



# **Implementation of the Independence Dignity and Choice in Long-term Care Act**

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## **List of Abbreviations**

ADLs – Activities of Daily Living

AoA – Administration on Aging

ARDC – Adult Resources and Disability Center

CMS – Center for Medicaid Services

DHSS - Department for Health and Senior Services

GO – Global Options

HCBS – Home and Community Based Services

IADLs – Instrumental Activities of Daily Living

LTC – Long-term Care

MFP – Money follows the Person

SAMS - Social Assistance Management System

## **Executive Summary**

The purpose of the Independence, Dignity and Choice in Long-Term Act of 2006 (the Act) is to provide greater choice in the type of long term care services NJ residents can receive through Medicaid. Because people who need long-term care (LTC) services overwhelmingly choose to remain in their homes and communities rather than going into nursing homes, the Act was designed to rebalance long-term care Medicaid funds toward home and community-based settings (HCBS) as opposed to institutional settings. Prior to statewide, comprehensive implementation, Atlantic and Warren counties were set up as pilot counties, with access to a new computerized clinical assessment system, a client tracking database (SAMS) and a fast-track Medicaid eligibility mechanism. However, the Department of Health and Senior Services (DHSS) has also been working toward transitions from nursing homes to HCBS throughout the entire state.

This report evaluates the implementation of the Act in the pilot counties. Through both interviews and data analysis, the report suggests that there has been a shift in the proportion of LTC Medicaid funding from institutional care to HCBS. In SFY 97, 93% of Medicaid funding went to institutional long-term care, while only 7% of such funding went to long-term care in HCBS. In contrast, the SFY07 budget allocated 77% of funding to institutional care and 23% to HCBS. While New Jersey is headed in the right direction, this progress cannot be attributed entirely to the Act's implementation, due to several intervening factors, particularly other longstanding efforts in the state to rebalance long term care funding.

The pilot programs in Atlantic and Warren counties have been fully implemented, albeit not without minor stumbling blocks. The two counties are using a more streamlined

process due to Global Options for Long-term Care (GO for LTC), which combines New Jersey's Medicaid waivers into one source of funding. The computer intake system and client-tracking database may be difficult to get used to and the Medicaid eligibility fast-tracking may not live up to the qualifier, "fast". While the state does not keep track of nursing home transitions by county, statewide 1,561 people have been transitioned from institutional long-term care to HCBS since the Act's passage.

The State has clearly made commendable progress in giving those in need of LTC a HCBS option. Of course there is more to be done, and thus we recommend the following:

- 1) For greater transparency, the State should issue this year's progress report as is required by the Act as soon as possible.**
- 2) The State should make clear the percentage of funding going to institutional care and HCBS in the State's year-end reports, beginning with the 2008 report, to better track progress.**
- 3) All assessments of the Act by the State should include data since the passage of the Act and its implementation to the present to improve accountability.**
- 4) Medicaid funded home and community-based services should be made available to the "Medically Needy" category of Medicaid recipients, beginning in SFY10 to provide the long term care choices consumers want and need.**
- 5) The State should continue funding the GO for LTC and expand the pilot program to the remaining counties in SFY 10.**

- 6) The State should consider increasing access and Medicaid reimbursement rates to attract more long-term care service providers to New Jersey.**
- 7) The State should provide county-level information on HCBS long-term care services for improved tracking and accountability.**
- 8) The State should offer county-level training for the new computer intake and tracking systems being implemented to expedite statewide expansion.**
- 9) The State should conduct further research on the “consumer experience” from the Act’s implementation to improve results.**

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## **I. Introduction**

The New Jersey State Legislature passed the Independence, Dignity and Choice in Long-Term Act of 2006 (the Act) to encourage greater availability of at home and community based long-term care services as an option to institutionalized long-term care for seniors. The Act, signed into law by Governor Jon S. Corzine on June 21, 2006, “rebalances the overall allocation of funding within the Department of Health and Senior Services for long-term care services through the expansion of home and community-based services” (NJSA C.30:4D-17.26).

The Act also established the Medicaid Long-Term Care Funding Advisory Council within the Department of Health and Senior Services (DHSS). According to the Act, the Council shall “monitor, assess, and advise the commissioner on the implementation and operation of the Medicaid LTC expenditure reforms” (NJSA C.30:4D-17.29). The Act named Atlantic and Warren counties as the starting point for implementation, which began on January 1, 2007 (NJSA C.30:4D-17.26) These modifications that took place in Atlantic and Warren counties included the “use of mechanisms for making fast-track Medicaid eligibility determinations, a revised clinical assessment instrument, and a computerized tracking system for Medicaid long-term care expenditures” (C.30:4D-17.28).

Research by AARP and others has shown that many people want to receive their LTC services in home and community based settings as compared to nursing homes. The intent of this report is to evaluate the pilot program phase of the Act and make recommendations to the State so that all NJ residents will have greater LTC choices. The report includes interviews of officials and caregivers in the two pilot counties as well as a

control-county (Cumberland). The report also analyzed data on nursing home occupancy and other aspects of long-term care. The report concludes that progress has been made in giving choices to seniors regarding their care, supported to a great extent by the increased flexibility the Act provided in appropriating Medicaid funds.

It is difficult to determine, however, whether much of this progress was due to the Act, or to other efforts that have been ongoing in New Jersey for more than a decade. In addition, numerous administrative and regulatory improvements may enhance the flexibility that the Act gives seniors and caregivers.

The report is structured as follows: Section II describes briefly the debate on home-based care. Section III discusses the methodology used to evaluate the Act. Section IV summarizes the data from both quantitative sources and interviews. Finally, Section V discusses the results, the limitations of the study and policy recommendations.

## **II. Home and Community-Based Services**

Long-term care (LTC) is an issue of great significance to the lives of some of the state's most vulnerable populations. Additionally, as health care budgets and costs increase faster than inflation<sup>1</sup>, long-term care is gaining significance at the state and federal level as a fiscal issue. The elderly and the disabled sometimes require a high level of care and how they receive this care has implications for their quality of life as well as for state budgets.

The term "long-term care" can refer to a variety of health and social services that people who have a chronic disability need. One example of this care is nursing home care, for others this care simply means having a home health aide or a personal shopper,

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<sup>1</sup> Vanessa Fuhrmans "Health-Care Premiums Climbing Faster Than Inflation, Studies Say" Wall Street Journal September 12, 2007

or it may mean adult day care services. These services can be provided in an institution, in the community, or in the home. Throughout this report services provided in the home or community will be referred to as home and community-based services (HCBS).

In both an institutional and a community based setting, the goal of long-term care is to provide assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) and to manage and treat chronic conditions. ADLs include daily activities such as eating, bathing, dressing, transfers, toileting, bed mobility, and locomotion. IADLs include activities specifically necessary for living independently, such as preparing meals, managing medications, and shopping for groceries (Kane 2001).

Traditionally, government funding of these services have been focused on nursing home care. There has been a growing movement in the last decade toward “shifting the balance” of funding toward HCBS. The *Olmstead v. LC* decision of 1999 and the Community Choice Waiver program have lead this shift. New Jersey’s *Independence, Dignity, and Choice in Long-Term Care Act* (the Act), is a prime example of this trend.

Two important trends have emerged in the efforts to reform long-term care: “balancing efforts” and “money follows the person.” State balancing efforts aim to align long-term care expenditures more equally between institutional and community care options (Hendrickson, 2006, ii). “Money follows the person” is a model designed to allow “maximum flexibility between nursing homes and home and community-based settings” to expand consumer choice (NJSA C.30:4D-17.24).

One of the ways that New Jersey is seeking to rebalance long-term care funding is through the Global Options waiver program (GO). This program combines three other federal waivers for more efficient administration of services and more flexibility for

patients to choose a set of services that suit their needs.<sup>2</sup> Another initiative is the Aging and Disability Resource Connection (ADRC). ADRC, funded through a federal grant, aims to create "one-door" access for people to receive home and community-based services. This program is currently being piloted in Atlantic and Warren counties.<sup>3</sup>

Home and community-based services include a wide variety of services such as health services, assisted living care, attendant care, caregiver/participant training, care management, chore service, environmental accessibility adaptations, home based supportive care, home-delivered meal service, personal emergency response systems (PERS), respite care, special medical equipment and supplies, social adult day care, transition services and transitional care management, and transportation.<sup>4</sup>

An important benefit of HCBS is that they create a market that is centered more on the consumer. Under the current system of funding the majority of public dollars go to nursing homes, while the majority of older Americans do not want nursing home care (Kane, 2001). Persons who need long-term care are traditionally underserved (Feder, 2000). Home and community based services may also relieve stress for “burnt out” family caregivers. Informal or family caregivers provide 80 percent of care for people who need help with ADLs.<sup>5</sup>

Kane argues that HCBS can increase quality-of-life among many domains including security, comfort, dignity, privacy, and autonomy (2001). It is unsurprising that many people prefer to age in their homes. A 2006 AARP study reveals that nine in

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<sup>2</sup> New Jersey Department of Health and Senior Services Global Options (GO) for Long-Term Care, What is the GO Waiver Program? March 17, 2009

<sup>3</sup> New Jersey Aging and Disability Resource Connection (ADRC)

<sup>4</sup> New Jersey Department of Health and Senior Services Global Options (GO) for Long-Term Care, What is the GO Waiver Program? March 17, 2009

<sup>5</sup> Barbara Coleman and Sheel Pandya “Family Caregiving and Long-Term Care” AARP Public Policy Institute November 2002

ten or 41.5 million adults age 60 or older prefer to stay in their homes (AARP Press Center, Oct. 27, 2006). Furthermore, another 2006 AARP study states “nearly 90 percent of adults 50 and older want to stay in their current home and community as they age” (AARP Press Center, Oct. 12, 2006). There are a variety of reasons why those 50 or older want to stay in their homes such as “attachment to their home and neighborhood, as well as close ties to friends, family and neighbors” (AARP Oct. 12, 2006).

On the fiscal side, Kaye, Le Plant, and Harrington recently published a study arguing that HCBS can save states money over time (2009). There are significant upfront costs associated with first offering these services, but these costs can be recouped over time. Even though states that offer HCBS are still experiencing a growth in long-term care spending, this growth is generally not as fast as the growth of states not offering extensive HCBS (Kaye et al. 2009). Kaye et. al. found that states with a high number of established HCBS programs decreased LTC spending by 7.9%, but states that had a high number of expanding HCBS programs increased spending on average by 24.2% (Kaye et. al., 265). The same study found no evidence of so-called “woodwork effects” (Kaye et al. 2009).<sup>6</sup> HCBS may save states money, and at the very least will not likely cause increased LTC spending beyond start-up costs (Kaye et al. 2009). The neutral to positive fiscal impact combined with the desire of older people to stay at home are strong reasons for states to offer these services.

All of these programs (Community Choice, Global Options) and external factors (the Olmsted decision) have influenced the allocation of senior care in New Jersey. One

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<sup>6</sup> Some theorize that offering HCBS would attract a much large client base, thus dramatically increasing cost, but no evidence of this was found.

of the challenges for an evaluation of the Independence, Dignity and Choice in Long-Term Act of 2006 is to isolate the impacts of the Act from all of these other factors.

### **III. Design and Methodology**

Qualitative interviews were used to evaluate the success of the LTC pilot program. Study participants were chosen from the two experimental counties, Atlantic and Warren, as well as a third control county, Cumberland. Picking a control county for this study was difficult because of the differences between Atlantic and Warren Counties. Atlantic is a largely urban county including a large casino industry; Warren is a rather rural county. The two counties have similar population sizes and populations of persons 65 years old or over, however. Cumberland County was picked because it has a population in between the other two counties and a similar percentage of the population that is 65 years old or over. The purpose of having a control county is to understand the intake process and access to home and community-based care in areas of the state that are not participating in the pilot program and to understand whether changes in Atlantic and Warren County can be attributed to the Act.

Department of Health and Senior Services officials (including those in Trenton and in County offices), family home caregivers, professional home caregivers, nursing home personnel, and advocates for the elderly were interviewed. All interviews were confidential and no direct quotes were used without the permission of the study participant. Officials were contacted by cold calling the three County Offices on Aging. Family home caregivers were contacted through an email to all AARP member activists in Atlantic, Warren and Cumberland Counties and from caregiver support group referrals. Professional caregivers and nursing home personnel were contacted through cold calls.

Finally, people who were known to be strong advocates for the elderly, including members of the Medicaid Long-Term Care Funding Advisory Council<sup>7</sup> were chosen because of their statewide knowledge of the LTC system and were interviewed in order to gain an additional perspective on the implementation of the Act.

The purpose in interviewing County officials was to ascertain their perceptions about the implementation, get a sense of what has gone well with the pilot programs and what needs improvement. Higher-level officials were interviewed to obtain DHS's understanding of implementation. By interviewing family and professional caregivers, we hoped to learn about their experiences with the system and to get a feel for the "customer experience" of County Offices on Aging. The goal in speaking to nursing home personnel was to determine any impact the Act has had on nursing homes (such as a shift in the nursing home population or in the type of care required). Interview data was coded by hand and analyzed for themes.

Quantitative data on nursing home usage during the last decade was gathered. State budget numbers were analyzed to ascertain how much money the state government was spending on nursing homes before and after the passage of the Act. Additional data on financing the pilot programs through federal grants from the Center on Medicare and Medicaid Services (CMS), the Administration on Aging (AoA) and the reports that DHSS are required to file annually on the implementation of the Act were also collected.

#### **IV. Data**

When the Independence, Dignity and Choice in Long Term Care Act was enacted in New Jersey in 2006, the State's over-65 population totaled 1.1 million which is 13% of

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<sup>7</sup> The Advisory Council was established within DHSS to "monitor and asses... the implementation and operation of the Medicaid long-term care expenditure reforms" and to "develop recommendations for a program to recruit and train a stable workforce of home care providers" (N.J.S.A. C.30:4D-17.29).

the total population, 8.7 million residents in the state. This percentage has remained relatively stable since 2000. New Jersey's population is ranked 18<sup>th</sup> oldest in the nation, which will make the effects of the baby boomer generation maturation even greater (Himes 2001).<sup>8</sup>

### **Funding for Initiatives**

#### *New Jersey Budget Appropriations*

Most long-term care expenditures in the New Jersey budget are allocated through Medicaid. From 1998 to 2008, the total Medicaid budget has nearly doubled from \$1.9 billion to \$3.7 billion. The Medicaid funds are appropriated to two departments: Human Services and Health and Senior Services. The Medicaid appropriations to the Department of Health and Senior Services are mainly to cover long-term care expenditures. The Act requires a line item in the budget for Medicaid long-term care.

The Act's stipulated line item requirement has been fulfilled each year since the passage of the Act.

There shall be included a unique global budget appropriation line item for Medicaid long-term care expenditures in the annual appropriations act for fiscal year 2008 and each succeeding fiscal year in order to provide flexibility to align these expenditures with services to be provided during each fiscal year as necessary to effectuate the purposes of this act" (NJSA C.30:4D-17.32).

In SFY07, Governor Jon Corzine included \$30 million (a mix of state funds and federal matching funds) for the GO for LTC program. In SFY08, the line item allocated \$28 million for GO for LTC (again a mix of state funds and federal matching funds).

A major indicator of the Act's implementation progress is the shift in proportion of Medicaid Long-term care funding that has been spent in institutional and home and

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<sup>8</sup> Christine Himes "Elderly Americans" Population Reference Bureau 56 no. 4 June 2002

community based care. Unfortunately, this information is not included in the available New Jersey budgets. The state has issued two reports thus far on the progress of the Act: The Independence, Dignity and Choice in Long-Term Care Act Report in October 2007 and Independence, Dignity and Choice in Long-Term Care Act Annual Report in January 2008. These reports include varying data regarding this proportion of Medicaid funds between them, even stating two different proportions in the same report.

**Table I**

Percentage of Long Term Care Funding for Institutional Care as Represented by NJ Reports

	1997	2005	2006	2007
Independence, Dignity and Choice in Long-Term Care Act Report (October 2007)	93%			77%
Independence, Dignity and Choice in Long-Term Care Act Annual Report (January 2008)		73%	66%	
Independence, Dignity and Choice in Long-Term Care Act Annual Report: Appendix C (January 2008)		71.6%		

The 2007 report indicates that in SFY97, 93% of Medicaid long-term care funding went to nursing home care, while in SFY07 only 77% of long-term care funding went to nursing homes and 23% was rebalanced to home and community based services. The

2008 report, however, cites that the proportion in SFY06 was 66% institutional care to 34% HCBS as compared to 73% to 27% in SFY05. In the same report's Appendix C, SYF05's proportion is listed as 71.6% institutional care to 28.4% HCBS. While the trends are clearly positive, it is impossible to draw concrete conclusions about rebalancing without more consistent data. The Olmstead Decision and the Community Choice Counseling Program are also possible intervening causes for the large gains in rebalancing.

### *Grants*

DHSS has also substantially supplemented the rebalancing efforts from the Act with federal grants. In fact, the Division on Aging has received every federal grant it has for which it has applied.<sup>9</sup> In 2006, New Jersey was awarded \$2.3 million through the five-year Systems Transformation Grant from CMS to update the state's long-term care information technology infrastructure. New Jersey was also chosen for the CMS "Money Follows the Person" (MFP) five-year demonstration program. Combined with state matching funds, the state estimates this grant will total up to \$30.3 million from the Federal government over the five years, beginning in May 2007. The state also received \$500,000 from the Federal government to keep people who were not Medicaid eligible in home and community-based settings.

Additionally, the Federal Administration on Aging (AoA) awarded New Jersey a two-year grant of \$400,000 to expand the ADRC model and a three-year grant of about \$600,000 to implement low-cost community-based disease and disability prevention

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<sup>9</sup> Personal communication with Patricia Polansky, Assistant Commissioner, Division of Aging and Community Services, Department of Health and Senior Services, May 5, 2009.

programs. AoA had initially awarded New Jersey \$798,041 to start the ADRC program. In 2007, New Jersey received an additional \$187,500 from AoA for community-based Alzheimer’s care.

**GO for LTC: Statewide Nursing Home Transitions**

*Nursing Home Usage*

Between 2000 and 2006, the number of nursing home residents in Atlantic County decreased from 1,640 residents to 1,351 residents. After the Act, the number of nursing home residents in Atlantic County rose to 1,488 in 2008.

Warren County also experienced a steady decline in the nursing home population from 2000 to 2006. In 2000, there were 749 nursing home residents as compared to 607 in 2006. Yet, between the Act’s passage and 2008, there was a slight increase in the nursing home population to 610 residents in this county.

The control group, Cumberland County, experienced trends similar to Atlantic and Warren Counties in the nursing home population. In 2000, there were 1,211 nursing home residents in Cumberland County. By 2006, the population decreased to 1,052 residents. In contrast to the pilot counties, Cumberland experienced an increase in nursing home residents between 2003 and 2006 and then again in 2008.

**Table 2**

**Percentage of over-65 population in nursing homes.**

	Atlantic	Warren	Cumberland
2000	4.7%	5.7%	6.3%
2006	3.7%	4.3%	5.5%
2008 <sup>10</sup>	4.0%	4.3%	5.7%

<sup>10</sup> Data in this column represents nursing home population in 2008 divided by total over-65 population in 2007.

While the overall nursing home population has decreased since 2000, the decrease has occurred in both the pilot and control counties. Indeed the trends in the three counties appear to be nearly identical. This suggests that the Olmstead Decision or Community Choice may have been the true cause of the shift from institutional care to HCBS.

### *Nursing Home Transitions*

In New Jersey's 2006 "Money Follows the Person" proposal for a CMS Rebalancing Demonstration, the transition goal for 2007 and 2008<sup>11</sup> was 189 institutional residents transitioned from nursing homes to HCBS. The goal for the full five years of the demonstration, from 2006 through 2011, was 734 transitions (389 from State Developmental Centers and 345 from Nursing Facilities). New Jersey has exceeded federal expectations for the CMS Demonstration, yet the state has not reported the county distribution of transitions. This information would be useful in evaluation of the efficacy of pilot programs, i.e. did the use of the new systems enable the pilot counties to transition more nursing home residents than the other counties?

### **GO for LTC: ADRC Pilot Programs**

The ADRC pilot programs were advanced in Atlantic and Warren Counties well before the Act was passed. The ADRC model includes a clinical assessment tool and a Medicaid Fast Track Eligibility process, the purchase of a web-based client tracking system, and the design of a new business process to transition individuals from nursing homes to home and community-based services HCBS. Together, both counties made

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<sup>11</sup> New Jersey Department of Human Services "New Jersey Money Follows the Person Rebalancing Demonstration Application Proposal Summary" November 1, 2006

37,588 referrals, pre-screened 1,462 callers, conducted 623 in-depth clinical assessments, and assessed 175 physically disabled callers in 2007.

A Medicaid “fast track” component to accessing home and community-based services is an integral part of the two pilot programs<sup>12</sup>. Specifically, E.O. 100 mandates that DHSS attempt to cut out some of the “red tape” so that seniors are not automatically directed to nursing homes, while waiting for a lengthy Medicaid HCBS eligibility process.<sup>13</sup> According to one Warren county official the “fast tracking” process is still a “gray area.” The fast track rollout happened too quickly for government to keep up. This quick implementation was combined with a hiring freeze for state employees, has led to an uneven rollout. Fast track applications are processed not at the County Office on Aging, but at the Board of Social Services along with other Medicaid applications. The financial eligibility determination lies with the Board of Social Services, not with the County Office on Aging. If a person is found to be ineligible after receiving HCBS Medicaid dollars, that person must to repay up to three months of service provision.

#### *Cumberland County*

As the control county, Cumberland’s long-term care system represents the model used in counties where the Act has not been piloted. Prior to the GO for LTC funding combination, county offices on aging were forced to navigate five different funding sources, each of which were able to fund different services. The case manager would be tasked with balancing the different funding programs, while making sure that clients

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<sup>12</sup> Department of Health and Senior Services "Fast Track Eligibility Work Plan" viewed at <http://www.njstatelib.org/digit/o44/o442004d.pdf> Last viewed May 11, 2009.

<sup>13</sup> State of New Jersey, Executive Order 100.

received needed services.<sup>14</sup> In an interview with a representative from the Cumberland County Office of Aging and Disabled, the process to receive long-term care services was outlined as three major steps: an intake and interview, a referral to the appropriate county office, and a set up of services. The intake and interview process is “not easy” for the client; the interview includes personal and in-depth questions. Sometimes, clients are hesitant to answer the questions because of their personal nature, such as questions about finances and health status. The process is much easier for the staff because it is a step-by-step process that is easy to follow.

### *Atlantic County*

Atlantic County’s “no wrong door” approach to the pilot program aims to help anyone who calls, “regardless of age, disability, need or income” (2007 State Report). As one representative from the Atlantic County Division of Intergenerational Services described it, the main change that has arisen from the new pilot program is the order in which information is taken. Prior to the pilot program, the process was income-based. Before any health assessment, the caller would have had to be determined to be Medicaid eligible. There was no clinical screening process or in depth assessment; instead, the intake worker matched a person with needed services if they qualified for Medicaid, and if waiver slots were available. A long-term care assessment is no longer determined by income, but by care needs. If, after the in-depth assessment is complete, the caller does not qualify for Medicaid, the intake worker counsels the caller on private pay options.

One obstacle to the new program is that the process has become more complex for county intake workers. A new portion of the ADRC model is the Social Assistance

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<sup>14</sup> Rutgers Center for State Health Policy "A Case Study of New Jersey: Easy Access Single Entry." March 2005.

Management System (SAMS). This web-based client tracking data system advances the goals of the Act by allowing counties to keep track of clients. With any new computer system, certain setbacks can result, e.g. the staff needs to learn and get used to SAMS, billing problems, and computer and data entry issues.

Another change is that case managers are now responsible for authorizing informal caregiver services. Informal caregivers (any person besides the client's spouse) can be paid \$15 per hour for their services. This process has added to the complexity of the new system: the case manager has to "do a computer (criminal background) check", which is sometimes slow, and send the information to Trenton for verification.

There has been a shift in the proportion of time taken for each case. More time used to be spent acquiring services for the caller and less time used to be spent on the intake and screening process. Currently, it takes more time for the "business end" and less on the actual matching of services. More time is spent creating an interdisciplinary team to ensure available services and support in the community before placing the client in these services. The representative asserts that the case management role has changed, but it is worth it. Clients receive a program tailored to them, as opposed to a list of services to choose from. Prior to the pilot program, Medicaid eligible clients would need to be granted a waiver and they would have only about seven services to choose from. Now when someone calls, they get the whole package together.

One concern that the Atlantic County representative expressed was the need to work with the state to ensure the continued availability of HCBS resources. If there are not enough actual services (e.g. doctors, transportation, subsidized housing, etc.) in each

county, they will not be able to keep people in home and community based settings. Currently, there is no waiting list for HCBS, but there used to be one.

Family caregivers were interviewed in Atlantic County as part of the study. These caregivers expressed concern about the quality of HCBS and the complexity of the system of care. One caregiver, who has had a career in government service and arranged care for her elderly in-laws, responded this way when asked what she would change the system of access to care: “I never thought about how to change it, I just knew that I wanted to beat my brains against the wall throughout the whole thing.” The Medicaid application process was described as complex, requiring a lot of paperwork. One caregiver, who had contacted a nonprofit agency instead of the county office, explained that she did not think the county office had anything to offer her besides perhaps help with transportation to doctor’s appointments and adult day care.

The quality of HCBS was also brought up as an important issue. One caregiver expressed concern for the lack of regulations and standardization for service providers. She grew concerned when she realized that the home health aides (hired through a home health organization) caring for her loved ones were not only not paying Social Security and other taxes, but that the contract for these workers was written in such a way at make them employees of her loved ones and not the hired agency. There is clearly concern about quality of services provided for at least some caregivers.

### *Warren County*

While Atlantic County has focused on a “no wrong door” approach, Warren County’s pilot program is centered on “standardizing and streamlining”. The new process

is comprised of a comprehensive, streamlined delivery menu, stated a representative from the Warren County Division of Aging and Disability Services.

The representative explained that since the new process goes through the health status questions before the financial questions, it obviates some of the problems from the stigma associated with Medicaid. Also, if the client eventually does have to transition from a home-based approach to an institutional setting, the Medicaid eligibility screening will have been completed. This is especially helpful in such a stressful time.

Warren County's pilot program is experiencing similar implementation difficulties to those in Atlantic County. The staff is struggling to get used to SAMS and the new ADRC computer system. They were trained in a practice "sandbox", which helped them become familiar with the program. The ADRC process takes a lot of the guesswork out of eligibility determinations.

We were unable to reach any caregivers in Warren County to gain additional perspective on the implementation of the Act there. To gain additional information on implementation in both Atlantic and Warren counties, we then spoke to advocates for seniors.

### **Advocate Perspective**

We interviewed representatives of long-term care trade groups, elder rights attorneys, and other elder rights activists to obtain their perspective on the Act. The reaction of advocates could best be described as mixed. Most of the advocates pointed to specific flaws with the current system, but much as in the interviews conducted with state and county officials, the new computer system was touted as a significant positive change from the act. The increased ratio of HCBS to nursing home care was also cited as a

positive result (although, as discussed elsewhere in this paper the causality here is uncertain).

When asked to describe the process from the perspective of the family, advocates answered with strong terms such as “too complex” and “haphazard.” This difficulty for family members stems largely from the complexity of the Medicaid process. Family members call these advocates because they have “no clue where to begin”. Conversely, the system has become easier and more efficient for county intake workers due to efficient screening tools, more advanced computer systems, and standardization of procedures.

There were some “stumbling blocks” that advocates encountered with trying to access home and community based care for their population. One such difficulty mentioned is the slow pace at which the government moves. The lack of uniformity among New Jersey’s twenty-one counties was also mentioned several times as an obstacle that the state will need to address with the overall rollout of the program although obviously this is not as big of an issue in the pilot program. This lack of uniformity refers to differences in county offices, differences in the availability of information on HCBS, and in the number of HCBS available.

Another advocate highlighted the fact that home and community based long-term care services that are provided under the Act are not always the best fit for consumers. Home and community based services need to benefit the consumer in some manner that he or she would not receive in an institutional setting such as a nursing home.<sup>15</sup> If there is no benefit to the person staying at home other than a different living setting, institutional care might be more appropriate. If officials do not carefully screen

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<sup>15</sup> The interview subject did not provide examples of such services.

recipients, a new set of problems regarding people being directed to inappropriate care settings could be created. For example, if someone is in their home and they are getting all the services they need, but never see anyone except the caregivers, they will have no social connections and may be worse off as a result.

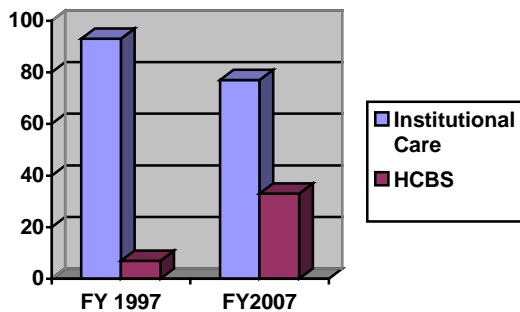
The advocates interviewed were supportive and congratulatory of New Jersey's successes with securing grant funding from the federal government. They were optimistic that the Act has called attention to the need for these efforts and touted DHSS for obtaining so many federal grants to supplement the rebalancing efforts. They pointed to the importance of this funding in the future success of the promotion of HCBS.

## **V. Results and Discussion**

While The Act was passed in 2006, it is important to be cautious in attributing long-term care accomplishments purely to its implementation. Two main alternate causes should be taken into account when discussing the gains in New Jersey's rebalancing efforts: the *Olmstead* Supreme Court Decision and the Community Choice Program. In 1999, the United States Supreme Court ruled that unnecessary institutionalization violates the Americans with Disabilities Act of 1990 (ADA). As a result of this decision, states are now required to provide HCBS to those who are otherwise entitled to institutional services through Medicaid. Concurrently, New Jersey was conducting a CMS Nursing Home Transition Demonstration Program called Community Choice. The Community Choice demonstration had goals similar to those of The Act: provide alternatives to institutional care and assist in transitions from nursing homes. During the years of the demonstration (1998-2001), more than 3,400 people transitioned from nursing homes to

HCBS. Thus, Medicaid dollars began to shift toward HCBS and away from nursing homes as early as 1998.

Therefore, New Jersey has certainly made substantial progress in rebalancing efforts in the past decade. Before the *Olmstead* decision, Community Choice, and The Act, in SFY97, 93% of the state's Medicaid long-term care funding went to institutional care. While, the SFY07 budget allocated 77% of long-term care funds to institutional care and 33% to HCBS (see figure).<sup>16</sup>



These advances make it difficult to evaluate the Act. The Act has only been in place for roughly two years and has undergone a slow implementation. All of the trends prior to its passage point toward an increased emphasis of HCBS. Data presented in the state reports on the Act seem to attribute gains that are most likely due to *Olmstead* and Community Choice to the Act.

Another thing that makes evaluating the implementation of the Act in the pilot counties difficult is the manner in which the Department of Health collections information on nursing home transitions. While the number of people transitioning out of

<sup>16</sup> But note the difficulties inherent in these numbers noted in Table I.

nursing homes back into their communities continues to rise, the Department does not collect data at the individual county level, but rather by regions (Northern, Central, and Southern). This data collection makes it difficult to attribute any gains to specific pilot counties.

The budget line item requirement for Global Options (GO) has been funded since the Act's passage. The state budget has also reflected other adaptations to rebalancing efforts. For example, the SFY08 budget, removed Medicaid reimbursement to nursing homes for bed hold while the patient is in the hospital. Nursing homes that have a low occupancy rate have made less of an effort to hold beds for patients because the likelihood of that patient being put on a waiting list is very small. This saves the state money by no longer paying for held beds and frees up room in nursing homes for other patients.

A positive theme that has emerged from interviews with officials and advocates alike is the flexibility that the new system grants long-term care recipients. While the alternative to a nursing home used to be a list of approximately seven services from which the patient chose a few. The new system gives patients a personalized set of services. In the previous system the patient would have to piece together his or her own system of care, with the new system the patient receives a personalized "plan" that takes into consideration all of his or her needs.

The streamlined computer system, ADRC, along with the new database, SAMS, have truly improved the long-term care delivery system in New Jersey. The ADRC system creates a single entry point for callers seeking long-term care. The new intake process

allows more callers to get the help they need by conducting the clinical questions before the financial questions. If callers are then found to be ineligible for Medicaid, the intake worker counsels them on private pay options. While providing counseling for those who are not Medicaid eligible does not meet the goal of rebalancing, it does provide a useful service to the community.

With any new process comes a learning curve. Through interviews, we learned that intake workers in the pilot counties are struggling to get used to the new computer programs and intake processes. There was also some concern about how complex the new intake system has become. It may cause the client to wait longer for services than they would have with the older system.

Both officials and advocates have noted a possible problem with a lack of HCBS resources such as staffing. Matching clients with HCBS, as is a major goal of the Act, will not be possible if there are not enough services to go around. A reason for the lack of services could be New Jersey's low Medicaid reimbursement rates. New Jersey's reimbursement rates are some of the lowest in the country<sup>17</sup>; plus, most of these services are paid for with Medicaid dollars.

Another area of concern is the varying quality of HCBS. There have been concerns about the quality of nursing homes for quite some time, and this is something we are just beginning to measure. Especially with the potential lack of service providers and the wide variation in quality among informal caregivers, quality assurances are

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<sup>17</sup> Public Citizen "Equal Pay for Equal Work? Not for Medicaid Doctors" The Health Research Group Publication no. 1822 September 5, 2007

vitaly important. Regulations of the home-care industry do exist (N.J.A.C. 8:43I) but the concern voiced by family members and advocates indicate that these regulations are either insufficiently stringent or inadequately enforced.

Another common theme among advocates was a point of contention with DHSS regarding who qualifies for home and community-based services through Medicaid. The Act specifies that, “Older adults and those with physical disabilities or Alzheimer's disease and related disorders that require a nursing facility level of or giving up the medical assistance that pays for their needed services, and thereby be denied the right to choose where they receive those services; their eligibility for home and community-based long-term care services under Medicaid should be based upon the same income and asset standards as those used to determine eligibility for long-term care in an institutional setting” (C.30:4D-17.24.2h.) This stipulates that those who are eligible for LTC through Medicaid should also be eligible for HCBS.

Medicaid has two programs that fund LTC services: Medicaid Only and Medically Needy. The Medically Needy program funds LTC for those with slightly higher income and asset levels than those who qualify for Medicaid Only funding. As of now, the Department has only allowed Money-Follows-the-Person to include recipients of Medicaid Only program. Advocates point out that the statute allows anyone who is eligible for institutional care under Medicaid to acquire HCBS. Thus the Medically Needy category of Medicaid recipients should also be eligible for HCBS through Medicaid.

One potentially troubling aspect of the implementation is the reliance on state budget appropriations for continuing support of HCBS. Given the current fiscal challenges the state is under, the programs runs the risk of being under-funded in the future. Given the need for adequate funding in order to make this project work, it is critical to ensure that the current budget crisis does not have too great an adverse effect upon the implementation of the Act.

Finally, it is important to remember that there is wide variation across New Jersey's twenty-one counties. Atlantic and Warren were chosen as pilot counties for the Act because they were closer to the ideal implementation (having already begun ARDC rollout), and were eager to start the program. This means that represent "best case scenarios" for implementation. Any difficulties exhibited in the pilot counties are likely to be exacerbated across the state and new challenges are likely to emerge. We did not evaluate the access to HCBS in more urban counties, but we anticipate problems could arise in these counties.

### *Limitations*

There are several limitations to the research. First of all, the time frame for the research (January – May 2009) was limited. There are also limits to the generalizability of the data. Convenience and purposive sampling was used in order to gain a more complete picture of the current system, not to generate data that will be generalizable to other counties or states. This study was not meant to be an exhaustive study of long-term

care; it was geared toward simply finding out more about the implementation of this act and to discover “best practices” to share with legislators and state officials.

Another limitation was the lack of access to family and informal caregivers and county officials. Presumably the reasons that we would want to talk to caregivers (to understand what financial, emotional, and time pressures they are under and how they can be relieved) are the very reasons that make it difficult to contact them. Their stories would have helped us better understand the consumer side of implementation, but it was exceedingly difficult to locate family caregivers in the three counties. A limited number of officials responsible for the implementation of the Act were interviewed. Although numerous contacts were made with ADRCs and County Offices on Aging, the current state fiscal climate, high workload, and pressures of implementing a new computer system, might have constrained the ability of those who would have been willing to speak with us.

The fact that the Act was passed recently in June of 2006 was also a limitation on the research. Although the research team had access to both the 2007 and the 2008 year-end report from the Advisory Committee, as of this writing there was no report issued in 2009. Access to this most recent report would have tremendously increased the amount of data and comparison points available for the quantitative analysis in this report.

## **VI. Policy Recommendations/Recommendations for Further Research**

An examination of the literature on HCBS shows that there is a policy rationale for supporting home and community based services. This study shows that New Jersey is moving more toward a home and community-based approach, both with funding and with general policy priorities. With this in mind, we recommend the following:

- 1) **For greater transparency, the State should issue this year's progress report as is required by the Act as soon as possible.** DHSS has not yet put out this year's report. Putting out the reports on time is not only required by law but is also necessary for evaluation and improvement of the system. New data would be useful for tracking the progress of the implementation of The Act.
- 2) **The State should make clear the percentage of funding going to institutional care and HCBS in the State's year-end reports, beginning with the 2008 report, to better track progress.** It would be extremely helpful if these numbers were transparent, constant and easily comparable. The state's two reports include varying data regarding the proportion of Medicaid funds between nursing home care and HCBS, even stating two different proportions in the same report. While the trends are clearly positive, it is impossible to draw concrete conclusions about rebalancing without more consistent data.
- 3) **All assessments of the Act by the State should include data since the passage of the Act and its implementation to the present to improve accountability.** Data citing improvements in care from 2002 or 1997 are not relevant to assessing the Act, which became law in 2006. Many factors (such as the *Olmstead* decision) began the process of shifting funding from nursing home care to HCBS. The trend of funding has been toward more community-based services, even

before the passage of the Act. While it is nearly impossible to segregate sources for the gains made since the act was passed, it is obvious that the Act cannot have been responsible for accomplishments before its passage. We recommend that future reports on the Act cite only data since its passage.

- 4) **Medicaid funded home and community-based services should be made available to the “Medically Needy” category of Medicaid recipients, beginning in SFY10 to provide the long term care choices consumers want and need.** The Act specifies that, “Older adults and those with physical disabilities or Alzheimer’s disease and related disorders that require a nursing facility level of or giving up the medical assistance that pays for their needed services, and thereby be denied the right to choose where they receive those services; their eligibility for home and community-based long-term care services under Medicaid should be based upon the same income and asset standards as those used to determine eligibility for long-term care in an institutional setting” (C.30:4D-17.24.2h.) We recommend that Medicaid eligibility be extended to those medically needy individuals who are slightly above Medicaid financial eligibility.
- 5) **The State should continue funding the GO for LTC and expand the pilot program to the remaining counties in SFY 10.** According to the Act, expansion of services to the remaining nineteen counties was to begin March 1, 2008. Over a year later total implementation of the Act has yet to happen. In order to provide the option of HCBS to a larger population, it is important that the state continue the rollout to the remaining counties. The state has been successful

in securing federal money to fund many helpful programs; it is important that they continue these programs, especially under the current fiscal climate.

- 6) **The State should consider increasing access and Medicaid reimbursement rates to attract more long-term care service providers to New Jersey.** There is a concern that waiting lists for HCBS might develop in counties with larger populations once the Act is rolled out. In order to encourage more caregivers and long-term care service providers to accept Medicaid patients the reimbursement rates need to be competitive under these conditions. It is important that those accessing HCBS have adequate access to these services.
- 7) **The State should provide county-level information on HCBS long-term care services for improved tracking and accountability.** This should include efforts to assess and perhaps regulate the quality and suitability of HCBS. Family members that participated in our study expressed concern over the quality of care they received. When asked if they had contacted county offices, many said that they had not even tried believing that they would not qualify for services. It is important for the state to serve as a clearinghouse for information about these services.
- 8) **The State should offer county-level training for the new computer intake and tracking systems being implemented to expedite statewide expansion.** The State has been developing and implementing more comprehensive databases and computer systems. While these are important advances, it is equally important that those using the systems be properly trained in them. From our research it appears that the state has been doing an excellent job acquainting their employees

with these news systems. Allowing employees to experiment in a “sandbox” setting of the computer system seems to be helpful for adjusting to the new software. We recommend that the State continue these useful training sessions.

- 9) **The State should conduct further research on the “consumer experience” from the Act’s implementation to improve results.** A systematic, randomized study of people who have had experience seeking care for him or herself or a loved one would help evaluate the implementation of the Act. More research into the effects of expansion of home and community-based care on the available supply of services in New Jersey communities also needs to be conducted. More outcomes based data regarding HCBS would be helpful to policymakers as they consider funding strategies and rules and regulations to “rebalance” more toward non-institutional care. This could be particularly important as the state considers expanding the pilot program to other counties dissimilar to Atlantic and Warren Counties.

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