Long-term Care:
A National Perspective and Implications for Georgia

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for

Georgia's Aging Population:
What to Expect and How to Cope

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I. Executive Summary

The aging "Baby Boomer" generation will be the most significant factor increasing the demand for long-term care services over the next half century [1]. Tomorrow's elderly (those age 60 and above) will have very different social, demographic, health, and economic characteristics than today's elderly [2]. Creating a "senior tsunami" beginning in 2011, this group will be more highly educated and exhibit more household diversity than previous generations entering traditional retirement age. The sheer size and inevitable aging of the Baby-Boom generation will continue to drive public policy debate [2], and the disabled older population will grow faster than the younger population, likely raising the economic burden of long-term care [3].

The elderly population is expected to grow from 35 million in 2000 to more than 80 million in 2050, with the largest growth among the "oldest-old" (people age 85 and older), who are disabled at the highest rates [4]. By 2050, the oldest-old will be nearly five percent of the total population, compared to just over one percent in 1994 [2]. According to calculations by the U.S. Bureau of the Census, the elderly population in Georgia will increase 143 percent between 2000 and 2030 versus a total population increase in Georgia of 46.8 percent.[1] This compares with national growth for the same age group of 104.2 percent over the same period. In fact, Georgia is among the top ten states expected to experience greater than average growth in the elderly population between 2000 and 2030. Georgia's aging population will be spread throughout the state, but concentrations will be greatest in suburban and rural areas, with the exception of the Savannah metropolitan area [5].

State-level elder disability projections are sparse and imprecise. One report estimates that while the percent of elderly individuals with disabilities in Georgia will remain fairly constant through 2025, the growth of elderly residents will double the number of people over 65 with disabilities [5]. This, in turn, will drive the need for and cost of long-term care services.

If decreases in the rates of disability continue, an increase in the retirement age may be the result, and the projected increase in medical spending will be moderated but not eliminated [6]. According to tabulations by Thomson Healthcare, the cost of Medicaid supported long-term care in Georgia grew 82 percent between FY2000 and FY2005 from $4,255,427,057 to

[1] U.S. Census Bureau, Population Division, Interim State Population Projections, 2005.

$7,736,524,326 [7]. Studies are quite mixed as to whether or not community care actually saves money over institutionally based care [8]. In fact, increases in community care use are largely driven by the Supreme Court's 1999 Olmstead Decision and by public preference rather than by proof of cost-effectiveness. Still, the 2006 average daily cost of nursing facility care in Georgia was $135 ($160 in Atlanta) - $49,275 per year. This compares with a national average of $194 per day and $70,810 per year.[2] Long-term care insurance has been promoted as one way to help pay for the increasing cost of care. However, long-term care insurance still plays only a limited role in long-term care financing.

Even if society finds a way to finance all the long-term care services the population needs, there remains the problem of an available workforce to provide direct care. The growth in the number of elderly likely will lead to a precipitous drop in the number of workers per older adult and an even larger decrease in the ratio of workers to frail older adults if current working and retirement patterns do not change [4]. In 2001, a Georgia taskforce released a report[3] declaring that the health care workforce in Georgia was in a state of "Code Blue." Policies and programs that support the creation of a career ladder for long-term care paraprofessionals may help increase future long-term care worker supply.

Approximately 9.5 million people currently need long-term care. While the need for long-term care is independent of age, 63 percent of people with long-term care needs are elderly, and the majority of the elderly population needing long-term care is age 85 or older [9]. According to a 2005 study of five states supported by the Commonwealth Fund, Georgia has the lowest percentage of dual eligibles[4] needing help with ADLs who receive paid assistance at home (31 percent) and the highest proportion with unmet need (65 percent) [10].

The U.S. Supreme Court's 1999 Olmstead Decision was a landmark human rights ruling in that it put states on notice that unnecessary segregation of individuals with disabilities is a violation of the Americans with Disabilities Act of 1990 [11]. Although the Olmstead case specifically addressed individuals with developmental disabilities, the reach of the decision includes individuals with any disability, including the elderly, and national and state policy has responded in order to be in compliance with the spirit and letter of the decision. The initiatives

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[2] http://www.aarp.org/bulletin/longterm/Articles/a2003-10-30-dailycost.html retrieved from the World Wide Web July 25, 2007.

[3] http://www.communityhealth.state.ga.us/departments/dch/v4/top/shared/con_dhp/dhp_publications/healthcare_workforce_final.pdf; retrieved from the World Wide Web August 13, 2007.

[4] Dual eligibles are those eligible for both Medicare and Medicaid services.

include Real Choice Systems Change Grants, the New Freedom Initiative, support for consumer direction, the Cash and Counseling Demonstration, the Money Follows the Person Rebalancing Demonstration, and the Aging and Disability Resource Center initiative.

Dr. Paul Hodge may have said it best when he concluded to the White House Conference on Aging Policy Committee in 2004:

> While many experts, pundits, and the press have made predictions about how the aging of the Baby Boomers will affect the United States, in actuality, no one really knows with any certainty what will happen. What is clear is that the policy implications and ramifications are unprecedented in history. America's aging will transform politics, retirement systems, health care systems, welfare systems, and labor markets. It will force a re-thinking of social morés and prejudices, from issues of age/gender discrimination in the job market to end-of-life care. Whether that transformation is positive or negative will depend on planning and preparation that must begin today [12].

II. Introduction

The aging "Baby Boomer" generation will be the most significant factor increasing the demand for long-term care services over the next half century [1]. Tomorrow's elderly (those age 60 and above) will have very different social, demographic, health, and economic characteristics than today's elderly [2]. Creating a "senior tsunami" beginning in 2011, this group will be more highly educated and exhibit more household diversity than previous generations entering traditional retirement age. The sheer size and inevitable aging of the Baby Boom generation will continue to drive public policy debate [2], and the disabled older population will grow faster than the younger population, likely increasing the economic burden of long-term care [3]. This paper explores the national literature to identify the probable impact of the aging population on long-term care at both the national and state levels. It then describes the long-term care needs of the aging population and highlights findings from a 2006 statewide survey designed to help Georgia prepare for the population's aging. Finally, the paper describes service delivery models currently in use at the national and state levels to serve the growing aging population.

III. The Impact of an Aging Population

A. Population Growth

The elderly population is expected to grow from 35 million in 2000 to more than 80 million in 2050, with the largest growth among the "oldest-old" (people age 85 and older), who are disabled at the highest rates [4]. By 2050, the oldest-old will be nearly five percent of the total population, compared to just over one percent in 1994 [2]. In states where senior populations will grow fastest over the next 35 years, "aging in place" rather than migration will drive this growth. In Georgia, for example, the senior population will increase by more than 40 percent from 2010 to 2020 due to the aging of existing residents versus less than three percent due to migration [13].

Georgia, overall, is a relatively young state, largely due to the Atlanta urban core and its attractiveness as an employment, education, and arts magnet. However, according to

calculations by the U.S. Bureau of the Census, the elderly population in Georgia will increase 143 percent between 2000 and 2030 versus a total population increase in Georgia of 46.8 percent.[5] This compares with national growth for the same age group of 104.2 percent over the same period. In fact, Georgia is among the top ten states expected to experience greater than average growth in the elderly population between 2000 and 2030. Paralleling national trends, Georgia's 85 and older age group will grow the fastest. Georgia's aging population will be spread throughout the state, but concentrations will be greatest in suburban and rural areas, with the exception of the Savannah metropolitan area, which will also see higher concentrations of elderly than the state average [5].

Estimates by Georgia State University's Fiscal Research Center show that between 1995 and 2000, Georgia attracted more elderly residents than it lost, perhaps due to generous income tax exemptions [14]. The greatest gains were in the oldest-old population group – those over age 85. Additionally, Furthermore, Georgia is "growing" a significant portion of its own elderly at an even higher rate than those migrating into the state. These trends will have important implications for the delivery of long-term care services in Georgia over the next few decades.

B. Growth in Disability Rates

Long-term care services are required as the result of a chronic condition, disability, or cognitive impairment [15]. Nationally, the number of elders using either nursing facilities, alternative residential care, or home care services is expected to increase from 15 million in 2000 to 27 million in 2050 [1]. Between 2000 and 2040, the share of disabled older adults receiving paid help will increase from about 22 to 26 percent, while the share receiving unpaid help will fall from about 28 to 24 percent [3]. This is significant, as the Rosalynn Carter Institute for Caregiving in Americus Georgia reports that more than 50 million family caregivers provide the greatest share of care for dependent elders as well as adults and children with disabilities and chronic illness.[6]

Model-based simulations performed by the Urban Institute show that even under the most optimistic scenario, the long-term care burden on family caregivers and institutions will increase substantially [3]. The Institute's intermediate disability growth model shows that disability rates

[5] U.S. Census Bureau, Population Division, Interim State Population Projections, 2005.
[6] http://www.rci.gsw.edu/; retrieved from the World Wide Web August 13, 2007.

at ages 65 and older will decline by a few percentage points between 2000 and 2020 but then rise through 2040 as the oldest Boomers reach their 80s. Between 2000 and 2040, the numbers of older adults with disabilities will more than double. Even in the most optimistic model, assuming that disability rates fall by one percent per year, the size of the disabled older population will grow by more than 50 percent between 2000 and 2040, and the ratio of disabled older adults to younger adults (ages 25 to 64) will increase [6].

State level elder disability projections are sparse and imprecise. According to the Census Bureau's Behavioral Risk Factor Surveillance Survey (BRFSS), Georgia's overall rate of disability (both young and old) as of 2003 was 18.3 percent – about in the middle of the rankings of states and less than the national average – again most likely due to Georgia's relatively young population. One report estimates that while the percent of elderly individuals with disabilities in Georgia will remain fairly constant through 2025, the growth of elderly residents will double the number of people over 65 with disability [5]. This, in turn, will drive the need for and cost of long-term care services.

C. Growth in Expenditures for Long-term Care Services

If decreases in rates of disability continue, an increase in the retirement age may be the result, and the projected increase in medical spending will be moderated but not eliminated [6]. The Congressional Budget Office estimates that total expenditures (public and private) on long-term care were more than $120 billion in 2000 and suggest total long-term care expenditures will increase at a rate of 2.6 percent per year above inflation to $154 billion in 2010, $195 billion in 2020, and $270 billion in 2030 [4]. The aging population is projected to increase total health care spending to 15.5 percent of Gross Domestic Product as soon as 2010 [16]. How those funds are allocated will likely mirror the distribution of health care dollars today: the most affluent elderly will receive adequate long-term care (although they may not receive the type of long-term care they want or need), while the less affluent will depend on the public programs [17].

Only 17 percent of individuals with long-term care needs seek assistance in nursing home facilities while the rest of the population obtains informal help in their respective communities [9]. A significant proportion of long-term care is provided on an informal basis by family and friends or paid for out-of-pocket because Medicaid does not pay for most *informal* long-term care services [18]. Custodial nursing home and personal care were considered "social" rather

than “medical” services by the authors of early health insurance plans, and this perspective was adopted by the designers of Medicare when it was created in the 1960’s [19]. Thus, long-term care developed in an environment where the Medicare program did not provide long-term care benefits, and, with the exception of Medicaid, the medical model, not the supportive care model, has been adopted by most other third-party payers. While some people are dually covered by Medicaid and Medicare, 58 percent of people needing long-term care report unmet needs and experience serious consequences as a result [10].

Knickman and Snell suggest that the economic burden of meeting the long-term care needs of Baby Boomers will be eased if social and public policy changes are made sooner rather then later. They suggest: (1) making sure payment and insurance systems for long-term care are developed that work better than existing ones, (2) taking advantage of advances in medicine and behavioral health to keep the elderly as healthy and active as possible, (3) making community services more accessible, and (4) altering the cultural view of aging to make sure all ages are integrated into the fabric of community life [4].

According to tabulations by Thomson Healthcare, the cost of Medicaid supported long-term care in Georgia grew 82 percent between FY2000 and FY2005 from $4,255,427,057 to $7,736,524,326 [7]. Over the same period, the cost of Georgia’s home and community-based 1115 Medicaid waivers grew by an annual compound rate of 17.6 percent, while the U.S. rate was 12.2 percent [20]. Georgia, in a sense, has been playing catch-up with the rest of the nation in expanding access to community-based care, as in FY2005 it ranked 49th out of 51 states and the District of Columbia in the ratio of Medicaid long-term care dollars it distributed to community based services versus institutional services. The national average was 37.2 percent of Medicaid long-term care dollars allocated to community-based services, while the median was 36.7 percent, and the Georgia ratio was 22.7 percent. Nineteen states allocated more than 40 percent of Medicaid long-term care dollars to community-based services, and eight states allocated more than 50 percent [21].

Studies are quite mixed as to whether or not community care actually saves money [8]. In fact, the increase in community care use is largely driven by the Supreme Court’s 1999 Olmstead Decision and by public preference rather than by proof of cost-effectiveness. Still, the

2006 average daily cost of nursing facility care in Georgia was $135 ($160 in Atlanta) - $49,275 per year. This compares with a national average of $194 per day and $70,810 per year[7].

There is widespread support from older adults for policies that would help them save for their future health and long-term care costs not covered by Medicare and also allow them to buy into Medicare before age 65 [22]. Long-term care insurance has been promoted as one way to help pay for the increasing cost of care. As recently as the Deficit Reduction Act of 2005, the federal government has promoted the purchase of long-term care insurance policies through a partnership with the Medicaid program – the Long-term Care Partnership program. However, long-term care insurance still plays a limited role in long-term care financing. The largest number of policies sold in a single year since the market was first analyzed (1987) was in 2002 when 104 companies sold more than 900,000 policies. There were 9.16 million policies sold from the inception of the market through the end of 2002, and the market grew an average of 18 percent per year between 1987 and 2002. However, purchasers of long-term care polices do not resemble their peers. They tend to be wealthier, younger, married, and college educated [23, 24]. In fact, an analysis of the federally-supported Long-term Care Partnership pilot shows that the program has not attracted large numbers of new purchasers [25].

In a 2006 survey[8] of Georgians over age 55 [26], 48 percent said they expect their income to be less than 300 percent of the federal poverty level. Only 16 percent of respondents said they have long-term care insurance, and only 18 percent more said they plan to have it in the future. At the same time, 66 percent said they have or plan to have supplemental health insurance. Respondents did indicate they have assets that could potentially contribute to the cost of long-term care. Sixty-percent said they already have or plan to have a pension, 82 percent said they already have or plan to have life insurance, and 69 percent said they already have or plan to have retirement savings or investments. Perhaps the greatest untapped potential for support of future long-term care needs is reverse mortgages. Only four respondents said they have a reverse mortgage, and only three percent said they plan to have one in the future. State policies that encourage individuals to liquidate their assets to support long-term care services might reduce the state's overall financial burden as the population ages.

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[7] http://www.aarp.org/bulletin/longterm/Articles/a2003-10-30-dailycost.html retrieved from the World Wide Web July 25, 2007.

[8] http://aysps.gsu.edu/ghpc/long_term_care/reports/Final%20Aging%20Report%202-2-07_1.pdf; retrieved from the World Wide Web August 13, 2007.

D. Long-term Care Workforce Growth

Even if society finds a way to finance all the long-term care services the population needs, there remains the problem of an available workforce to provide direct care. The growth in the number of elderly likely will lead to a precipitous drop in the number of workers per older adult and an even larger decrease in the ratio of workers-to-frail older adult if current working and retirement patterns do not change [4]. According to estimates developed by Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation, after 2010 the demand for direct care workers in long-term care settings becomes great. Projections show that in 2040 there will be only about nine younger adults to support each disabled older adult, down from about 15 younger adults in 2000 [3]. The increase in worker demand will occur at a time when the supply of workers who have traditionally filled these jobs is expected to increase only slightly.

The Bureau of Labor Statistics estimates that by 2010, direct care worker jobs in long-term care settings should grow by about 45 percent from the year 2000. Paraprofessional long-term care employment will account for eight percent of the estimated increase in the nation's jobs for workers in occupations generally requiring only short-term on-the-job training. Since many industries will be competing for the same supply of workers, pay and working conditions will play a key role in attracting new workers and consequently influencing the supply of long-term care services [1].

In 2001, a Georgia taskforce released a report[9] declaring that the health care workforce in Georgia was in a state of "Code Blue." The report cited FY2000 nursing facility staff vacancy rates of between 12.6 percent for Certified Nurse Assistants and 15.4 percent for Registered Nurses [27]. The report also highlighted the problem of the workforce itself aging. The majority of Georgia's nurses are over age 40, and less than 10 percent are under age 30. Contributing to the decline in health care workforce, the report cites stagnant inflation adjusted wages.

One effort to help increase the supply of long-term care service workers in Georgia is a project of the Better Jobs Better Care Program[10] supported by the Robert Wood Johnson Foundation and the Atlantic Philanthropies. The project expanded in Georgia in 2005 to help

[9] http://www.communityhealth.state.ga.us/departments/dch/v4/top/shared/con_dhp/dhp_publications/healthcare_workforce_final.pdf; retrieved from the World Wide Web August 13, 2007.
[10] http://www.bjbc.org/content/docs/BJBCIssueBriefNo6.pdf; retrieved from the World Wide Web August 13, 2007.

incumbent and newly hired workers enter and advance in health care careers through education and training programs that result in apprenticeship certification by the U.S. Department of Labor [28]. Additional policies and programs that support the creation of a career ladder for long-term care paraprofessionals may help increase future long-term care worker supply.

IV. The Needs of an Aging Population

One of the obstacles that the growing number of people living with chronic illnesses face is medical care that does not meet their needs for effective clinical management, psychological support, and information [29]. People who require long-term care services need ongoing personal assistance with activities that are essential to everyday life [9]. These needs are divided into two general categories: 1) Activities of Daily Living (ADLs) which include activities such as eating, bathing, and dressing, and 2) Instrumental Activities of Daily Living (IADLs) which include activities such as money management, housework, and shopping [2, 9, 30].

Approximately 9.5 million people currently need long-term care, and while the need for long-term care is independent of age, 63 percent of people with long-term care needs are elderly, and the majority of the elderly population needing long-term care is age 85 or older [9]. On average, older adults have high rates of chronic disease [22]: almost 38 percent of people aged 65 and over are diagnosed with a severe disability, and 47 percent of those aged 85 and older have Alzheimer's disease or other forms of dementia [15].

People with chronic illnesses, disabilities, and functional limitations are likely to be the greatest users of medical and supportive care services, but are often forced to navigate a system that is not organized around their needs and requires them, their families, and caregivers to perform most of the coordination functions themselves [19]. The primary reason for the growing number of people needing long-term care services not having care that meets their needs may be the mismatch between their needs and care delivery systems largely designed for acute illness [29]. Some suggest the changes needed to help older consumers get what they want include empowering older persons and their agents to make better decisions, including providing them with more structure and better consumer information, revising attitudes toward safety and protection, and developing more vigorous advocacy by and for seniors [31]. Advocacy by others

on behalf of the elderly may be critically important in light of high rates of dementia in the over 85 population.

According to a 2005 study of five states supported by the Commonwealth Fund, Georgia has the lowest percentage of dual eligibles[11] needing help with ADLs who receive paid assistance at home (31 percent) and the highest proportion with unmet need (65 percent) [10]. Conversely, a survey of Georgians over age 55 report that the majority believe they are either healthier than or as healthy as their peers [26]. When respondents were asked what they believed they needed to maintain or improve their health and wellness in the future, 29 percent said a better diet and exercise, recognizing the contribution of the individual toward health outcomes. Eighteen percent said better access to regular health care. These Georgians appear to be on two ends of a spectrum: those who need help but are not receiving it and those who perceive themselves to be quite healthy.

The same survey respondents highlighted the fact that they may need assistance not only for their own health but also for the health of those for whom they care. Twenty percent said they care for an individual over age 65, and 12 percent said they care for other adults or children – some with disabilities. More than 20 percent said they need financial assistance to continue providing the current level of care to their loved one, and 18 percent said they need in-home help.

When all respondents were asked to think about what they might need in the future for their own long-term care needs, almost 20 percent did not know what they might need, which may support the belief that most do not plan in advance for their future long-term care needs. Sixteen percent again mentioned in-home care, and other answers included access to regular medical care, access to transportation, government benefits, meals, and prescription drug assistance.

[11] Dual eligibles are those eligible for both Medicare and Medicaid services.

V. Service Delivery Models for an Aging Population

A. The Olmstead Decision and State Responses

The U.S. Supreme Court's 1999 Olmstead Decision was a landmark human rights ruling in that it put states on notice that unnecessary segregation of individuals with disabilities is a violation of the Americans with Disabilities Act of 1990 [11]. Although the Olmstead case specifically addressed individuals with developmental disabilities, the reach of the decision includes individuals with any disability, including the elderly, and national and state policy has responded in order to be in compliance with the spirit and letter of the decision. The initiatives include Real Choice Systems Change Grants, the New Freedom Initiative, support for consumer direction, the Cash and Counseling Demonstration, the Money Follows the Person Rebalancing Demonstration, and the Aging and Disability Resource Center initiative.

After the Olmstead Decision, 42 states and the District of Columbia formed task forces, commissions, or state agency work groups to review their long-term care programs, with 11 states releasing their plans and reports in 2002. Arkansas, Washington, Hawaii, and Utah were among the first states to release comprehensive plans to alter the delivery of institutionally based services. The plans included such components as providing additional funds for the Medicaid home and community-based services (HCBS) developmental disabilities waiver program; allowing funds for nursing home residents to be transferred to community care services if a resident relocates to a community setting; issuing recommendations on implementation of self-directed services and on the respective roles of residential habilitation centers; informing and educating consumers about long-term care choices; supporting individuals in finding appropriate places to live; and assuring adequate housing, transportation, and employment for people with disabilities [32].

Georgia formed an Olmstead Planning Committee in 2000 and finalized recommendations by November 2001. In June 2002, Governor Roy Barnes issued an Executive Order and charged the Council on Aging, the Governor's Council on Developmental Disabilities, the Long-term Care Advisory Committee for the Department of Community Health, and the Governor's Advisory Council on Mental Health, Mental Retardation, and Substance Abuse with ongoing review and reporting responsibilities on the state's compliance with Olmstead requirements. Specific to the aging population, the following was accomplished between 2000 and 2002:

- **Community-based services** - Georgia increased the number of consumers served by home and community-based waivers.
- **Increased length of stay in community services** - Overall, the length of time individuals receive Community Care Services Program (CCSP) services increased from 34 months to 39 months. Those who eventually move into nursing homes (38 percent of CCSP recipients) are able to stay at home and (on average) delay moving from their own home for five additional months. [33]

Georgia's Olmstead Strategic Plan[12] outlines six goals related to moving the state forward in its long-term care planning:

1. Create a practical structure for implementation of a plan which draws on the advice of the Olmstead Planning Committee report.
2. Identify areas for improvement in the delivery of community-integrated services and supports for people with disabilities and the aging population.
3. Ensure that consumers, family members, and other stakeholders are involved in the ongoing process for improving community-integrated services.
4. Establish sustainable State processes for identification, assessment and planning for qualified individuals.
5. Continue the process for annual budget planning to support agency operational plans related to the Olmstead Working Plan.
6. Set the strategic direction for state agency operational strategies to address the plan.

The U.S. Department of Health and Human Services' (HHS) response to the Olmstead Decision was to adopt in 2000 a long-term care Systems Change Framework which reforms the access, services, financing, and quality of home and community-based services. Using the HHS long-term care Systems Change Framework as a guide, Oregon, South Carolina, Vermont, Wisconsin, and others have piloted promising practices in long-term care reform that may guide other states to carefully and systematically plan programs that expand consumer choice, strengthen collaborative efforts, and keep the consumer at the core of the program development [34].

[12] http://dch.georgia.gov/vgn/images/portal/cit_1210/45/13/31848286olmstead_plan.pdf; retrieved from the World Wide Web August 13, 2007.

B. Georgia's Real Choice Systems Change Grant

Georgia received a total of $4,169,000 under the Real Choice System Change Grant to support Nursing Facility Transition, the Independence Plus Initiative, Quality Assurance and Quality Improvement in Home and Community Based Services, and housing transition programs and initiatives [35].

A stakeholder group including consumers, family members, representatives from state organizations, service providers, and advocacy groups defined the goals of Georgia's Real Choice Systems Change Grant as follows:

- Address system barriers to integrated community living,
- Develop an ongoing mechanism for consumer involvement in all aspects of the integrated community service delivery system for elderly people and people with disabilities,
- Develop a process for effective communication and collaboration to enhance planning and implementation of integrated community services system changes, and
- Ensure an accessible, integrated community service system for elderly people and people with disabilities.

Georgia's overall intent is to facilitate the design and implementation of effective and enduring improvements in the state's community long-term care systems. These improvements are to enable individuals of all ages with disabilities or long-term illnesses to participate in their communities [36].

C. The New Freedom Initiative

In 2001, the Bush administration created the New Freedom Initiative, a multi-agency effort to improve access to community living and the economic status of persons with disabilities in order to implement the Olmstead ruling. He followed that with an executive order - *Community-Based Alternatives for Individuals with Disabilities* - which directed several federal agencies to work with states to comply with the Olmstead Decision and the Americans with Disabilities Act [11].

As part of the New Freedom Initiative, the Department of Health and Human Services made a policy clarification that permitted HCBS waiver programs to cover one-time costs such

as security deposits on apartments and utility set-up fees for people who are transitioning from institutions to community living arrangements. This move was important, as one of the most critical links in transitioning individuals from institutions to community care is affordable and supportive housing. From 1999 to 2002, the number of participants in HCBS waiver programs grew by more than 25 percent nationally [37].

D. Consumer Direction

Consumer direction in long-term care is based on the premise that individuals with long-term care needs should have primary control over who, what, when, where, and how the services are delivered [38]. The past 15 years have produced a wave of new state programs that have introduced consumer direction into home-based services for elderly persons and those living with disabilities. Building upon earlier models developed for younger adults with physical disabilities, consumer-directed models are now being adapted to recipients of all ages with federal, state, and foundation support. These models shift responsibility for key service decisions from professionals to recipients and challenge the traditional home care agency model [39]. The delivery and financing models within which the consumer is empowered to control the details of the service plan raises many new legal concerns about the respective rights and responsibilities of the parties to those relationships. The most relevant of these issues are quality assurance, consumer's rights, and worker's interest [40]. Elderly recipients of home-based care may be challenged by high rates of dementia and rely more on family members and caregivers to assist in the control of the service plan.

E. The Cash and Counseling Demonstration

Cash payments – a disability approach – rather than payments for a defined set of services – a health insurance approach – is a valuable contribution to the long-term care policy debate [41]. The federal Cash and Counseling Demonstration and Evaluation (CCDE) was designed as an experiment to shift the paradigm in HCBS long-term care from a professional/bureaucratic model of service delivery to one emphasizing consumer choice and control. The CCDE also inspired changes in Medicaid law and policy, including sections of the Deficit Reduction Act of 2005 intended to promote consumer-direction in Medicaid [42]. The basic Cash and Counseling model appears adaptable to different state environments and

populations (73 percent of enrollees in the Arkansas demonstration were elderly). The Cash and Counseling approach is not for everyone, but it is a choice many participants desire [43].

Findings from the Arkansas Cash and Counseling Demonstration suggest that relative to agency-directed services, giving consumers control over their personal care greatly increases their satisfaction, reduces most unmet needs, and does not adversely affect participants' health and safety [44]. The consumer-directed cash option is positively associated with age, experience hiring and supervising workers, more severe levels of disability, having a live-in caregiver, and minority status [45]. Cash and Counseling can lessen some of the burden associated with caring for a child or adult with disabilities, and the experiences of hired workers suggest consumer direction is a sustainable option, but support networks for workers might be a needed program improvement [46].

Medicaid costs are generally higher under consumer-directed Cash and Counseling models because those in the traditional system do not always get the services to which they are entitled. To keep total Medicaid costs per recipient at the level incurred under the traditional system, consumer-directed programs need to be carefully designed and closely monitored [47].

In 2005, Governor Sonny Perdue endorsed the Cash and Counseling concept [48]. The state has applied for an amendment to add participant direction to its 1915(c) HCBS waiver program for elder adults and adults with physical disabilities, and has already received approval for amendments to their physically Disabled and MR waivers [49].

F. Money Follows the Person

The concept of "money follows the person" is the idea that funding is tied to a specific individual and can change as the individual's needs change regardless of the setting in which services are delivered. "Money follows the person" is one of the primary goals of rebalancing efforts and a key priority for consumers and advocates, even though state budget processes generally budget separately for each long-term care service. To address the concern, states like Texas, Vermont, Wisconsin, Oregon, Washington, Minnesota, Nebraska, Iowa, and others have used variations of "global budgeting" which consolidate institutional and HCBS budgets within the same administrative subdivision, imposing a cap on the total spending and administrative flexibility within the spending limit. As waiver program participants' needs and preferences

change, global budgeting enables the money to more readily follow the person because the funding is redirected administratively [37].

In May 2007, the Centers for Medicare and Medicaid Services announced the second round of "Money Follows the Person" grant awards to 13 states and the District of Columbia. The program's national goals are to:

- Increase the use of home and community-based, rather than institutional, long-term care services,
- Eliminate barriers or mechanisms that prevent Medicaid-eligible individuals from receiving support for appropriate and necessary long-term services in the settings of their choice,
- Increase the ability of the state Medicaid program to assure continued provision of home and community based long-term care services to eligible individuals who choose to move from an institutional to a community setting, and
- Ensure that procedures are in place to provide quality assurance for individuals receiving Medicaid home and community-based long-term care services and to provide for continuous quality improvement in such services.[13]

Georgia is the recipient of $34,000,000 over five years to support its grant program in an effort to transition at least 1,347 individuals from institutions to community living.

G. Aging and Disability Resource Centers

The Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services (CMS) launched the Aging and Disability Resource Center (ADRC) initiative in 2003. The ADRC initiative is part of a nationwide effort to restructure services and supports for older adults and younger persons with disabilities, and it complements other long-term care system change activities designed to enhance access to community living. ADRCs serve as integrated points of entry into the long-term care system, commonly referred to as "one stop shops," and are designed to address many of the frustrations consumers and their families experience when trying to access needed information, services, and supports [50].

[13] http://www.hcbs.org/files/110/5497/PR_MFP.pdf; retrieved from the World Wide Web August 13, 2007.

In September 2004, Georgia was awarded a three-year ADRC grant from the AoA and CMS. The grant resulted in the development of two pilot site ADRCs, one serving the Atlanta region and the other serving the greater Augusta region. In the Atlanta area, the Atlanta Regional Commission Area Agency on Aging (AAA) partnered with the Atlanta Alliance on Developmental Disabilities to implement a decentralized Resource Connection model, while the Central Savannah River Area AAA implemented a centralized Resource Connection model.

In September 2006, Georgia was awarded additional funds by the AoA and CMS for two years to increase the knowledge and understanding of the ADRC model within and among the aging, disability, health care professional, and consumer communities. The goals are to be achieved through a series of training sessions around the state for the purpose of expanding viability.

Additionally, the General Assembly appropriated $700,000 for State Fiscal Year 2007 to expand the ADRC model to AAAs in Northeast Georgia, Coastal Georgia, and the Southern Crescent. It is hoped that the ADRC model will expand to all areas of the state to provide a "no wrong door" approach for individuals of any age or disability in need of long-term supportive care.

VI. Conclusion

The characteristics of initiatives that have been able to improve the financing and delivery of care to people in need of long-term care services are: prepaid, risk-adjusted financing; integrated Medicare and Medicaid funding streams; a flexible array of acute and long-term benefits; well organized, redesigned care delivery systems that tailor benefits to individual need; a mission-driven philosophy; and considerable creativity in engaging government payers. The experience of these initiatives illustrates both the obstacles to, and the opportunity for, meaningful, widespread care delivery reform for vulnerable, chronically ill populations [51].

Dr. Paul Hodge, Chairperson of the Global Generations Policy Institute and Director of the Harvard Generations Policy Program, may have said it best when he concluded to the White House Conference on Aging Policy Committee in 2004:

> While many experts, pundits, and the press have made predictions about how the aging of the Baby Boomers will affect the United States, in actuality, no one really knows with

any certainty what will happen. What is clear is that the policy implications and ramifications are unprecedented in history. America's aging will transform politics, retirement systems, health care systems, welfare systems, and labor markets. It will force a re-thinking of social mores and prejudices, from issues of age/gender discrimination in the job market to end-of-life care. Whether that transformation is positive or negative will depend on planning and preparation that must begin today [12].

REFERENCES

1. *The Future Supply of Long-term Care Workers in Relation to the Aging Baby Boom Generation*. 2003, Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation (ASPE), the Centers for Medicare and Medicaid Services (CMS), and Health Resource and Services Administration (HRSA) and from the Department of Labor's Office of the Assistant Secretary for Policy, Bureau of Labor Statistics (BLS) and Employment and Training Administration (ETA).
2. Hobbs, F.B. and B.L. Damon, *65+ in the United States*, U.S.D.o. Commerce, Editor. 1996, U.S. Government Printing Office.
3. Johnson, R.W., D. Toohey, and J.M. Wiener, *Meeting the Long-Term Care Needs of the Baby Boomers: How Changing Families Will Affect Paid Helpers and Institutions*. 2007, The Urban Institute, the Retirement Project: Washington, DC.
4. Knickman, J.R. and E.K. Snell, *The 2030 Problem: Caring for Aging Baby Boomers.* Health Services Research, 2002. **37**(4): p. 849-884.
5. Landers, G., et al., *Georgia's Aging Population: What to Expect and How to Cope*. 2005, Fiscal Research Center, Andrew Young School of Policy Studies, Georgia State University: Atlanta.
6. Cutler, D.M., *Declining Disability Among the Elderly*. Health Affairs, 2001. **20**(6): p. 11-27.
7. Burwell, B.S., Kate; Eiken, Steve *Medicaid Long Term Care Expenditures FY2000 to FY2005*. 2006, Thompson Healthcare: Eagan, MN
8. Weissert, W.G., C.M. Cready, and J.E. Pawelak, *The Past and Future of Home- and Community-Based Long-Term Care.* The Milbank Quarterly, 2005. **83**(4): p. Online-only.
9. Tumlinson, A. and S. Woods, *Long-term Care in America: An Introduction*. 2007, National Commission for Quality Long-term Care.
10. Komisar, H.L., J. Feder, and J.D. Kasper, *Unmet Long-term Care Needs: An Analysis of Medicare-Medicaid Dual Eligibles.* Inquiry, 2005. **42**(Summer): p. 171-182.
11. Desonia, R., *Is Community Care a Civil Right? The Unfolding Saga of the Olmstead Decision*. 2003, National Health Policy Forum: Washington, DC.
12. *The Booming Dynamics of Aging: from Awareness to Action*, in *White House Conference on Aging*. 2005: Washington, DC.
13. Frey, W.H., *Mapping the Growth of Older America: Seniors and Boomers in the Early 21st Century*. 2007, The Brookings Institution: Washington, DC.
14. Edwards, B. and S. Wallace, *State Income Tax Treatment of the Elderly.* 2004. **24**(2): p. 1-20.
15. *The MetLife Market Survey of Nursing Home & Home Care Costs.* 2004, MetLife Mature Market Institute: Westport, CT.
16. Neese, R., *The Demographics And Economics Of Chronic Disease.* Health Affairs, 2002: p. W125-6.
17. Callahan Jr, J.J., *Policy Perspectives on Workforce Issues and Care of Older People.* Generations, 2001. **25**(1): p. 12.
18. Ahlstrom, A., *The Long-Term Care Partnership Program: Issues and Options*. 2004, The Brookings Institution: Washington, DC. p. 11.

19. Anderson, G. and J.R. Knickman, *Changing The Chronic Care System To Meet People's Needs.* Health Affairs, 2001. **20**(6): p. 146-160.
20. Eiken, S.B., Brian; Selig, Becky *Medicaid HCBS Waiver Expenditures FY2000 through FY2005*. 2006, Thomson Healthcare Eagan, MN
21. Burwell, B.S., Kate; Eiken, Steve *Distribution of Medicaid Long Term Expenditures Institutional vs. Community-Based Services, FY 2005*. 2006, Thomson Healthcare: Eagan, MN
22. Collins, S.R., et al., *Will You Still Need Me? The Health and Financial Security of Older Americans*. 2005, The Commonwealth Fund.
23. Cohen, M.A., N. Kumar, and S.S. Wallack, *Who buys long-term care insurance?* 1992. p. 208-223.
24. *Who's Buying Long-term Care Insurance?*, in *Research Highlights*. 2000, Polisher Research Institute: Philidelphia. p. 1.
25. Ahlstrom, A., et al., *The Long-Term Care Partnership Program: Issues and Options*. 2004, The George Washington University and the Brookings Institution: Washington, DC.
26. Landers, G., et al., *Data Collection and Analysis in support of the State Plan on Aging and Community Care Services Program Waiver Renewals*. 2007, Georgia Health Policy Center: Atlanta.
27. *Code Blue: Workforce in Crisis*. 2001, State of Georgia Health Strategies Council: Atlanta.
28. Seavey, D., *Engaging the Public Workforce Development System: Strategies for Investing in the Direct Care Workforce*. 2006, Institute for the Future of Aging Services: Washington, DC.
29. Wagner, E.H., et al., *Improving Chronic Illness Care: Translating Evidence Into Action.* Health Affairs, 2001. **20**(6): p. 64-78.
30. *Long Term Care Insurance in 2002*, in *Research Findings*. 2004, America's Heath Insurance Plans: Washington, DC.
31. Kane, R.L. and R.A. Kane, *What Older People Want From Long-Term Care, And How They Can Get It.* Health Affairs, 2001. **20**(6): p. 114-127.
32. Coleman, B. and W. Fox-Grage, *State Long-term Care: Recent Developments and Policy Directions*. 2003, National Conference of State Legislatures.
33. Fox-Grage, W.F., Donna; Horahan, Kevin; Hansen, Allison; Straw, Tara, *The States' Response to the Olmstead Decision: How Are States Complying?* 2003, National Conference of State Legislators: Washington, DC.
34. Aguilar, J., et al., *Long-Term Care Systems Change for the Aged and Americans With Disabilities: State Profiles*. 2005, U.S. Department of Health and Human Services, Emerging Leaders Program: Washington, DC.
35. Shirk, C., *Trading Places: Real Choice Systems Change Grants and the Movement to Community-Based Long-Term Care Supports*. 2007, National Health Policy Forum: Wahington, DC. p. 19.
36. Landers, G., J. James P. Cooney, and M. Zhou, *The Effect of Peer Support On Recidivism Rates for Mental Health Hospital Admissions and Crisis Stabilization Episodes*. 2006, Georgia Health Policy Center: Atlanta.
37. Shirk, C., *Rebalancing Long-Term Care: The Role of the Medicaid HCBS Waiver Program*. 2006, National Health Policy Forum: Washington, DC.

38. Stone, R.I., *Consumer Direction in Long-Term Care.* Generations, 2000. **24**(3): p. 5.
39. Benjamin, A.E., *Consumer-Directed Services At Home: A New Model For Persons With Disabilities.* Health Affairs, 2001. **20**(6): p. 80-95.
40. Kapp, M.B., *Consumer Direction in Long-Term Care: A Taxonomy of Legal Issues.* Generations, 2000. **24**(3): p. 16.
41. Feder, J., *Long-term Care: A Public Responsibility.* Health Affairs, 2001. **20**(6): p. 112-3.
42. Doty, P., K.J. Mahoney, and L. Simon-Rusinowitz, *Designing the Cash and Counseling Demonstration and Evaluation.* Health Services Research, 2007. **42**(1p2): p. 378-396.
43. Mahoney, K.J., et al., *The Future of Cash and Counseling: The Framers' View.* Health Services Research, 2007. **42**(1p2): p. 550-566.
44. Foster, L., et al., *Improving The Quality Of Medicaid Personal Assistance Through Consumer Direction.* Health Affairs, 2003: p. hlthaff.w3.162.
45. Mahoney, K.J., et al., *Determining Personal Care Consumers' Preferences for a Consumer-Directed Cash and Counseling Option: Survey Results from Arkansas, Florida, New Jersey, and New York Elders and Adults with Physical Disabilities.* Health Services Research, 2004. **39**(3): p. 643-664.
46. Foster, L., S.B. Dale, and R. Brown, *How Caregivers and Workers Fared in Cash and Counseling.* Health Services Research, 2007. **42**(1p2): p. 510-532.
47. Dale, S.B. and R.S. Brown, *How Does Cash and Counseling Affect Costs?* Health Services Research, 2007. **42**(1p2): p. 488-509.
48. Murphy, K., *States try offering more choice in long-term care*. 2005, Pew Research Center: Washington, DC.
49. Brenda C. Spillman, K.J.B.a.B.A.O., *Beyond Cash and Counseling:An Inventory of Individual Budget-based Community Long Term Care Programs for the Elderly*. 2006, Kaiser Commission on Medicaid and the Uninsured: Washington, DC. p. 14.
50. *The Aging and Disability Resource Center (ADRC) Demonstration Grant Initiative Interim Outcomes Report*. 2006, The Lewin Group. p. 1-2.
51. Master, R.J. and C. Eng, *Integrating Acute And Long-Term Care For High-Cost Populations.* Health Affairs, 2001. **20**(6): p. 161-172.