seven days to enroll a new consumer into CAP/Choice as an employer of record. There is a significant amount of paperwork to complete, including application for an employer ID number, and enrollment with the IRS, NC Department of Revenue, and NC Employment Security Commission to ensure the employer's share of taxes are paid by the financial intermediary in accordance with labor laws.

When the CAP/Choice pilot began in Cabarrus, Good Health Services agreed to serve as the initial financial intermediary. However, they soon learned that a reimbursement rate of \$50 per month per consumer did not make it profitable for them to continue in

this capacity. Easter Seals/UCP stepped up to serve as a financial intermediary for two years, but elected not to renew their contract after June 30, 2007. Cabarrus had to act quickly to engage another financial intermediary, and on July 1, 2007 entered into a contract with Paychex/Advantage Payroll as the new financial intermediary. It should be noted that Cabarrus County Finance Department declined to serve as financial intermediary for the CAP/Choice program because of the time and cost involved in processing each CAP/Choice Consumer as an individual employer of record, i.e. each a separate business. However, Cabarrus DSS does retain part of the financial intermediary responsibility by paying the providers for supplies and equipment ordered by CAP/Choice consumers, and billing Medicaid for the reimbursement of all CAP/Choice related expenses. Personal assistants are paid twice a month and Paychex debits a county bank account for the costs associated with processing the payrolls. Cabarrus County endorses the prospect of engaging a state-wide financial intermediary in the future.

The majority of current CAP/Choice consumers were transitioned to CAP/Choice from CAP/DA. However, as word of CAP/Choice spreads through the community, more individuals have begun requesting CAP/Choice at time of initial application and are being approved directly onto CAP/Choice. Older individuals that elect CAP/Choice typically have a designated representative because of being more physically frail and/or having a diminished cognitive ability to self direct care. They are more prone to illnesses such as pneumonia, skin break-down, COPD, and bronchitis and seem to be admitted to the hospital more frequently. On the other hand, younger CAP/Choice consumers might go in occasionally for reasons such as PT rehab or reactions to treatments.

Examples of items purchased as “Goods and Services” in the CAP/Choice budgets included: durable medical equipment that could not be purchased under standard Medicare/Medicaid such as a reclining bath bench for a consumer with quadriplegia; replacement of durable medical equipment that was worn out but inadequate time had elapsed since item was last purchased to allow Medicare/Medicaid to pay for replacement; additional accessories for durable medical equipment not typically covered by Medicare/Medicaid; battery for a specialty Hoyer Lift that was initially privately purchased and therefore type of replacement battery non-covered; special type sling for a Hoyer Lift that would not otherwise be covered.

It was the expectation in piloting CAP/Choice that mistakes would inevitably be made by the care advisors, consumers, and the financial intermediary. This proved to be the reality; however, the pilot has been a learning experience and most errors have been successfully resolved. Although it is the care advisors’ ultimate responsibility to determine whether a prospective client is appropriate for CAP/Choice, most are given the opportunity to try participation if they so choose, and have succeeded. In the past three years, there have been no consumers in Cabarrus County who desired to transition back to CAP/DA, or were required to do so. Current participants are staunch advocates for the continuation of CAP/Choice as a participation option. They report that the freedom it offers them provides more hours of care coverage, more flexibility to

maintain independence in their lives, and more opportunities to engage in the community.

Duplin County

In Duplin County Cap/Choice is implemented through CAP/DA at Carolina East Home Care and Hospice. The financial intermediary is in-house. The county has 21 consumers, and the average age and gender is reflective of its overall CAP/DA consumers: about 30% male and an average age between 60 and 70. Consumers are admitted to CAP/DA through that program's criteria (nursing facility eligible, approved level of care, Medicaid recipient). The consumer is advised about CAP/Choice upon admission. If the consumer or his/her representative is interested they are evaluated for the program. The consumer will stay on CAP/DA until the case manager feels they are capable of handling responsibility of self-directed care. Some consumers are ready within a couple of months; others require more teaching and direction.

Consumers are often motivated to participate in CAP/Choice by having more control of their home workers, who are difficult to find in Duplin County. An additional motivation is, because the pay rate for the worker under CAP/Choice can be less than through an agency provider (\$14.88/hr.), the consumer frequently can get more care assistance hours in the home. Consumers like familiar people to be in their homes and seem to trust the workers that they hire.

Fraud and abuse of the program has not been an issue in Duplin County. The community programs director felt that the initial set-up of the program is crucial to preventing or at least keeping abuse of the program to a minimum. The admission process to the CAP/Choice program provides the time necessary for the case manager to evaluate the consumer. Appropriate teaching and investigation of any concerns prior to enrollment in CAP/Choice are crucial in avoiding fraud and abuse.

The CAP care advisor stated there should be a state consultant (specifically for CAP/Choice) for reference and guidance and a state fiscal intermediary would be best to handle financial management. As a pilot program, Duplin followed general guidelines to the best of its ability. Specific details should be provided from the state for this program to be successful. The care advisor believes that CAP/Choice is a great program that works well for some; but that the state has a responsibility to the consumers and providers to provide what is appropriate.

CAP/Choice Start-up in Forsyth County

When CAP/Choice was offered in Forsyth County to the participants currently receiving CAP/DA, one care advisor assessed the appropriateness of 33 CAP/DA consumers and offered the program to five. Of these, three consumers refused to participate for reasons such as: liability issues for the consumer related to the worker lifting the consumer, health issues that required the consumer to rely on a family caregiver who would have to assume the additional responsibility as the employer, and things were going smoothly

on CAP/DA so the consumer did not want to change.

Two consumers elected to participate in the program and have benefited greatly. One is a quadriplegic who is very intelligent and had taken pre-law classes. In CAP/DA the aide was not allowed to take the consumer to the library, but CAP/Choice allows this. In addition to the intellectual stimulation received at the library, the consumer is able to obtain more in-home aide hours (has 2 aides) as well as supplies at more reasonable prices and with home delivery. As a result of more caregiver hours and respite hours, the consumer has been less of a burden and stress on family members who provide care.

Another consumer has Multiple Sclerosis and the spouse is the primary caregiver. Through CAP/Choice the participant was able to maximize in-home aide hours with 2 aides at 48 instead of 40 hours a week. The confidence in the aides provides the consumer and family with peace of mind and reduced concern in finding a back up caregiver if necessary.

In addition to the CAP/DA requirements, those specific to CAP/Choice in Forsyth County are that the consumer: a) has been on CAP/DA for 1 year; b) has a representative, and c) is deemed appropriate by the care advisor. The characteristics the care advisor seeks in a consumer or representative are intelligence and responsibility, and the availability of a support system to do tasks like manage time sheets. It also is helpful if there is technical literacy and the availability of a fax machine to send in time sheets instead of mailing them. The care advisor tries to discourage enrollment if there is no responsible representative, if the consumer and/or the representative does not understand CAP/Choice requirements and have the capacity to manage them.

Regarding the liability issue, the care advisor attempts to help the consumer and aide seek mutual protection through a notarized statement regarding lawsuits and compensation for negligence, etc. Even so, consumers have not followed through with the care advisor's suggestion. CAP/DA requires a certified nursing assistant, whereas in CAP/Choice the consumer may hire whomever they wish, such as friend or family member. There is a greater level of comfort in hiring an aide with whom the consumer has had a prior relationship.

Although CAP/Choice aides do not receive health insurance, vacation and sick benefits through their employer, they may have insurance through their husband's work, through their own insurance policy, or they may also work for an in-home aide agency and receive benefits through it.

As with CAP/DA, the care advisors perform monthly unannounced home visits to the consumer and care advisement has not changed. The care advisor encourages the consumer to manage their own issues with their aide if they should arise. After the initial consumer training, CAP/Choice requires less of the care advisor's time and as a result less agency time. The county decided to freeze the CAP/Choice program due to the

administrative burden involved.

Differences between Cabarrus and Duplin, and Forsyth CAP/Choice implementation requirements: In addition to the CAP/DA requirements, those specific to CAP/Choice in Forsyth County are that the consumer: a) has been on CAP/DA for 1 year; b) has a representative, and c) is deemed appropriate by the care advisor.

Participant Stories – Three pilot; Three CAP/DA Waiting List

Pilot participants

The main two reasons why the participants were interested in participating in the Pilot were in-home care, which they felt would help them “get back on their feet”; and that the nursing facility was an inappropriate setting due to age or family situation. Through the Pilot the participants expected to receive basic care in the home to supplement family care. Participants hoped that the equipment and medical supplies and in particular, the additional personal care assistance provided by the Pilot in their homes would help them avoid nursing facility placement. One participant hoped to return to work eventually as a result of having a wheel chair and two caregivers to cook, bathe, and position the participant for therapy. When asked “What services do you feel are essential to your success in avoiding nursing facility placement?” all three of the participants responded “caregivers”, one also said outpatient therapy such as speech therapy, occupational therapy and physical therapy.

As for services or supports the participants received before going into the hospital; one received Social Security disability, one received some personal care services that provided light house keeping and meal preparation; and one received no services at all. Events that made the hospital stay necessary were spinal injury, stroke, and a serious illness. None of the participants believed that any additional or alternative services would have made their hospital stays unnecessary.

Two participants received care from family members who resided in the home and outside the home. When the caregivers or participants needed help other than paid assistance, they relied on family members outside the home. The additional assistance required of these external family members was the same or less than before the participants’ hospitalization. The three participants responded that prior to being admitted to the hospital, family members outside the home: were not necessary to provide help; “helped in the same ways;” or “helped with grocery shopping and paying bills.” Social support and personal assistance by family members not residing in the home ranged between once daily to once a week. Before their hospitalization, participants indicated that they could manage without this additional assistance; whereas now they could not. None of the participants had ever resided in a nursing facility and stated they would not under any circumstances. The exception to this avoidance of nursing facility placement was one participant who reluctantly admitted “unless [there was] no other choice.”

When asked if there was anything additional they would like to share regarding the pilot project, the participants said “It is a wonderful program,” and “an excellent program.” One participant declared, “Psychologically it helps young people to be in a familiar area and around people who love them and want to take care of them.” If there was no Pilot “then [they] would be in a bind.”

CAP/DA Waiting List Participants

Participants who were on the CAP/DA waiting list stated they were interested in the CAP/DA program because of their need for personal care assistants. Two stated they didn't know a lot about the CAP/DA program, but one hoped to be able to get someone “who cares” to come in every day. One person hoped it would help avoid nursing facility placement.

Services that were being received by the CAP/DA waiting list participants included: care assistance five days a week as well as medical equipment and supplies; Easter Seal transportation to appointments; and Reynolds Home Care to help with bathing, cleaning and cooking. While on the CAP/DA waiting list, one person was hospitalized four times and one was hospitalized once. Neither of these participants felt additional or alternative services would have prevented the hospitalization(s). All three had to go to the emergency room while on the CAP/DA waiting list (1 – two times; 2 -- one time each). Two of the three did not feel additional or other services would have made the emergency room visit unnecessary. One said if there was a driver the auto accident probably would not have happened.

All three felt that transportation, caregiver, and chore services were essential to avoiding nursing facility placement. One person had no one to turn to for help. Two had relatives and friends who provided care and they felt they could not manage without them. Care received informally included: daily oversight, transportation, cooking, and personal care when needed and as necessary. Two of the participants on the CAP/DA waiting list had never resided in a nursing facility. One would agree to be admitted to a nursing facility if care giving became a burden to relatives and friends.

Other comments made by the participants included: “It takes a very long time to receive CAP/DA because of the waiting list;” one participant “Misses doctors' appointments because of lack of transportation;” and one participant “Doesn't like having everybody doing everything...”

Discussion and Recommendations

This Pilot attempted to assess what services are critical for individuals with disabilities to remain in their home and community, and for transitioning individuals out of acute care settings back into their communities. The survey also attempted to assess the barriers and facilitating factors in individual circumstances that are important in stopping or reversing placement into a nursing facility as well as what particular resources are most helpful in sustaining and improving existing local programs and services. During the

planning process, Team members identified several issues as the most important to resolve, including:

- Obtaining funding in addition to Medicaid, such as VA and Home and Community Care Block Grant for CAP/Choice consumers
- Avoiding situations created by waiting lists for services where individuals are forced to go into nursing facilities
- Prioritizing individuals who need services
- Thinking about the consumer in terms of community provision of services rather than in terms of agency specific provision of services
- Minimizing barriers in the system
- Providing advance planning with families so there is a plan in place when a crisis occurs

The challenges that arose in the Pilot project reflected the importance of resolving the issues identified by the Local Leadership Team. While an effort was made to focus on the “community consumer” by including all the providers involved with the population of individuals who have significant physical disabilities in the planning process, this effort seems to have backfired during the pilot implementation. It appears that the planning process became confusing based on its participatory methodology. While providing a greater level of control over pilot implementation, lack of specificity hindered the accurate identification of appropriate participants.

Key informants said the pilot implementation was a challenge due to confusion about agency roles, different rules and philosophy when compared to other CAP programs; a largely different population than was previously served; marketing the pilot in the context of the foregoing issues; and the length of time involved in setting up services for patients who were being discharged from acute care settings. Key informants made several suggestions for future pilots, including: a) having an interim period between planning and pilot start-up to review and consider different approaches and possibilities; b) having an intermediary perform research on previous pilot projects prior to pilot start up; c) having consumers involved with the other pilot projects tell their experiences; and d) seeking greater input from providers regarding pilot criteria and populations. Based on these responses, it appears that in the future planning intermediaries must clearly define and frequently reiterate the goals of the initiative, the Team objectives, and agency members’ role in the process.

Pilot implementation was also difficult due to the lack of reimbursement for the financial intermediary as well as hours spent on researching and starting up the pilot. Surry and Forsyth as well as Cabarrus and Duplin expressed the need for a state-level consultant for guidance as well as putting into place a state fiscal intermediary.

The Team attempted to prioritize individuals for the Pilot who would need CAP/Choice services. However, the eligibility criteria were not a good fit for identifying Pilot participants. Barriers that were identified during the Pilot included the: a) discharge process which happened too quickly for services to be in place when the patient arrives

home; b) Medicaid process which took too long for services to be implemented upon hospital discharge; and c) priority of discharge planners to process patients quickly into a safe environment which was in conflict with identifying and referring patients to the Pilot. Obtaining appropriate referrals from the discharge planners was difficult because of lack of access to the hospitals and the onerous discharge process. Another issue related to discharge from an acute care facility is that individuals with significant physical disabilities who are being discharged from acute care frequently do not have the capacity, either cognitive or functional, to take responsibility for self directing their care. This reflects a need to provide the option of using the traditional home care agencies or to have advance planning with families so there is a plan in place when a crisis occurs.

Although the Local Leadership Team discussed the possibility of removing the age restriction, the members felt that it probably would not increase participation in the pilot. The members' conclusion may be accurate in that the CAP/Choice population served by Cabarrus and Duplin Counties includes a range of adults of all ages. The CAP/Choice population is very different in Cabarrus than it is in Duplin. Cabarrus mostly has a younger population, mostly male, in their 40s who are quadriplegic; whereas Duplin has an older population, mostly female, in their 60s and 70s. The Team also identified the issue of waiting lists for services and the Medicaid eligibility process, which create situations where individuals are forced to go into nursing facilities. Key informants' suggestions for ameliorating these issues included establishing a "presumptive Medicaid eligibility" process to speed up access to services; and informing people about their options when they enter the acute care facility so that there is plenty of time to process paperwork and provide services upon discharge.

While there were improvements in coordination and cooperation among providers, a closer relationship was deemed necessary to serve the broad population of individuals with disabilities. Moreover, key informants recommended expansion of already existing services, including: in-home aides, transportation, case management through other providers; availability of and funding for housing and home modifications.

Key informants also suggested that CAP/Choice might be implemented through another program such as CIL, due to the difference in philosophy from other CAP programs. Yet, Cabarrus and Duplin Counties implement CAP/Choice through CAP/DA seemingly without barriers. Other concerns expressed by key informants were the need for a participant representative and the high possibility for fraud and abuse due to lack of program oversight. Cabarrus and Duplin Counties do not require a representative and concerns with fraud and abuse were not founded in their three years of experience with CAP/Choice. However, oversight of a care advisor was indicated, as one care advisor recommended that her colleagues in other counties assume that mistakes will happen, but that these will subside as time passes and a participant's experience with CAP/Choice increases.

Possible Successes based on Participant Outcomes

The CAP/DA and CAP/Choice monthly rate for skilled level of care is \$3,537 and for intermediate level of care is \$2,730. In fiscal year 2007, the average cost for an individual residing in a nursing facility was \$26,420 compared with an average cost of \$21,991 for an individual on CAP/DA. Based on these numbers, it would cost the state \$53,115,153 to serve 6,709 individuals on the CAP/DA waiting list, versus \$63,809,299 to serve them in a nursing facility.

For the three Pilot participants it appears that costs were lower than the total monthly CAP/Choice rate. Listed below are the estimates, as of September 16, 2008, of participants care costs through the Pilot from their enrollment date through the end of August, 2008.

- One participant's costs: \$8,161.73 from 6-11-08 at a CAP skilled rate of \$3,537 x 2.5 months = \$8,820)
- One participant's costs: \$23,150.92 from 11-29-07 at a CAP skilled rate, through 8/28/08, of \$3,537 x 9 = 31,833)
- One participant's costs: \$22,541.94 from 10-05-07 at a CAP skilled rate of \$3,357 x 10 months = \$33,570)

Pilot participants responded positively in that the Pilot met their expectations and all three experienced positive results: one avoided nursing facility placement and all received services quicker than they otherwise would have; one has transitioned from skilled to intermediate level of care; one achieved greater independence through the ability to transfer from bed to wheelchair; and one is increasing muscle strength and coordination through supplementing at-home PT/OT exercises with the *Wii* program.

The main reasons for participating in the Pilot were flexibility and increase in in-home aid hours as well as the ability to obtain non-traditional services and supplies. The main reasons for the CAP/DA waiting list participants were a need for care assistants, transportation, and chore services. After hospitalization, Pilot participants as well as CAP/DA waiting list participants required higher levels of care and had greater need for assistance from family members. Both groups of participants stated that their greatest care requirement was to have in-home care assistance, in particular assistants "who care". In addition, it was important to obtain medical equipment and supplies. Both groups also expressed a desire to remain independent. When comparing CAP/DA participants with Pilot participants, CAP/Choice does not appear to reduce hospitalizations. However, direct comparisons cannot be made among these individuals. All six participants emphatically stated they did not want to go to a nursing facility; and only one had previously resided in one.

Across nine months in the Pilot, one participant transitioned from skilled to intermediate level of care in mid-to-late August, 2008. This participant had two hospitalizations (12/07; 4/08) and one emergency room visit (6/08). The participant is physically much better, is using a wheel chair, but needs assistance to use a walker and continues to have difficulty communicating.

Across ten months in the pilot, one participant had two - twelve plus days of hospital stay, none of which were 30 or more days (10/07 and 11/07). Other hospitalizations were: 12/11 – 12/23/07; readmit 12/24/07; readmit 1/31/08; readmit 2/08; readmit 3/17; readmit 4/17; readmit 6/25; readmit end of June through mid-July; readmit 8/13.

This participant received a new bed through a donation from the Department of Social Services. The type of bed is a Sleep Number bed that electrically adjusts the foot and head; is full-size and has the adjustable firmness feature of Sleep Number beds. It provides more comfort for the participant and the height is good for direct transfers to the wheel chair. Prior to the last hospitalization, the participant's physical condition had improved allowing the transfers to happen more easily. The participant continues to focus on upper body strength during therapy sessions and is waiting for specialized braces to come in to add additional support to both legs.

Across two-and-a-half months in the pilot one participant had no hospitalizations. Medicaid funds were used by this participant for non traditional services, such as purchasing a *Wii* to help with in-home physical and occupational rehab in addition to going two times a week to outside rehab. The *Wii* has made it possible for the participant to supplement PT/OT rehab at home. While it is too early to tell, the participant has muscle soreness that indicates strengthening.

In conclusion, the number of Medicaid beneficiaries in United States who direct their own personal assistance services is small, compared to those who receive traditional agency directed services in the community. Researchers (Claypool and O'Malley, 2008) found that participation rates in three of the four programs they studied were around 10% of those eligible. As with the North Carolina Rebalancing Initiative Pilot Project, these researchers suggest that the low rates could be attributed to a lack of knowledge about the opportunity to self-direct, or a lack of ability to assume the required responsibilities of hiring, scheduling, and processing payroll time sheets for the direct care workers. Many states are adopting some form of consumer-directed care. The evaluation research reported here demonstrates the value of monitoring a pilot as it is implemented. The evaluation findings do not permit unequivocal policy recommendations for the state. Instead, a policy judgment about consumer-directed care depends on weighing the benefits to consumers and their families against increases in job pressures for agency workers and in unconventional Medicaid expenditures. Many conclude that the benefits of consumer-directed care justify its cost.

Claypool, H. & O'Malley, M. (2008, March). Consumer Direction of Personal Assistance Services in Medicaid: A Review of Four State Programs. Washington, D.C.: Kaiser Commission on Medicaid and the Uninsured.