Community Alternatives Program for Disabled Adults (CAP/DA): 2003

A report to the NC General Assembly

health policy

North Carolina Insititute of Medicine

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Community Alternatives Program for Disabled Adults (CAP/DA)

CHARGE

The North Carolina General Assembly directed the NC Institute of Medicine (NC IOM) to study the CAP/DA program, and to recommend ways to improve the administration of the program.[1] Specifically, the General Assembly asked the NC IOM to consider the following:

1) Whether the lead agency for CAP/DA should also be a provider of direct services under CAP/DA
2) Whether case managers should be employed by the provider agency
3) Whether funds for CAP/DA should be reduced below the ninety percent (90%) maximum that currently exists
4) Review current policy for service requirements, management, and supervision as it pertains to strengthening the family and case manager and agency requirements
5) Whether case managers and provider agencies should have increased responsibility for upholding guidelines
6) Whether oversight of CAP/DA by the Division of Medical Assistance needs strengthening
7) Alternative funding sources for CAP/DA
8) Determination of funding needs for CAP/DA based on corroboration with long-term care policy initiatives
9) What changes should be made to CAP/DA to reduce cost of services per person in order to serve more individuals within existing funds
10) Any other matters the North Carolina Institute of Medicine considers pertinent to the study.

These issues could be roughly categorized into the following questions: 1) Is there a potential conflict of interest that could adversely impact on the operation of the CAP/DA program when local CAP agencies also provide direct services? 2) Is additional oversight or supervision needed at the state or local levels? 3) Are there more efficient ways to operate the program to serve more people with existing funds? 4) Are there other matters the NC IOM considers pertinent to the study? The NC IOM was directed to report its findings to the 2003 General Assembly.

Because of the short time frame involved in studying this program, the NC IOM did not follow its usual task force process, but relied instead on a series of key informant interviews to address the questions raised by the NC General Assembly. Specifically, we spoke with 49 individuals, including agency staff within the Division of Medical Assistance (DMA), local CAP/DA agency staff, consumer advocates, home health and nursing home staff, and a few CAP-DA consumers. In January 2003 we held a one-day meeting with the key informant interviewees to share their reaction to a series of options developed through the interviewing process.

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[1] Sec. 10.16(c) of the 2002 Session Law Chapter 126.

This report begins with an overview of the CAP/DA program, and then presents the analysis of the legislatures' questions.

PROGRAM OVERVIEW

The CAP/DA program is one of four different Community Alternative Programs offered to Medicaid recipients who would otherwise need institutionalization. [2] The state operates the CAP programs under federal community-based waiver (42 U.S.C. § 1915(c)), which permits the state to offer additional services as long as the program is cost neutral. Under traditional Medicaid coverage, the state must provide coverage to all eligible individuals. However, states can limit the number of people served under community-based waiver programs, even if they would otherwise meet program requirements.

The state began implementing the CAP/DA program in 1982 in four counties (Catawba, Durham, Mecklenburg, and Moore). The state chose to offer this program as a county-option, therefore not all counties agreed to offer the CAP/DA program until 1995. In North Carolina, the federal government pays 62.56% of program costs, the state pays 31.82%, and counties pay 5.62% (SFY 2003). From October 1, 2001 to July 31, 2002, the state froze the program so that no new people could be served. Thus, the county could not serve new people when a CAP/DA client left the program, for example, through death or placement in a nursing home. The number of people served during this time period declined from 10,230 per month in October 2001, to 8,049 per month (as of August 1, 2002). In the 2002 session, the General Assembly appropriated an additional $61,227,161 for the program. As a result, the state was able to re-open the CAP/DA program. Each county was given additional "slots" (or numbers of people that could be served)–allocated based on the number of slots the county lost during the freeze. Counties with high CAP/DA attrition rates during the freeze received more of the redistributed slots. The program is currently funded to serve 9,648 eligible individuals.

The number of individuals served by county varies considerably, from a low of six CAP/DA clients per 1,000 Aged, Blind or Disabled Medicaid recipients in Wayne County, to a high of 203 clients per 1,000 in Avery county in SFY02. See Appendix A. In the past, each county could petition the state for additional CAP/DA slots. Thus counties with aggressive lead agencies and supportive county commissioners were able to build up the CAP/DA program, while other counties were limited in the number of clients they could serve. This historical variation among counties is not based on any objective standard of need. When the state distributed the new slots after reopening the program, it did nothing to address the historical inequities in the availability of the CAP/DA program across counties.

[2] The state offers several different Community Alternatives Programs (CAP) that are designed to provide additional assistance to individuals who would otherwise need to be institutionalized, including the CAP/C program for medically fragile children who would otherwise need to be institutionalized, CAP/MR-DD for individuals who would otherwise need to be placed in an intermediate care facility for the mentally retarded (ICR-MR), and CAP/AIDS for people with AIDS or children who are HIV positive who would otherwise need institutional care.

Eligibility Requirements:

CAP/DA is available to older adults or people with disabilities age 18 or older who would otherwise need nursing facility level of care. To qualify, individuals must meet both medical/functional and financial eligibility requirements. Individuals must be at risk of nursing home placement, but must also have some possibility of being safely cared for in the community.[3] Eligible individuals include those who:

- Live in a private residence and are at risk of being placed in a nursing facility (or live in a nursing facility and desire to return to a private residence).
- Require nursing facility care (intermediate- or skilled-level nursing care).
- Need CAP/DA services to remain safely at home.
- Can have his or her health, safety, and well-being maintained at home within the Medicaid cost limit; and
- Desire CAP/DA services instead of institutional care.

To ensure that the program is targeted to those who would otherwise need nursing facility level of care, a doctor must certify that such level of care is needed. The physician must complete a one-page "FL-2 form" that includes information such as current level of care, recommended level of care, primary and secondary diagnosis, and other information about the client including: whether the person is disoriented, demonstrates inappropriate behaviors (e.g., wandering, verbally or physically abusive); whether the person needs help with bathing, feeding, dressing or total care; the last physician visit; whether the person can walk; functional limitations (including contractures or limited sight, hearing, and/or speech); whether the person can participate in social activities; any neurological problems, problems with bladder or bowel control; ability to communicate; skin problems; respiration problems; nutrition status; and use of medications. This form is then submitted to Electronic Data Systems (EDS), the states' Medicaid claims processor, who must review the form to determine if the client needs either intermediate or skilled nursing level of care. Individuals cannot qualify for CAP/DA without first being approved by EDS. The same nurses that review the "FL-2 forms" to determine if a person needs nursing facility care also review the "FL-2 forms" to be determine a person's eligibility for CAP/DA services.

In addition to the medical/functional needs eligibility criteria, individuals who apply for CAP/DA must also meet financial eligibility requirements. This program, like other Medicaid programs, is generally limited to individuals with low incomes and few resources. To qualify, individuals typically can have no more than $739 in countable monthly income; and $2,000 in resources (2002 eligibility figures). However, unlike traditional Medicaid, only the applicant's income and resources (e.g., the person who needs CAP/DA services) are considered, and not that of his or her spouse. Individuals with income in excess of the monthly income limit can still qualify as CAP/DA clients under the "medically needy"

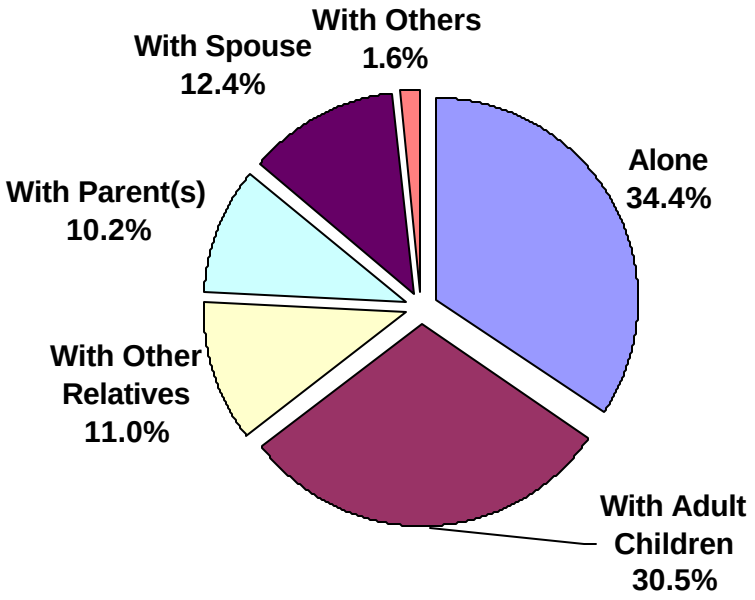
[3] Some individuals, who lack family or other community supports, are rejected from the CAP-DA program, because the agency cannot assure that the individual can remain safely at home. Typically, individuals in the CAP-DA program must rely on family or other caregivers for some support because the CAP-DA program funding restrictions would not support full-time aide services.

program if they have large medical expenses.[4] Approximately 92% of CAP/DA clients qualify with incomes below the federal poverty guidelines; and 8% qualify as medically needy.

Demographics:

The CAP/DA program serves largely an elderly population, although younger people with disabilities can also qualify. In SFY 2002, 75% of the people served were 65 years or older, and 25% were younger people with disabilities. Approximately 43% of the CAP/DA clients were age 80 or older. Females are the most likely to be served in the program, representing 81% of the clients served. Most of the CAP/DA individuals live with others, only 34% live by themselves (Chart 1).

Chart 1
Living Arrangements of CAP/DA clients (2002)



Source: Medical Review of North Carolina. CAP/DA Quality Assurance Review semiannual report for the review months of October 2001 through March 2002. October 31, 2002.

Because CAP/DA clients must otherwise need nursing level of care, they are generally frailer than those living in the community and qualifying for regular Medicaid. However, as one may expect, CAP/DA clients are generally less frail than those who reside in a nursing

[4] Two special rules apply if an individual qualifies as medically needy (i.e., their income is more than the federal poverty guidelines and they have expensive medical needs). Unlike traditional Medicaid, the deductible for the CAP/DA program is calculated on a one-month rather than six-month basis. Further, CAP/DA clients may use the costs of services provided under the care plan (including home delivered meals) to meet the Medicaid medically needy deductible.

home. Approximately 87% of CAP/DA clients have functional, medical, or cognitive impairments that would qualify them for residence in an intermediate care facility (ICF),[5] while 13% have functional, medical, or cognitive impairments that would qualify them for residence in a skilled nursing care facility (SNF).[6] In contrast, 56% of nursing home residents qualify for ICF, and 44% qualify for SNF level care.

The need for CAP/DA services is expected to grow in the future, as the baby-boomers age. Between 1996 and 2020, the overall state population is expected to grow 27.6%, but the population that is 65 or older is expected to grow 76.2%.[7] By 2025, the percentage of adults age 65 or older is expected to be 21.4% of the state's population.[8] Approximately 60% of these individuals will need long-term care sometime in their lives.

Services:

In addition to regular Medicaid services, individuals who qualify for CAP/DA can obtain coverage for some additional services; however, the total cost of home care must be within a monthly cost limit. Historically, the monthly cost limit was set at 95% of the average cost of nursing home care. However, the CAP/DA monthly limits have not been increased since July 2000, so now the monthly limits are less than 90% of the average nursing home payments.

Table 1
Cost Based on Level of Care

Level of Care	CAP/DA monthly limit	Average Nursing Home Costs	Percentage of CAP/DA to Average Nursing Home
ICF	$2,553	$2,927	87%
SNF	$3,360	$3,843	87%

In addition to the regular Medicaid services, CAP/DA clients can also receive:

- Case management
- Adult Day Health Care

[5] ICF in nursing homes means the level of care must be provided on a 24-hour basis with a minimum of eight hours of nursing coverage daily. If care is provided at home, through CAP/DA, it means that the person's personal support system, coupled with community based waiver services, can provide the care necessary for the client to remain safely in the home setting.
[6] SNF in nursing homes means that skilled nursing services must be medically necessary and provided on a 24-hour basis, seven days a week. If care is provided at home, through CAP/DA, it means that the person's personal support system, coupled with the community based waiver services, can provide the care necessary for the client to remain safely in the home setting.
[7] NC Division of Aging. The Growth of the Older Population in NC Counties: 1996-2020. Available on the Internet at: http://ssw.unc.edu/cares/boomproc/copo9620.htm (accessed January 27, 2003).
[8] NC Institute of Medicine. A Long-Term Care Plan for North Carolina: Final Report. January 2001. Citing: NC Department of Health and Human Services, Long-Term Care Policy Office. National Trends in Long-Term Care: How Does North Carolina Stack Up? Oct. 1, 1998.

- CAP/DA In-Home Aide Services (Level II and III Personal Care).[9] In-home aide services may not be provided on the same day as Medicaid personal care services or during the same hours of the day as home health aide services.
- CAP/DA Waiver Supplies (reusable incontinence undergarments, disposable liners for the reusable incontinence undergarments, incontinence pads for personal undergarments, oral nutritional supplements, and medication dispensing boxes)
- Home Mobility Aids, including wheelchair ramps, widening of doorways for wheelchair access, safety rails, non-skid surfaces, handheld showers and grad bars
- Preparation and delivery of meals
- Respite care (in-home and institutional). The total respite care a client receives may not exceed 720 hours, or 30 days/year.
- Telephone alert. CAP/DA will pay for the monthly service charge, but will not pay for the purchase or installation of equipment in the client's home.

CAP/DA clients are also entitled to other Medicaid-covered services, including but not limited to: hospital and physician services, prescription drugs, medical transportation, durable medical equipment, home health services, home infusion therapy, hospice, personal care services, and private duty nursing. Under regular Medicaid, a person can receive up to 60 hours of personal care services (PCS) each month, according to a plan of care authorized by the client's physician. Typically, elderly or disabled Medicaid individuals living in the community are required to pay copayments for certain services (for example, $1 for generic drugs, $3 for brand name, $3 for doctor's visits). CAP/DA clients, like nursing home clients, are exempt from the copayment requirements.

Administration:

The Division of Medical Assistance administers the CAP/DA program at the state-level. County commissioners select a lead agency to administer the program at the county level (called "appointed lead agencies"). The following organizations can serve as appointed lead agencies: Departments of Social Services (44 counties), health departments (17 counties), hospitals (25 counties), or Aging agencies (14 counties). Typically, the lead agency is responsible for the client assessment and case management, and for establishing an advisory committee. However, in seven counties, the lead agency contracts with another agency for program administration and oversight, including client assessment and case management (called "contractual lead agencies"). There have been occasions when the lead agency cannot run the CAP/DA program so they contract with another agency. DMA monitors the agency that actually provides the services.

The local lead agency is responsible for completing a client assessment when the person is first determined to be eligible for CAP/DA. A nurse (RN) and a social worker use a standardized assessment instrument developed by the North Carolina CAP/DA program to conduct the assessment. The assessment covers areas such as:

[9] Similar services are available through the regular Medicaid benefits (except that they are called personal care services).

- Physical health including diagnosis, medical history, home care services, medications, alcohol/drug abuse, assistive devices, nutrition, skin, sensory and communication, and continence;
- Problems with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) including whether the client can perform the activities independently, with prompting, minor hands-on help, or totally dependent, and who provides the help;
- Social support including household composition, informal caregivers outside of the home, primary caregiver, client's concerns, and family/household dynamics;
- Home environment including location, dwelling type, and client's living area, and information about the structure, heating/cooling, source of water, cooking appliances, pests, telephone, fire, safety, and security;
- Economic status including income and expenses of client and spouse, and financial management; and
- Mental health including orientation, memory, ability to perform simple arithmetic tasks, emotional state, judgment, wandering, function, and behavior.

Information from the assessment is used to develop an appropriate plan of care. The initial assessment is conducted in the person's home unless the person is in a hospital or nursing facility waiting to be discharged.

As previously mentioned, the CAP/DA lead agency is responsible for case management. Registered nurses (RNs) or social workers serve as case managers. Their responsibility includes developing a care plan and coordinating and overseeing the provision of services to CAP/DA clients. With some limited exceptions, the care plan must be revised when a service is added, increased, reduced or eliminated. In developing the care plan, the case manager examines the client's functional capacity, medical needs, social support system, and the availability of other community resources to determine what services are appropriate. Case managers must ensure that CAP/DA clients are aware of their right to select services from among CAP/DA enrolled providers. Case managers are also responsible for conducting annual reassessments (called continued needs review or CNR).[10]

The amount of case management provided varies, depending on the needs of the individual client. The cost of case management services also varies considerably between counties, from a low of $324 per client in Warren County (FFY01), to $2,034 per client in Graham County. Part of this variation may be due to a variation in hours of case management services provided per eligible individual, and part of this may be due to a failure of certain agencies to bill the state for these services. According to a recent study conducted by the Division of Medical Assistance, case management actually costs the counties $52/hour, but the state only reimburses counties $42.56/hour. The Division of Medical Assistance does not begin paying for case management services until the "FL-2 form" has been approved, so any work done by the case managers in managing the waiting list is not compensated. We

[10] The continued need review is coordinated by the case manager. The CNR includes a level of care review, a new assessment and care of plan. The physician must fill out and sign a new "FL-2 form" to determine the client's current level of care, but the "FL-2 form" does not need prior approval from EDS for ongoing care, unless the level of care changes (for example, from intermediate care to skilled care, or visa versa).

heard from the respondents that most agencies lose money on the case management services provided to CAP/DA clients.

Oversight:

This program is monitored at both the local and state levels. At the local level, the case manager must oversee the care plan to determine whether the services identified in the care plan are being delivered, and whether the care plan should be changed (for example, because of a change in the client's functional or medical conditions).

In addition to the local monitoring, DMA has six CAP/DA consultants that conduct annual on-site reviews of each program. The state also contracts with Medical Review of North Carolina (MRNC) for a monthly review of a random sample of active cases. For each case included in the monthly review, MRNC obtains assessments and care plans, copies of the "FL-2 form", a list of the services that were not reimbursed by Medicaid, and a list of informal services provided to the client. In addition, the state provides MRNC with a profile of claims paid for each case, so that MRNC can compare the services provided to the care plan (to determine if authorized services were provided according to the care plan, or conversely, whether services not authorized under the care plan were being provided).

In general, the MRNC review shows that local counties are following program rules and providing services that are listed on the care plan. MRNC found "errors" in only 5.9% of the 630 cases evaluated between October 2001 and March 2002. Errors generally focus on the degree to which the waiver services in the care plan were not provided, or services not identified in the care plan were provided. The most frequently identified error was that the client's annual reassessment was not approved by the fifth day of the month of the annual anniversary. The next highest error was that unauthorized home mobility aids were provided without clarifying documentation. There were only six cases (less than one percent of the cases reviewed) where approved services were not provided as ordered in the care plan. In these cases, MRNC determined that clients were not in any significant danger of harm or injury due to not receiving the services.

MRNC also examines "deficiencies" that are created when the assessment form is not accurately completed. There appears to be a greater number of "deficiencies" than "errors"—MRNC noted that there were deficiencies in 413 cases (for a total of 751 deficiencies), or 66% of the cases reviewed. The most frequently cited deficiency is in the incomplete information provided in the ADL/IADL and the social support sections of the assessment instrument regarding who assists the client. This accounted for 21.7% of all deficiencies. An almost equally large number of deficiencies (18.4%) were due to unexplained discrepancies between the information provided in the ADL/IADL and physical health sections of the assessment and/or the "FL-2 form" regarding ADL performance.

The CAP/DA case managers are required to visit their clients at least once every three months, to ensure that services are being provided as authorized under the care plan. In addition, home health agencies and home care agencies are subject to oversight by the NC Division of Facility Services (DFS). DFS inspects approximately 30% of home health agencies each year, but an agency may be inspected more frequently if subject to a complaint

investigation. Certified home health agencies are surveyed a minimum of every thirty-six months. The frequency of the routine surveys is based on the results of the last survey. Non-certified home care agency surveys are complaint driven.

Cost-effectiveness:

Every year, the Division of Medical Assistance analyzes the average CAP/DA and nursing facility placement costs to determine the cost-effectiveness of the CAP/DA program. In determining the overall costs of the program, the Division of Medical Assistance compares average nursing home costs (separately for intermediate and skilled-level) to the average home care costs provided under CAP/DA (e.g., CAP/DA services, personal care services, home health, durable medical equipment). The costs of physician's services, hospitalizations, prescription drugs, and other Medicaid covered services are not included in the comparison. Because of the individual CAP/DA spending cap—which equals 87% of average nursing home costs—the costs spent per individual CAP/DA client are necessarily less than what would have been spent had the same client been admitted to a nursing home.

Table 2
Average CAP/DA and Nursing Facility Placement Costs

		1998-1999			1999-2000			2000-2001		
		SN	IC	NF	SN	IC	NF	SN	IC	NF
NF	Annual	$19,749	$18,416	$19,129	$19,559	$19,273	$19,424	$19,525	$20,459	$19,986
	Per Day	$88	$69	$78	$91	$73	$82	$99	$80	$88
	Avg. LOS	222	266	242	214	264	238	198	255	226
CAP/DA	Annual	$14,689	$14,143	$14,246	$15,705	$15,036	$15,150	$17,225	$16,000	$16,193
	Per Day	$55	$40	$51	$57	$52	$53	$62	$56	$57
	Avg. LOS	266	281	278	276	288	286	277	286	285

Source: Division of Medical Assistance. CAP/DA Annual Report Summary. April 3, 2002.

A more recent analysis that includes all Medicaid costs also shows that CAP/DA clients are, on average, slightly less costly than nursing facility clients. In an sample of paid claims for SFY 2002, the average costs for intermediate level CAP/DA clients was $2,574, compared to $2,722 for residents in an intermediate care facility, and $2,454 for a resident in an Adult Care Home.

This analysis shows that individuals receiving CAP/DA services receive less costly care than those residing in a nursing home. However, this analysis does not answer a related question—whether the CAP/DA program appropriately identifies individuals who need nursing facility services, and if so, whether they would otherwise move into nursing homes if the CAP/DA program were not available. In other words, does the CAP/DA program help substitute less costly home care services for more costly nursing facility services; or is the CAP/DA program a net expansion of Medicaid eligibles—covering individuals who would not otherwise move into a nursing home?

The recent CAP/DA freeze provides some reason to suggest that the frail elderly and people with disabilities who need nursing facility-level of care may not immediately end up in a nursing home if CAP/DA services were unavailable. Over the 10 months of the CAP/DA freeze, the number of people in nursing homes and adult care homes receiving Medicaid remained relatively stable.[11] DMA did not keep data on the number of people on the waiting list for CAP/DA services for the full 10 months of the freeze; however, in the initial three months, the number of people on the CAP/DA waiting list grew from 5,713 to 6,739. More recent counts of the waiting list are not available. It is unclear what would happen to nursing home admissions if the CAP/DA program had been frozen for longer periods of time. Unfortunately, we have no definitive data to show how many people would move into a nursing home without the CAP/DA program.

Further, the program is only required to target individuals who have a level of need that would merit nursing facility care. Some individuals choose not to enter a nursing home, even though their level of need would warrant nursing home level of care. Many of these frail individuals rely heavily on family and friends to provide support. Because these informal caregivers often have other responsibilities (i.e., job and family), they are not always available to meet the complete needs of the frail individual. Absent the CAP/DA program, the needs of many of these frail individuals would be unmet.

LEGISLATIVE QUESTIONS

Conflict

Several of the legislative questions were directed at whether it is appropriate for the lead agency to also provide services; or whether case managers should be employed by the same agency that provides services. These questions appear to be directed at the potential for a conflict of interest—e.g., that the lead agency or case manager refer clients to their own agency for in-home services (in order to keep in-home aides employed or to raise revenues for the agency) and/or order unnecessary in-home services. Additionally, the appearance of a conflict could exist in the supervision of care—when one employee of the agency is responsible for ensuring that services are being provided by another employee of the agency. This conflict—real or perceived—exists in 44 counties (hereinafter referred to as "conflicted counties"). Thirteen of these counties are urban counties (defined as Metropolitan Statistical Areas[12]); and the remainder are rural counties (defined as non-Metropolitan Statistical Areas).

We heard that some of the "conflicted counties" originally began providing in-home services because there were few other in-home aide agencies in the county and/or that the existing in-home aide agencies were insufficient to cover the needs of eligible clients throughout the county. Analysis of existing data indicate that there are slightly fewer in-home aide providers

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[11] Patterson L. Division of Medical Assistance. Data from Medicaid monthly PER reports.

[12] The 1990 standards provide that each newly qualifying MSA must include at least:

- one city with 50,000 or more inhabitants, or
- a Census Bureau-defined urbanized area (of at least 50,000 inhabitants) and a total metropolitan population of at least 100,000 (75,000 in New England).

in "conflicted counties" than in "non-conflicted counties" (Table 3). On average, there are eight in-home aide agencies in "conflicted counties", with ten in "non-conflicted counties". "Conflicted counties" appear to be enrolling more individuals into the CAP/DA program. "Conflicted counties" served, on average, 113 clients in SFY 2002, whereas "non-conflicted counties" served 100 clients. Similarly, "conflicted counties" have, on average, a larger number of CAP/DA slots per 1,000 aged, blind and disabled individuals (97 vs. 57 respectively). While "conflicted counties" appear to serve more clients, there appears to be only a small difference in the amount of money spent on in-home aide services per client; with "conflicted counties" spending slightly less ($16,858) than "non-conflicted counties" ($17,202). We did not have the data to analyze what percentage of in-home aide services are provided directly by the lead agency (i.e., the agency that helps develop the care plan).

Table 3
Analysis of "Conflicted" vs. "Non-Conflicted Counties" (SFY 2002)

	"Conflicted Counties"			**"Non-Conflicted Counties"**		
	Total	**Urban**	**Rural**	**Total**	**Urban**	**Rural**
Avg. # Providers	8	11	7	10	13	8
Avg. # Clients	113	142	101	100	122	86
Avg. CAP/DA Slots	104	129	93	91	112	77
Avg. CAP/DA slots per 1,000 weighted ABD	97	73	107	57	46	64
Avg. In Home Aide Payment/ Client	$16,858	$17,202	$16,714	$17,290	$17,202	$17,347

Although we heard some anecdotal information that case managers in some agencies have felt pressured to refer clients to their own agency in order to keep the staff fully employed; this seemed to be the exception rather than the rule. In many counties, the clients are initially referred into the program from personal care service providers, which are already providing services to the client in the regular Medicaid program. These clients are reported to have existing relationships with in-home aide workers and have strong preferences to maintain these relationships.

While the state CAP/DA manual requires counties to offer clients freedom of choice of providers, there are no mandatory procedures to ensure that this rule is always followed. Many of the "conflicted counties" employ strategies to ensure freedom of choice and to address the perceived conflict of interest, but these strategies are not uniform across "conflicted counties."

The Division of Medical Assistance should standardize certain procedures to ensure that clients have freedom of choice. This is particularly important in the "conflicted counties"—as standardized procedures could help reduce any real or perceived interest in self-referrals. To this end, the NC Institute of Medicine recommends that the Division of Medical Assistance institute the following:

1. **Each CAP/DA lead agency should provide clients with a list of participating CAP/DA agencies and ask the client (and his or her family, as appropriate) to choose an in-home aide agency. This form can ask the client to specify more than one choice (in order of preference), in case the client's chosen agency is unable to serve the client (for example, if the agency lacks sufficient numbers of in-home aides to serve new clients). The client (or responsible party) should sign the form, indicating his or her preferences, and this form should be maintained as part of the client's records.**

2. **Each CAP/DA lead agency should create an "objective" referral system to use in referring clients who do not have a preference for in-home aide agency. For example, the system could be based on geography (assigning clients on the basis of the agency that provides the most coverage to that part of the community); or clients can be assigned to an in-home agency on a rotating basis. The criteria for assigning clients to an in-home aide agency need not be uniform across counties. However, each county would have to develop an objective referral system and to be approved by the Division of Medical Assistance. DMA must ensure that systems used in "conflicted counties" do not lead to inappropriate self-referrals.**

3. **Each CAP/DA client should be given information about how to change agencies or lodge a complaint (if they are unhappy with the care provider or the care they are receiving). In addition, clients should be informed, in writing, about their right to contact the state CAP/DA consultants in the Division of Medical Assistance if their problems cannot be resolved at the local level.**

Oversight:

The legislature directed the NC Institute of Medicine to study the oversight of the CAP/DA program, at the state and local levels. Specifically, the NC IOM was asked to review current policies for service requirements, management, and supervision; determine whether case managers and provider agencies should have increased responsibilities to uphold the guidelines; and determine whether the Division of Medical Assistance should oversee the program more closely. We broke this down into two sections: local CAP/DA lead agency responsibilities, and Division of Medical Assistance responsibilities.

County responsibilities:

After the initial client assessment, case managers help the client and his or her family to develop a care plan. Services provided under the care plan are monitored by the case manager. The case manager must confirm the need for CAP/DA waiver supplies, home mobility aids, and medical supplies at least quarterly; review the provision of services with the client and provider agency at least monthly; and visit the client to observe the provision of adult day health or in-home services being provided to the client at least once every 90 days.

Under state licensure laws, home care agencies[13] must also conduct an in-home visit to observe the care being provided at least once every 90 days. Federal Medicare rules require certified home health agencies[14] to observe the care being provided every 60 days. If skilled care is also being provided, federal rules require that aide services be monitored every 14 days. Given that home care agencies are responsible for on-site visits at least every 90 days; some informants questioned whether case managers should be required to visit the home of every client every 90 days to observe the provision of in-home aide services. If in-home visits were not required of all clients—particularly those clients who are stable and have responsible family members in the home that can monitor the provision of care—then case managers may be able to have higher case loads, thereby serving more CAP/DA clients. However, most of the CAP/DA program managers were strongly opposed to this change. They felt that an in-person visit should be performed no less frequent than every 90 days to see if the client's condition has changed and if the care plan should be modified.

One problem, identified by local CAP/DA staff, is that case managers do not have access to their client's claims paid profile, which is currently being provided to the Medical Review of North Carolina for its monthly case reviews. Some of the CAP/DA staff thought that this information would be helpful in determining whether Medicaid was inappropriately paying for services that were not approved as part of the client's care plan, as suggested in a small number of cases reviewed by MRNC. While there may be some benefit in providing local case managers with their clients paid claims profile, it could also lead to an excessive administrative burden to the case managers. Therefore, if this is pursued further, it should be done on a pilot basis—perhaps with a small sample of cases.

State Oversight

The Division of Medical Assistance has six CAP/DA consultants who work with the county CAP/DA agencies across the state. These agencies provided in-home aide services to 10,613 CAP/DA clients in SFY 2002. In general, the CAP/DA program has more state-level supervision than other services offered by Medicaid. As a comparison, the Division of Medical Assistance has only one person in charge of monitoring all of the personal care services provided to 27,346 Medicaid recipients in SFY 2002.

The six CAP/DA consultants provide technical assistance to CAP/DA programs, and are supposed to conduct an on-site visit of each CAP/DA agency at least once/year. However, because of the budget constraints and recent travel restrictions, some of the CAP/DA agencies have not been visited for almost two years. During the on-site reviews, the

[13] Home Care Agency—An agency that provides home care that is mainly to assist with activities of daily living and housekeeping. Home care includes assistance with walking and exercise; self-administered medication; reporting changes in the clients conditions and needs; completing appropriate records; personal care; homemaker services or home health aide services; and other services needed to maintain or improve the client's functional ability. Home care is supervised by either a registered nurse or licensed social worker. Home care agencies are licensed by the state

[14] Home Health Agency—An agency that provides home care services, like skilled nursing care, physical therapy, occupational therapy, speech therapy, and care by home health aides. A home health agency provides care that is supervised by one or more physicians, registered nurses, or licensed social workers. Home health agencies also maintain clinical records on all patients and are licensed by the state to provide home health care.

consultants look at the overall structure and operation of the program, review client records, and talk to providers and/or clients. If problems are uncovered, DMA will try to work with the director of the lead agency to resolve the problem. Problems might include misplaced paperwork, medications on the assessment that do not match those listed on the "FL-2 form," or failure to deliver an assistive device that was ordered on the client's care plan. If problems cannot be resolved through informal discussions with the lead agency, then the consultants may attempt to intervene with the county managers office. In most instances, problems are resolved, however because the CAP/DA program is a county option, the state lacks any ultimate authority to mandate changes should they be warranted.

The CAP/DA program managers were generally very positive about the role of the CAP/DA consultants. They thought that the feedback provided by the CAP/DA consultants was more helpful than that provided by the MRNC reviews. The consultants focus on program operations, whether services being provided are needed, and the care provided to clients. In the view of many of the CAP/DA program managers, the MRNC review is focused on process—for example, whether forms are filled out correctly—not on the quality or appropriateness of care provided to clients.

Although most of the key informants thought that the state oversight of the CAP/DA program was adequate, most agreed that state oversight could still be improved. Based on these suggestions, the NC Institute of Medicine makes the following recommendations for implementation:

4. **The Division of Medical Assistance should develop standards or "best practices" for case management, in-home aide services, and the responsibilities of lead agencies. These standards should be developed with the input of lead agencies, service providers, and other knowledgeable individuals. The service standards should include suggested guidelines for when services are needed and the number of hours that should be provided, while allowing for individual variation based on the client's unique circumstances. This can address county variations in use of services and ensure that clients are provided consistent care across the state. DMA should report to the NC General Assembly on its progress by 2005.**

5. **DMA should ensure that each CAP/DA lead agency is monitored routinely, but not less frequently than once every two years. Agencies with complaints or problems uncovered during the last monitoring should be subject to more frequent visits.**

6. **If problems are uncovered during annual monitoring visits or through complaint investigations, DMA should develop a corrective action plan with specific time frames in which to make the needed corrections. If an agency fails to comply with these provisions, DMA should have the authority to take additional steps to ensure compliance, including but not limited to changing the lead agency. If no other agency is willing to assume responsibility in a particular county, DMA should have the authority to negotiate a regional arrangement with lead agencies in surrounding counties.**

Other suggestions that DMA should explore further include:

- Administering customer satisfaction surveys, to obtain feedback on the services provided by the local CAP/DA agency and by the in-home aide agencies.

Reducing Program Costs:

One of the overriding legislative concerns appeared to be how to serve more individuals within the existing CAP/DA budget. The legislature specifically asked the NC IOM to study:

- Whether funds for CAP/DA should be reduced below the ninety percent (90%) maximum that currently exists
- What changes should be made to CAP/DA to reduce cost of services per person in order to serve more individuals within existing funds
- Alternative funding sources for CAP/DA

Since the maximum CAP/DA monthly payment rate has not been increased in two years, it has effectively already been reduced. Uniformly, the people we interviewed thought that the state should not further reduce the CAP/DA maximum that can be spent on CAP/DA clients. However, a number of other alternatives were proposed. These ideas were not unanimously supported by all of the respondents. Ideas generally fall into three categories: 1) ensuring that CAP/DA services are targeted to those most in need; 2) programmatic changes to reduce costs; and 3) implementing pilot projects to test new CAP/DA program funding methods or care delivery systems.

Targeting CAP/DA services to individuals most in need:

When the moratorium on new CAP/DA placements was lifted in August 2002, the Division of Medical Assistance established a new policy for who must be given priority in CAP/DA placements. Specifically, priority must be given to nursing home residents who were interested in returning to the home, and who could be safely cared for at home with CAP/DA services. This rule helps the state address the U.S. Supreme Court's holding in *Olmstead vs. L.C.*, that individuals should not be inappropriately institutionalized.[15] The Division of Medical Assistance is currently assessing data on the number of people that have

[15] In *Olmstead vs. L.C.*, 119 S.Ct. 2176 (1999), the United States Supreme Court held that unjustified institutionalization of two women with mental disabilities constituted unlawful discrimination under the Americans with Disabilities Act. The Supreme Court held that states must provide community treatment when three conditions are met:

1) The state's treatment professionals determine that such treatment is appropriate;
2) The affected people do not oppose the treatment; and
3) The treatment can be reasonably accommodated, taking into account the resources available to the state, and the needs of other people with mental disabilities.

While this case was brought in the context of two women with mental disabilities who were inappropriately kept in a state mental institution, the holding would also apply people who are inappropriately institutionalized in nursing homes (if the other conditions are met). In addition, North Carolina, in its Olmstead plan, also places a priority on moving individuals out of nursing homes when they are interested in community placement and can be appropriately cared for in the community.

moved from nursing homes back into community since the CAP/DA program was re-opened and priority was placed on serving nursing home residents.[16] The state has no other CAP/DA priority categories to ensure that CAP/DA services are provided to those individuals most in need.

Issues have been raised about whether the CAP/DA services are targeted to those most in need. In an analysis of SFY 2002 paid claims for a sample of 300 intermediate level CAP/DA clients, the clients billed Medicaid for an average of 8.9 home health visits per year.[17] Only 225 of the 300 CAP/DA clients in the sample actually billed for home health services in 2002 (the average number of home health visits for these clients averaged 11.8/year). CAP/DA clients were more heavily reliant on in-home aide services, billing for an average of 1,277 hours of in home aide services per year. Under federal law, every person who qualifies for CAP/DA services should have a functional, medical, or cognitive impairment that meets the requirement for admission to a nursing facility. The fact that CAP/DA clients billed for an average of less than one Medicaid-paid home health visit per month raised the question about whether these clients really need nursing facility level of care.

However, after studying this issue further, it became clear that we lack the information needed to draw any conclusions. Medicaid paid claims data are not adequate to measure client acuity. The DMA analysis did not capture all the nursing services provided to CAP/DA clients. Many CAP/DA clients also receive home-health services that are covered by Medicare (not Medicaid), and thus would not be reflected in these data. Some home health agencies also provide no-charge visits. Further, some of the services that that are provided by nurses may be delegated to a family member. For example, nurses may teach family members how to provide wound care, diabetic care (insulin administration, diet control, foot care, etc.), medications, pain management, tube feedings, tracheostomy care, nebulizer treatments, and oxygen, and how to change colostomy bags and handle catheters. Nurses also teach families how to observe for exacerbations of conditions, such as how to tell if the client's congestive heart failure is worsening or how to prevent deconditioning of the client.

There are other data, albeit a few years old, which suggest that CAP/DA services are targeted to individuals with significant impairments. A Duke Long Term Care Resources study of 18 CAP/DA agencies between 1997-1998 examined how CAP/DA clients leave the program. Of the 407 CAP/DA clients who left the program during this time period, 80% left because they died, were admitted to a nursing home, or were hospitalized during the study period. Only 3% left to enter an adult care home.[18] These data suggest that CAP/DA

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[16] The Division of Medical Assistance recently obtained a federal grant—the Nursing Facility Transitions grant. With funding from this grant, the state is expected to: identify people who may be inappropriately placed in a facility or who may have the ability live in the community; initiate a process to transition these people into a community setting; and develop and maintain an infrastructure to support this process. The three-year grant, which began in October 2002, provides funding for client services and case management.

[17] Analysis by the Division of Medical Assistance. February 12, 2002.

[18] Bell JP, Leak SC. The Aging at Home Program: A Successful Partnership in Caring. Duke Long Term Care Resources. Occasional LTC Policy Paper Series. Paper No. 8. July 1999. Available on the Internet at: http://www.ltc.duke.edu/occasional_8.htm (This study examined the 18 counties that participated in the Aging

clients are sufficiently impaired to warrant nursing-facility level of care. Comparison data for similar nursing home discharge categories are not available.

Additional data are needed to determine if clients are appropriately placed in the CAP/DA program. To address this issue, the NC IOM recommended that:

7. **The Division of Medical Assistance conduct a study to determine the acuity level of people placed in the CAP/DA program. The study should collect data on nursing services provided to these clients through other payment vehicles, nursing services provided to clients through trained family or friends, and data on why clients leave the CAP/DA program and where they go when they leave. In addition, DMA should conduct a more thorough assessment, using a validated instrument [such as one of the Resident Assessment Instruments (RAI)], of a sample of CAP/DA clients to determine whether the needs of these clients are sufficiently acute to warrant nursing home placement.**

Another way to ensure that CAP/DA services are targeted to those most in need is to develop a better screening tool. Currently, DMA uses the "FL-2 form" as a screening tool to determine the appropriate level of care for potential nursing home and CAP/DA clients. Uniformly, respondents noted dissatisfaction with the current "FL-2 form." This form was not designed to be a comprehensive assessment tool and therefore it does not provide sufficient detail to truly reflect the clients medical, functional, psychological, or family support structure. Unless it is completed fully and accurately, the "FL-2 form" may not provide sufficient medical information to determine the appropriate level-of-care. Some of the respondents suggested that the state replace the "FL-2 form" with a RAI-type instrument that can be used to gather more information to determine level of care. Eventually, an improved instrument could be used to support a case-mix payment system. An RAI-type tool would provide more detailed information to ensure that the state is targeting the most appropriate population for CAP/DA services.

DMA is currently in the process of revising its "FL-2 form," using the Minimum Data Set (MDS) for nursing facilities, which has similar data elements, as a point of departure. The goal is to capture the necessary medical information with the shortest form possible so EDS can make accurate level of care determinations in a timely manner. It is also important to keep the form brief so that it does not become an administrative burden to physicians. The revised form will be available electronically as well as in a paper-based version. The form is being tested in Wake County during the month of February 2003 and should be available in other counties by April 2003. To further ensure the appropriateness of the "FL-2 form", DMA is consulting with CAP staff, nursing facility administrators, hospital discharge planners, physicians, and other knowledgeable people, and will continue to receive feedback from these groups as they finalize the form.

The revised "FL-2 form" should serve as a more accurate screening tool for level of care and payment rate than the original. In addition to a revised screening tool, there is a need for a

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at Home Program III, funded by The Kate B. Reynolds Charitable Trust. Aging at Home Program III helped counties expand existing CAP/DA programs).

better care planning assessment tool. The Division of Medical Assistance tested the RAI-HC tool (a validated assessment tool for use with a frail elderly or disabled population living at home) in 17 counties in July 2000.[19] After becoming familiar with the new instrument, the CAP/DA case managers generally found the instrument to be "more objective" and "quicker," although suggestions for further improvement were made. However, because of the tight budget restrictions, the new assessment tool was never implemented. The new "FL-2 form" combined with a validated assessment tool (such as the RAI-HC) for care planning, should enable the state to move toward a case-mix adjusted payment system, so that individuals with more severe needs get higher payment caps, and individuals with less severe needs get lower caps. This is similar to the system that DMA is developing for nursing homes.

To address this, the North Carolina Institute of Medicine recommended:

8. **The Division of Medical Assistance should continue the development and testing of the new "FL-2 form," seeking input from expert consultants in validated assessments instruments and case mix systems, physicians, nursing home administrators, CAP/DA local agencies, EDS, home health agencies, home care agencies, and consumer groups. After this instrument is implemented, DMA should develop a case-mix payment system that sets the maximum CAP/DA payment based on a person's medical, functional, psychological and support needs. DMA should be required to report its progress on this to the North Carolina General Assembly by the beginning of the 2004 Session.**

Programmatic changes to reduce costs:

Two programmatic changes were suggested that could potentially lead to cost savings: expanding CAP/DA waiver services to cover adult day care services; and allowing a small amount of CAP/DA funds to be used for non-traditional waiver services. Adding additional service options to the CAP/DA waiver program would not increase costs since the clients must still meet their monthly cost limits, and the new services would not be available to other Medicaid recipients.

Currently, the state will pay for adult day health[20] facilities as one of the CAP/DA waiver services, but not adult day care.[21] The state should explore the possibility of providing personal care services through adult day care settings—as it may be more economical to provide personal care services to groups of individuals in a congregate setting than paying for the provision of in-home aide services in individual homes. This option may be particularly beneficial to individuals who have working relatives who need someone to care

[19] Walton J. CAPDA – RAI-HC Pilot: Preliminary Findings. March 2001.

[20] Adult Day Health Care - A community-based day care program that provides health, social and recreational care, along with rehabilitative services. Staffing is by trained paraprofessionals and is under the supervision of a registered nurse. The program is ideal for the elderly or physically impaired adult who needs assistance in a protective setting during the day.

[21] Adult Day Care - The provision of group care and supervision of adults who may be physically or mentally disabled in a place other than their usual residence on a less than 24 hour basis. Services are designed to support the adult's personal independence, as well as their physical, social, and emotional well-being.

for their family member during the day; but who are available to care for the frail elderly or disabled family member at night and on the weekends. While personal care services may be provided more economically in a group setting, the state would also have to factor in the additional transportation costs of transporting clients to the adult day care center in determining cost effectiveness.

Another suggestion was that DMA give counties the authority to use a small amount of CAP/DA funds to address home safety issues. Occasionally, CAP/DA supervisors are faced with situations where they are unable to serve otherwise eligible individuals in their homes because the home is not safe. This may be because of small structural problems, or problems with pests (rodents, roaches, etc.). In some of these instances, small amounts of money could make the house habitable (i.e., by making home modifications or hiring an exterminator). However, CAP/DA funds cannot currently be used for this purpose. While CAP/DA case managers can often find other community funds to address this problem, these funds are not always available. CAP/DA managers described instances where individuals were sent to Adult Protective Services or placed in nursing homes because the CAP/DA agency lacked the funds needed to make the changes necessary to ensure the safety of the individual. For the first six months, the state should require that these requests for flexible funds be subject to prior approval—to ensure that the CAP/DA agency has first attempted to obtain other community funding, and that the services are needed. At the end of the six-month period, the Division can re-examine the cost-effectiveness of requiring that these services be subject to prior approval.

To address these recommendations, the NC Institute of Medicine recommends that:

9. **The Division of Medical Assistance should explore the array of CAP/DA services offered to ensure that they are meeting the needs of the clients and to determine whether services could be provided in a more cost-effective manner. For example, DMA should explore the cost-effectiveness of adding adult day care to the list of authorized services. In addition, DMA should institute a process to allow local CAP/DA agencies, with prior-approval from the state, to use a small amount of program funds to address home safety-needs.**

Pilot programs to test new funding models or care delivery systems:

Under the current CAP/DA payment structure, there is little financial incentive for counties to try to save money. Counties are given a certain number of "slots" (e.g., people they can serve). Counties that find ways to "save" monies cannot use these savings to serve additional clients. Several of the respondents seemed interested in testing new ways of funding the CAP/DA program so that they could use some of the "savings" to serve additional clients. These models generally involve capitating payments to the counties or giving counties an aggregate budget, allowing them to share in program savings. However, others were concerned these payment systems could encourage counties to "underserve" CAP/DA clients. Thus, if new payment models are developed, they should first be pilot tested in volunteer counties that have the fiscal sophistication to operate under capitation. Additional state oversight would be needed to ensure that CAP/DA programs were

developing appropriate care plans and providing the services necessary to treat the CAP/DA eligible client.

There were several ideas suggested that could be tested as new payment models:

1. *Capitate CAP/DA funding at the county level and let the county use some of the savings to cover additional eligibles*. One suggestion was to capitate the CAP/DA funding at the county level, and then let the county share in any savings generated by being prudent managers of care. The county would continue to have individual limits in CAP/DA expenditures, but in addition to the individual limits, each county in the pilot would be given an aggregate county budget limit. If the county's expenditures were under the county expenditure cap, it could use some of the money saved to provide services to additional eligibles. Some of the savings could be recaptured by the state and redistributed to counties that currently serve a smaller percentage of potential CAP/DA eligibles.

2. *Capitate all long-term care services in a county*. The Division of Medical Assistance could also explore the option of capping all long-term care services for the frail elderly and people with disabilities who would otherwise need nursing home level of care. This would include, but not be limited to, personal care and home health services provided to people at home (including CAP/DA services) or adult care home settings, as well as nursing home services. The state would contract with a non-profit or public agency to act as the case manager, with the responsibilities of managing all of the person's long-term care needs. Capitated funding would be provided per individual, using a case-mix reimbursement methodology. Any savings generated from reduced institutional care could be put back into community services (with some shared savings to the state, to be used to redistribute to the counties serving a smaller percentage of potential CAP/DA eligibles).

In addition, there may be different models of case management to better help manage the care of people with chronic illness or disabilities. These models are currently being considered for testing on Medicaid's chronically ill population and may also be applicable for CAP/DA.

DMA should explore new methods of chronic care management and alternate payment methodologies that could lead to better health outcomes for Medicaid recipients, improved targeting of services, and which would have the potential of producing overall program savings. Testing new payment models appears to have interest from some of the CAP/DA lead agencies. However, there are a lot of unanswered questions about the feasibility of this approach. Thus, to address this issue, the NC Institute of Medicine recommends that:

10. **The Division of Medical Assistance create a work group of interested organizations to explore alternative service delivery and CAP/DA payment methodologies or chronic care management systems that could lead to improvements in care to individuals and potentially lower per capita costs in the CAP/DA program. These models should be tested, on a pilot basis, with counties that are interested in exploring these new delivery system models. Any savings should be shared between the counties and the state. These**

pilots should be evaluated to determine their cost effectiveness and the impact on clients before expanding to other counties across the state. The Division of Medical Assistance should report to the NC General Assembly on its progress on this recommendation by the beginning of the 2005 General Assembly.

Other Issues Deemed Pertinent by the North Carolina Institute Of Medicine

In addition to the specific questions raised by the General Assembly, the NC Institute of Medicine was directed to study any other pertinent issues. After speaking with the key informants, the NC Institute of Medicine determined that there were two other issues that should be addressed: 1) ensuring a minimum availability of CAP/DA services across the counties, and 2) developing a consumer directed care model.

Ensure a minimum availability of CAP/DA slots across the counties:

One of the major problems with the CAP/DA program is the wide variation in program availability across counties. The number of CAP/DA clients served varies from a low of six clients per 1,000 Medicaid aged, blind and disabled clients in Wayne County (referred to as "low-CAP/DA counties") to a high of 203 CAP/DA clients per 1,000 in Avery County. This variation appears to be independent of the number of licensed nursing home beds in a county, or the use of personal care services. This variation can be explained, at least in part, by the willingness of the County Commissioners or lead agency to hire additional case managers in publicly-funded lead agencies to serve more clients. In the past, counties that wanted additional slots could petition DMA for new slots; however, this is no longer possible. With the freeze, counties were effectively frozen into their existing CAP/DA allotment. The new CAP/DA slots were allocated based on the number of slots lost during the freeze, so that low-CAP/DA counties continued to have low slot allotments. Because the overall number of CAP/DA clients is fixed; counties that want to grow their programs no longer have the ability to do so. The problem is compounded by the recent freeze. Lead agencies had to dismiss case managers during the freeze because they could not afford to pay them while their caseloads dropped. Lead agencies are now reluctant to rehire case managers and/or have difficulty rebuilding their staff to a level that could support additional slots now that the freeze is over.

DMA has never addressed the inequitable distribution of CAP/DA slots. Because of the initial state enabling legislation gave County Commissioners the authority to decide whether or not to participate in the CAP/DA program, the state feels that it has little control over the operation of the program or how many clients a program serves. Further, the initial legislation gave the County Commissioners the authority to designate a lead agency; so the Division does not have the authority to change county lead agencies if the designated lead agency fails to hire the case managers needed to serve additional clients. Further, given the state's low reimbursement for case management services, we heard that there would be few other agencies in the county who would be willing to assume the responsibilities of lead agency.

There are a number of options to ensure more equitable distribution of CAP/DA slots across the state. Specifically, the NC Institute of Medicine recommends that:

11. **The General Assembly should enact legislation to ensure that CAP/DA is a mandatory program that is provided in every county. The General Assembly can still establish budgetary limits, however the program should no longer be optional to the counties. Counties Commissioners should have authority to select a lead agency, but DMA should have the authority to change lead agencies if lead agencies fail to hire sufficient numbers of case managers to expand CAP/DA availability or other problems arise in program administration that cannot be resolved through corrective action.**

DMA should have the authority to change lead agencies if, for example, the County Commissioners in low-CAP/DA counties refuse to hire sufficient number of case managers to ensure equitable access to CAP/DA services. However, for DMA to be able to address this issue, the state must pay a reasonable amount for case management services (so that other agencies may be willing to serve as lead agencies).

12. **The Division of Medical Assistance should work with CAP/DA lead agencies, county commissioners, and other interested parties to develop a methodology for distributing CAP/DA slots to ensure equitable distribution of the services across the state over time (i.e., counties that serve a disproportionately low number of aged, blind, and disabled individuals in the CAP/DA program should be given first priority in any new slots distributed to the counties). In addition, DMA should establish minimum standards to ensure at least a basic access to CAP/DA services in each county.**

    - **The state should recapture some of the CAP/DA slots from counties that are not using their full CAP/DA allotment and reallocate those slots to counties that are below the state average in percentage of potential eligibles served.**
    - **Any new appropriations provided should be allocated under the new slot distribution methodology.**
    - **Additionally, DMA should consider other approaches, including but not limited to increasing the CAP/DA case management reimbursement, changing CAP/DA lead agencies, or regionalization of CAP/DA programs, to ensure a more equitable distribution of CAP/DA slots.**

Increasing reimbursement for case management services will not lead to higher overall program costs if the state maintains the overall payment limit per client. However, it may lead to a reduction in other services per client in order to keep overall program costs within the payment maximums. This may also lead to a decrease in the number of hours spent in case management services to some clients; however, there appears to be considerable variation among counties in the amount of case management services provided (or at least the amount of case management services currently billed to the state). Further, there are currently no data to suggest that the counties that bill less—presumably providing fewer hours of case management—are providing lower quality service to eligible clients.

Consumer Directed Care model:

Under the current CAP/DA rules, case managers must develop a care plan, and work with families to identify in-home aides from a list of licensed home care agencies. Case managers play an active role in directing the client's care, regardless of whether the services of a case manager are needed or desired. Clients have limited ability to hire relatives to provide in-home aide services. According to CAP/DA program rules, in-home aide agencies can only hire a spouse, parent, child, or sibling if he or she meets the following requirements:

- Is at least 18 years of age,
- Meets the aide qualifications, and
- Gives up employment or the opportunity for employment to perform the service. This restriction only applies to a spouse, parent, child, or sibling. The agency can hire other relatives who meet the aide qualifications without regard to giving up employment.

Clients cannot directly hire and fire their own in-home aide providers. Instead, they choose a home care agency that provides the in-home aide. Clients who are dissatisfied with either the aide or the agency can seek to change the caregiver and/or the agency. However, clients who want to hire family members as their in-home aide have difficulties because of the need to go through home care agencies and the restrictions that home care agencies have in hiring family members as in-home aides.

While clients do not have total freedom of choosing an in-home aide provider, clients The Department of Health and Human Services has created a broad-based work group to develop a framework for public funded consumer directed services in North Carolina. The work group is made up of community based providers, representatives from the NC Association for Home and Hospice Care, consumers and consumer advocacy organizations for aging, mental health and disabilities, as well as various DHHS agency representatives. There are many issues that need to be addressed in consumer-directed care models, including the development of payment mechanisms and adequate consumer protections. The Department has two grants from the Center for Medicare and Medicaid Services (CMS) to promote consumer direction as an option for long term care services in community-based settings. The Department is pursuing the necessary federal waiver to implement consumer directed care for the CAP programs. In the meantime, DHHS plans to pilot consumer directed care models in at least three sites beginning in later summer 2003. The pilots will continue for a couple of years. An evaluation of the consumer-directed care model implemented in Arkansas with a frail elderly population found overwhelming support for the program among elderly program participants.[22]

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[22] Foster L, Brown R, Carlson B, Phillips B, Schore J. U.S. Department of Health and Human Services. Cash and Counseling: Consumer's Early Experiences in Arkansas. Executive Summary. Mathematica Policy Research, Inc. October 2000. http://www.aspe.hhs.gov/daltcp/reports/earlARes.htm (Accessed January 30, 2003). Arkansas is one of four states implementing consumer-directed care under a Cash and Counseling Demonstration project. IndependentChoices, is the Arkansas Cash and Counseling Demonstration project and has offered 174 Medicaid eligibles the opportunity to receive a monthly cash allowance for their personal assistance services. The program allows participants to hire caregivers or purchase equipment that would enhance their ability to live independently. In addition to the monthly allowance, the demonstration offers

13. **The NC Institute of Medicine recommends that consumer-directed pilots be tested in the CAP/DA program (along with other state programs), and that the Division of Medical Assistance report back to the 2005 General Assembly on the progress of these pilots.**

CONCLUSION

Based on the feedback we received in our interviews, the CAP/DA program is meeting a critical need in providing in-home services to frail older adults and people with disabilities. The program enables many people, who would otherwise need nursing facility level of care, to be cared for in the community. Nonetheless, there are several ways in which the program could be improved. First, the state needs better screening and assessment tools, to ensure that program appropriately targets individuals in need of nursing facility level of care. Once these tools are developed, the state should move to a case-mix adjusted payment system, so that the individuals who are the most frail receive higher monthly payment limits, and conversely, those who are less frail or have more natural supports, receive lower payments. The state should also test new methods for reimbursing counties or delivering care to determine if these methods could help reduce overall program costs. The state should also explore whether other services should be covered—such as adult day care services—which may be able to provide aide services more efficiently in a congregate setting. The recommendations are described more fully in the body of the report.

CAP/DA programs appear to be doing a good job developing care plans and monitoring the care provided to their clients. However, there is an appearance of a conflict of interest—in that some counties that develop the care plan also are providers of in-home services. This report contains several recommendations, that if implemented, could help address the conflict and ensure that clients receive the full range of choice of in-home aide providers. While not eliminating the conflict altogether, it could help reduce the potential for self-referrals.

One of the biggest problems identified in the CAP/DA program is the inequitable distribution of CAP/DA slots. The Division of Medical Assistance has never developed a system for distributing CAP/DA slots based on an objective determination of need.

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counseling services. As part of the counseling services, the state will help the clients develop spending plans and provide bookkeeping services to help pay for caregivers.

Based on an evaluation of IndependentChoices, 73% of the program's recipients were 65 years or older, in poor health, and had high levels of functional disability. This finding contradicts the thought that consumer-directed care programs would appeal primarily to younger adults with physical disabilities or to the elderly with less severe disabilities. After nine months, two-thirds of the recipients were still participating in the program. Of those who no longer participated, nine percent died, and 24% disenrolled (59% of those who disenrolled decided to return to their agency for personal care services). Nearly all of the participants (92%) used some or all of the money to hire at least one caregiver. More than 90% of the participants hired family members or friends as paid caregivers. Most of the participants chose a fiscal intermediary to serve as their payroll agent for their caregiver. Eighty-two percent of participants reported that the demonstration improved their quality of life.

Instead, the slots are distributed based on the historical usage of CAP/DA slots—so that certain county programs end up serving a much higher percentage of its frail elderly and people with disabilities. The NC Institute of Medicine has made a series of recommendations about how to address this historical inequity, so that the frail elderly and disabled have an equal likelihood of being able to access CAP/DA services, regardless of where they live. The need for the CAP/DA program, or a similar system of community-based supports, will likely grow as the baby-boomers age—so that now is the time to ensure equitable access to these services.

The tight state budget forces all of us to re-examine state-funded programs to ensure that they are still warranted and operating as efficiently as possible. Given the short amount of time, and the lack of funding for our study, the NC Institute of Medicine was limited in the extent to which it could examine cost-effectiveness. Further study of this program is warranted. While further efficiencies may be found, it is unlikely that this program can be cut significantly without causing harm to many of the North Carolina's most frail citizens.