A LONG-TERM CARE PLAN FOR NORTH CAROLINA: FINAL REPORT

Submitted by The North Carolina Institute of Medicine
Task Force on Long-Term Care to the
North Carolina Department of Health and Human Services

January 2001

NORTH CAROLINA INSTITUTE OF MEDICINE

Citizens dedicated to improving the health of North Carolinians

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EXECUTIVE SUMMARY

No set of issues related to the health of North Carolinians is more important or more complicated than those dealing with long-term care for the state's older adults, people with disabilities, and their families. The proportion of older adults in North Carolina's population is increasing at a faster rate than in most other states. The number of older adults is expected to grow from 12.8% of the state's population in 1998 to 21.4% by 2025. Sixty percent of persons beyond the age of 65 will need long-term care services either in-home or in a residential setting sometime in their lives, as will many younger people with disabilities. In view of these facts, the North Carolina General Assembly in 1999 asked the Secretary of the North Carolina Department of Health and Human Services (DHHS) to develop a long-term care system that could provide a continuum of care for older adults, people with disabilities, and their families.[1] The Department was directed to report its progress to the General Assembly no later than January 2001.[2]

No set of issues related to the health of North Carolinians is more important or more complicated than those dealing with long-term care for the state's older adults, people with disabilities, and their families.

In the fall of 1999, the Secretary of the North Carolina Department of Health and Human Services, the Honorable H. David Bruton, M.D., asked the North Carolina Institute of Medicine (NC IOM) to convene a statewide task force to assist DHHS in developing a comprehensive long-term care plan. Robert A. Ingram, Chairman of Glaxo Wellcome Inc. agreed to co-chair the Task Force on Long-Term Care along with Secretary Bruton. The full Task Force, including 49 of the state's leading citizens and professionals, was appointed in the early fall. The group included members of the North Carolina General Assembly and representatives of county commissions, local governments, long-term care providers and industry associations, consumer advocacy groups, and businesses. In addition, the Task Force included agency directors within DHHS charged with the provision or oversight of long-term care services to older adults or people with disabilities. The Task Force began meeting in November 1999 and held 11 day-long meetings through December 2000.

The Task Force examined long-term care issues for both older adults and people with physical or cognitive disabilities. However, most of the focus was on the long-term care delivery and financing systems for older adults and people of other ages with acquired physical and cognitive disabilities (i.e., those disabilities that occurred after childhood).[3]

NORTH CAROLINA'S LONG TERM CARE POLICY

Ideally, long-term care services would be provided by home and community-based programs or families on behalf of their loved ones. These services should enable individuals to live as independently as possible without casting them into poverty. Without adequate private long-term care insurance or public funding, some individuals in need of long-term care services are faced with three options: (1) find a family member to provide unpaid care; (2) pay a caregiver out-of-pocket; or (3) enter a long-term care facility where, as they more quickly use up their resources to pay for institutional care, they are more likely to qualify for public subsidies. This raises questions of the availability of services and financing needed for people to live independently without institutionalization.

The Task Force members determined that North Carolina needed a general statement of policy orientation to guide the future direction of long-term care policy development for all individuals in this state.[4] The state's long-term care policy should be *to support older adults and people with disabilities and their families in making their own choices with regard to living arrangements and long-term care services that will result in appropriate, high-quality, cost-effective care provided in the least restrictive setting.*[5] *The state's long-term care policies and program activities should strengthen the capacity of families to serve as caregivers;*[6] *however, individuals in need of additional long-term care services should have access to certain core long-term care services.*[7] *North Carolina's long-term care system should be accessible and understandable for both public and private pay consumers, and uniform for all in need of these services.*[8]

The state's long-term care policy should be to support older adults and people with disabilities and their families in making their own choices with regard to living arrangements and long-term care services that will result in appropriate, high-quality, cost-effective care provided in the least restrictive setting.

THE STRUCTURE OF THE NORTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES

The Task Force realized the challenge facing the state in meeting the long-term care needs of the citizens of the state as the population ages. This challenge is made more difficult by the fragmentation within DHHS among the agencies delivering, financing, or regulating long-term care services. For example, within the DHHS, there are at least eight different Divisions that play a role in the long-term care system: Division of Aging; Division of Facility Services; Division of Information Resource Management; Division of Medical Assistance; Division of Mental Health, Developmental Disabilities and Substance Abuse Services; Division of Public Health; Division of Services for the Blind; Division of Social Services; and Division of Vocational Rehabilitation.

The multiplicity of governmental divisions at the state level has made it difficult in the past to develop a coordinated long-term care policy for the state. The NC IOM worked with the DHHS to develop a plan to enhance communication and coordination among the various divisions. With the full support and involvement of the directors of the various key divisions of the Department, the Task Force recommends that the Secretary establish a Long-Term Care Cabinet and an Office of Long-Term Care. The Office should establish a Forum on Long-Term Care to involve consumers and other key stakeholders in the development and implementation of the state's long-term care system.

ENTRY INTO THE SYSTEM OF LONG-TERM CARE

The Task Force discovered how very complex the current patchwork of programs, services, providers, and state and federal laws can be when a person or family is confronted with the (often urgent) need for long-term care services. People needing information about long-term care services locate this information in multiple ways. They may call an agency requesting information and assistance or go to an agency requesting services. While most communities offer some form of information, referral, and assistance to older adults and their family caregivers, it is also clear that the amount and quality of this help varies enormously around the state.

Multiple agencies provide different types of long-term care services. Departments of Social Service; Councils and Departments on Aging; Area Programs on Aging; Health Departments, Area Mental Health, Developmental

Disability and Substance Abuse Programs; home health agencies; adult day care and day health centers; adult care homes; assisted living facilities; nursing homes; hospitals; group homes for people with developmental disabilities or mental illness; adult developmental vocational programs; and community respite facilities are some of the major providers of long-term care services. Some of these services are available to both publicly-funded and private-pay individuals; other services are limited to individuals with specific sources of payment. Persons seeking services may know of some of these agencies, but not others. Few individuals understand all the services available in a given community, or which agencies can help with payment for these services.

Agencies currently use a multiplicity of telephone screening, level of services eligibility, and care planning instruments. The use of multiple, and often incompatible, screening and assessment instruments by different agencies causes problems:

- There is little or no sharing of client assessment information across multiple agencies working with an individual and his or her family. Thus, individuals and families are often subjected to multiple assessments, and coordination of services between agencies may be lacking.
- Coordinated and continuous care planning and care management is limited. Care managers cannot monitor changes in functional or health status as individuals move throughout the long-term care system.
- It is difficult for public programs to plan for long-term care services because the state lacks data about the use of long-term care services and the functional or health status of people using different types of services.

The current fragmentation and duplication within the long-term care system causes confusion for consumers. The Task Force recommends that the state establish a uniform portal of entry system for long-term care services to make the system more accessible to the public.

Given the fragmentation and duplication within the current system and resulting confusion it causes for consumers, the Task Force concluded early in its deliberations that one of its goals would be to propose a system that would allow consumers to find their way into and through the system with ease, regardless of the consumer's source of payment for long-term care services. In addressing these issues, the Task Force recommends that the state establish a uniform portal of entry system for long-term care services. Individuals would be able to enter the system through multiple agencies—but would be asked for and provided similar information regardless of which agency they initially contacted. In addition, the Department should establish uniform screening, level of service, and care planning assessment instruments. With the client's consent, information obtained by one agency could be shared with another to reduce unnecessary assessments. Whatever system is developed will have to include confidentiality provisions that comply with the federal Health Insurance Portability and Accountability Act.

AVAILABILITY AND NEED FOR LONG-TERM CARE SERVICES

The North Carolina General Assembly directed the DHHS to develop a system that provides a continuum of long-term care services for older adults and people with disabilities.[9] To address this requirement, the North Carolina Institute of Medicine Task Force on Long-Term Care examined what core long-term care services should be available to everyone in the state, the availability of existing services, the need for additional long-term care services, and local planning efforts needed to encourage the development of needed services.

Certain "core long-term care services" should be available and accessible to consumers across the state.

Core long-term care services: Ideally, every individual should have a choice of long-term care services that would best meet their needs and would result in high-quality, cost-effective care provided in the least restrictive setting. However, the Task Force recognized that it was not realistic to expect all of these services to be readily available throughout the state. Instead, the Task Force identified the "core services" that should be available and accessible to consumers both geographically and economically, including: long-term care information and assistance services; transportation; housing and home repair and modification; home delivered meals; durable medical equipment and supplies; medical alert or related services; nursing services; respite care/adult day care/day health or attendant care; in-home aide services; home health care; adult care homes (various types); nursing homes; and care management for high-risk or complex conditions.

According to a study commissioned for the NC IOM Task Force on Long-Term Care by Millennium Healthcare Solutions, 57% of older adults who have problems with one to two activities of daily living (ADLs) and 49% of those who have problems with three or more ADLs rely on informal (unpaid) support as their sole source of care. Another 23% and 46%, respectively, rely on both formal (paid) and informal support. The state has a critical interest in supporting family and informal caregivers so that they can continue to provide care to older adults and people with disabilities who need long-term care services.

Availability of long-term care services: The Task Force tried to determine the availability of existing long-term care services. Limited data are available for this purpose. Building on an earlier study,[10] the Task Force obtained utilization data for Medicaid personal care services (PCS), the Community Alternatives Program for Disabled Adults (CAP/DA), and Home and Community Care Block Grant (HCCBG) and Social Services Block Grant (SSBG) in-home aides, adult day care/adult day health, and home delivered meals.[11]

The availability of long-term care services varies greatly by county. For example, the rate of licensed nursing home beds per 1,000 older adults ranged from 25.4 in Brunswick county to 89.1 in Hyde county (state average: 42.2/1,000). There was even greater variation in utilization of CAP/DA services. Utilization varied from 8.39 individuals per 1,000 Medicaid aged and disabled in Johnston county to 200 per 1,000 in Avery county (state average: 36.0/1,000). The Task Force was unable to identify any consistent pattern of service availability across multiple categories of long-term care services.

Some of the counties that were low in the provision of in-home services among certain funding streams were the same counties that were higher in the provision of in-home services among other publicly-funded programs. Some providers are willing to participate in certain publicly-funded programs, but do not participate in others. There are different reasons why private agencies do not participate in Medicaid, such as low reimbursement rates or a lack of capacity to accept additional clients. However, the failure of these agencies to participate in all publicly-funded programs causes problems. First, individuals who are receiving services from one provider may be forced to switch to another provider if they change their source of public subsidy, which causes a disruption in the client's continuity of care. In addition, this system is an inefficient way to use limited long-term care dollars. Ideally, Medicaid-eligible individuals would be covered by Medicaid funds; rather than through limited Home and Community Care Block Grant or Social Services Block Grant funds.

Need for long-term care services: While the Task Force was able to get some information about the existing array of services, it had limited capacity to determine the *need* for long-term care services; it was difficult to determine whether the existing array of services was adequate to meet the long-term care needs of older adults or people with disabilities today or in the future. The North Carolina Institute of Medicine contracted with a private consulting firm, Millennium Healthcare Solutions, to obtain projections of the need for in-home, community and residential long-term care services for the years 2000, 2005, and 2010. These projections suggest that there are currently 10,800 older adults 65 years of age or older who have unmet needs relating to activities of daily living.[12]

However, the Task Force recognized the limitations inherent in any estimates based, at least in part, on older national studies, which may or may not mirror the experience of North Carolinians. Therefore, the Task Force recommends that the state make arrangements to collect North Carolina-specific data to determine the need and demand for long-term care services in the state.

Long-term care planning efforts: A comprehensive planning process is needed statewide at both the state and local levels to encourage capacity building for long-term care services and the development of a consumer-friendly system of care and services. The state should provide technical assistance to county or regional planning bodies to: assist in the development of a consumer-centered system of care and services, encourage the "balanced" development of core services in counties or regions, and develop the readiness to work with standardized instruments and data sharing across agencies.

LONG-TERM CARE WORKFORCE

North Carolina is in the midst of a long-term care workforce crisis. Efforts to design a long-term care system that ensures availability of services and high-quality care are somewhat meaningless, absent a supply of trained professional and paraprofessional staff—including nurse aides, nurses, doctors, and allied health professionals. The Task Force Report addresses workforce supply (shortage) issues pertinent to each of the major categories of long-term care professionals and paraprofessionals in our state.

North Carolina is in the midst of a long-term care workforce crisis. Efforts to design a long-term care system that ensures availability of services and high-quality care are somewhat meaningless, absent a supply of trained professional and paraprofessional staff—including nurse aides, nurses, doctors, and allied health professionals.

Nurse aides and other paraprofessionals provide most of the direct long-term care services to individuals, whether at home or in a residential facility. These workers help individuals with their most basic needs—including bathing, dressing, eating, and toileting. In addition, paraprofessionals often help with housekeeping tasks, and may help administer medications, change bandages, or monitor changes in a person's health status.

North Carolina, like the rest of the nation, is experiencing a severe shortage of paraprofessionals trained and willing to work in the long-term care industry. The annual turnover rate among aides who work in nursing homes exceeded 100% in 1999. The annual turnover rate was even higher among aides who work in adult care homes (140%). North Carolina will need more than 21,000 additional nurse aides and other paraprofessionals to meet the long-term care needs of older adults and people with disabilities over the next five years.

There are a number of reasons for the problems in recruiting and retaining paraprofessionals, viz., low wages, few benefits, no career path, physically demanding work, lack of opportunity for meaningful input into client care, inadequate recognition and appreciation, and inadequate exposure to "real life" job demands during training.[13] The state's low unemployment rate further exacerbates the current paraprofessional shortage in long-term care.

Clearly more needs to be done to address the shortage of trained paraprofessional and professional staff to provide long-term care services. The Task Force recommends that the state implement policies that would improve the training, salaries, and benefits offered to these staff. In addition, the industry has a role to improve the work environment and increase job satisfaction among long-term care paraprofessional employees statewide.

ASSURING THE QUALITY OF LONG-TERM CARE

Long-term care has a number of characteristics that differentiate it from other levels and types of health care services. First, the *goals* of care may be very different than in other types of health care services. Second, the goals of long-term care may lack *clarity* or *societal consensus* because of the conjunction of therapeutic/clinical and social purposes of these services and programs. Many of the goals of long-term care may conflict with one another (as in the case of prolonging life versus controlling pain; freedom of movement versus safety). Some of the trajectories of physical or mental health among long-term care consumers may be inevitable and irreversible, therefore making conventional health outcomes largely irrelevant to the evaluation of long-term care quality. The measure of success may not necessarily include the goal of "improvement;" instead, "delaying decline" may be a significant achievement.[14]

One of the most challenging aspects of quality assurance, especially in long-term care, is the necessity of making "trade-offs" among different aspects of daily living arrangements, some having positive and some negative influence on the overall quality of life.

The Task Force confronted the difficulty of addressing issues of quality in long-term care in a way that would be inclusive of structure, process, and outcome dimensions. The Task Force concluded that quality of care, to the client of these services, "…combines a *personal* and *internal* response to the events and conditions they experience with a basic expectation that the *technical quality* meets some standard."[15] It is for this reason that measures of consumer satisfaction should be included as one of the ways of measuring the quality of long-term care; although consumer satisfaction is "an insufficient test of quality," since there are some technical aspects of care consumers may be incapable to judge.[16]

One of the most challenging aspects of quality assurance, especially in long-term care, is the necessity of making "trade-offs" among different aspects of daily living arrangements, some having positive and some negative influence on the overall quality of life. For example, there is often a real dilemma in long-term care as decisions are made about the relative allowable freedom of movement for frail elders who are at risk of falls. The fact that such trade-offs are an unavoidable aspect of quality of care decision-making in long-term care is well recognized, but there are often insufficient arrangements for the inclusion of clients/residents/families in making such decisions. When shared decision making occurs, there can be a mutual understanding of the difficulty of achieving goals that may seem diametrically opposed, but also an appreciation of the unfairness of judging quality from one side or the other of such decision dilemmas.

The Task Force on Long-Term Care takes the view that both sanctions and rewards are required to motivate efforts within this industry that will assure good quality of care. In recognition of the complexity of quality assessment issues in long-term care, the Task Force took note of suggestions that there is a need to reconsider how quality is defined, what standards are possible, how these standards are incorporated in assessment instruments and measures used by regulatory agencies (county, state, and federal), and how results of these assessments are shared with the general public. The Task Force recognized that past efforts at ensuring quality have been largely punitive, focusing on imposing penalties and correcting deficiencies among the few "bad" facilities; rather than trying to raise the level of quality among all facilities. More emphasis should be placed on providing incentives to all facilities to improve quality, and to remove regulatory and other barriers that impair these efforts. This effort should be a joint project between regulatory agencies, the long-term care industry, consumers, and other interested parties. In addition, as the growth of home and community-based services and consumer directed care is encouraged, adequate attention to defining and measuring quality for these services must be addressed.

FINANCING LONG-TERM CARE SERVICES

The North Carolina General Assembly directed the DHHS to explore different ways to finance long-term care services. The Final Report of the Task Force on Long-Term Care divides the discussion of financing into three sections: (1) current public expenditures for long-term care services; (2) methods to expand public financing of long-term care services; and (3) methods to expand private financing of long-term care services and expenditures.

Public financing: Since 1991, the Division of Aging has produced a state/county expenditure profile of services provided to persons 60 and older. North Carolina spent $1.3 billion in SFY 99 on publicly-funded long-term care services for older adults. This is an increase of 8% over SFY 98, and a 173% increase since 1990. Over this same period of time, the population of older adults in North Carolina increased by 19.4%.

Medicaid finances almost four-fifths of the long-term care expenditures for older adults in North Carolina. More than two-thirds of the long-term care expenditures for older adults are spent on institutional care (70.4%), which includes nursing homes, intermediate care facilities for the mentally retarded (ICF-MRs), mental health/substance abuse inpatient care, and mental retardation centers. Over the last nine years, there has been some shift in financing away from institutional care, such as from nursing homes, ICF-MRs, mental health/substance abuse inpatient care, and mental retardation centers, to adult care homes and home and community care services.

Similar trend data about publicly-financed long-term care services for younger adults with disabilities (18-59) are not routinely collected or reported. One of the Task Force's recommendations is to ensure that these data are collected at the state and county level and shared with the counties for local planning purposes.

Methods to expand public financing of long-term care services: The Task Force explored different options to expand public funding of long-term care services. Medicaid appeared to be one of the most viable options since the federal government will pay approximately 62.5% of long-term care costs for

The Task Force recommends expanding Medicaid coverage, since the federal government pays almost two-thirds of the long-term care costs for all Medicaid-eligible individuals. In contrast, the other major public programs are block grants—that is, they have fixed federal funding. Funding for these programs can be exhausted, leaving eligible individuals without access to needed services.

Medicaid-eligible individuals. Medicaid is an entitlement program, which means that the federal government will pay its 62.5% share to meet the long-term care needs of *all* eligible individuals. In contrast, the other major public programs are block grants—that is, they have fixed federal funding. Funding for these programs can be exhausted, leaving eligible individuals without assistance with services.

The Task Force recognized that there are current inequities in Medicaid income eligibility rules. Individuals can qualify for institutional nursing home care or residential care with higher income limits than can individuals living at home. Further, not all individuals living at home are treated equitably. As a general policy, the Task Force wanted to strive toward more equitable treatment of all Medicaid-eligible individuals, whether living at home or in a residential facility. As the state expands Medicaid eligibility, it should first move to eliminate inequities in the treatment of individuals living at home and then move to eliminate any potential institutional bias.

The Task Force's top financing priority is to recommend expansion of the Medicaid "Medically-Needy Income Limits" up to 100% of the federal poverty guidelines to help expand eligibility to older adults or people with disabilities with high medical or long-term care expenses. In addition, the state should expand the number of people served through the Community Alternatives Programs (CAP). CAP provides services and supports to enable people who would otherwise need institutionalization to remain in their homes.

In addition to the expansion of Medicaid and the exploration of ways to leverage federal monies, the Task Force identified a need to expand state funding of home and community-based services for those individuals who are not Medicaid-eligible. If the state expanded the medically needy income limits it would free resources to use for the non-Medicaid eligibles. However, additional resources are still needed.

The Task Force supported efforts to expand the purchase of private long-term care insurance, especially among younger "baby-boomers."

Private financing of long-term care services: At the General Assembly's request, the Task Force explored the use of reverse mortgages, private long-term care insurance, medical savings accounts, changes in Medicaid eligibility and asset protection, and cost-sharing as a way to increase consumers' financial responsibility for long-term care. As a general rule, the Task Force did not view reverse mortgages or medical savings accounts as a viable means of financing long-term care. The Task Force also recommends against further restrictions in Medicaid eligibility rules. The current Medicaid eligibility rules are already a barrier for some older adults who are afraid to apply for Medicaid, CAP, or other long-term care services. Further, people who have a lot of assets can afford to buy legal advice about how to shelter their assets. The only people who are likely to be "caught" by new restrictions would be those with fewer resources.

In contrast, the Task Force does support efforts to expand the purchase of private long-term care insurance. Most long-term care policies provide coverage for home health, adult day care, and assisted living facilities in addition to nursing home care. Some policies also provide coverage of alternative benefits. For example, if the insurer can maintain the person in-home cheaper than in an institution, then they will pay to keep the person in the home if the provider, insurer, and insured agree. The purchase of private long-term care insurance offers two benefits: (1) it helps pay for needed services, thereby allowing the individual to preserve his or her assets; and (2) it provides people with a greater

choice of providers than people who rely on Medicaid or other public sources to pay for services.

The Task Force recognized that private long-term care insurance is not a significant financing source for long-term care services in the immediate future, nor is private long-term care insurance a panacea for everyone. If a person already has health problems that are likely to mean they will need long-term care, they may not qualify to buy a policy. Also, long-term care policies are expensive, especially for people who are already older adults. For these reasons, the Task Force recommends targeting public education campaigns to the "baby-boomers" who may be able to afford these policies at their present ages.

The Task Force also explored the idea of requiring individuals to share in the cost of long-term care services. The newly authorized Older American's Act gives the states more flexibility to impose some cost-sharing, and the Task Force recommends that the Department use this flexibility to establish a sliding scale fee based on an individual's ability to pay.

Finally, the Task Force explored ways to provide some financial support that recognizes the contributions of family caregiving. Some options include additional income tax relief for long-term care responsibilities and expenses, reform of Social Security to credit family caregiving, incentives for businesses to offer elder care, subsidized elderly care for low-income persons going from welfare to work, and direct cash payments or vouchers for use by family caregivers instead of receiving formal services. Some of these supports are state options, while others require policy changes at the federal level. The Task Force supported the need for further study of these options to determine what the state could do to support caregivers.

The state should provide local counties with transition support as well as capacity building funds to help them make the changes necessary to bring their programs in line with new state requirements.

LOCAL INITIATIVES AND DEMONSTRATIONS

Local communities and regional coalitions have been leaders in the effort to reform the long-term care delivery system. The Task Force learned about the efforts of many local communities to improve the long-term care system. In fact, many of the Task Force recommendations derive from the experiences of local communities. In many instances, local communities acted in advance of state policy changes so as to improve services and meet consumer demand. By acting as incubators of new long-term care systems change, these counties assumed a risk that their initiative would not be in-line with state long-term care policy. Yet, the Task Force wants to support these local leaders—in that their experiences at the local level have helped to inform and improve statewide policy efforts. Therefore, the Task Force recommends that the state provide transition support as well as capacity building funds to local communities to help them make the changes necessary to bring their programs in line with new state requirements. In addition, the Task Force recommends that the state invest in further pilots and demonstrations before statewide implementation of some of the Task Force recommendations.

NEXT STEPS TOWARD THE IMPROVEMENT OF LONG-TERM CARE FOR NORTH CAROLINIANS: TOP PRIORITIES

Long-term care involves an important and complicated set of issues critical to the overall health of North Carolina's population. The NC IOM Task Force on

Long-Term Care has sought to understand, and then communicate through the chapters of this report, its analysis of the current and likely future issues facing our state with regard to this vital aspect of health and human services needed by our older adults and people with disabilities.

The Task Force has conducted lengthy discussions and analyses regarding entry into the long-term care system, the availability of and need for long-term care (now and over the coming decade), pressing workforce issues facing the long-term care industry of our state, efforts to assure quality in long-term care, financing options, and the need for local demonstration and pilot efforts that address critical issues for which there is inadequate current information to guide statewide long-term care policy.

The Task Force recommends the creation of a Cabinet for Long-Term Care and a new Office of Long-Term Care within the Department of Health and Human Services. The goal is to develop comprehensive, coordinated long-term care policies across the various agencies charged with delivering, financing or regulating long-term care.

The Task Force made a total of 47 recommendations to improve North Carolina's long-term care delivery, financing, and regulatory systems. Some of these recommendations require immediate action; others can wait and/or are contingent on the prior implementation of other recommendations. To help guide the work of the state's policy makers, the Task Force identified the most pressing recommendations—those that require more immediate action. These recommendations fall into four areas: (1) infrastructure; (2) quality; (3) workforce; and (4) access/financing.

Infrastructure: Early in its deliberations, the Task Force recognized the fragmentation that exists at the state level among the different agencies charged with delivering, financing, or regulating long-term care. Thus, one of the Task Force's top recommendations is for a more cohesive process to establish state-level long-term care policies and programs. The Task Force recommends the creation of a Cabinet for Long-Term Care within the Department of Health and Human Services comprised of all the Division Directors charged with financing, regulating, or providing long-term care services. In addition, the Secretary of the Department of Health and Human Services should create a new Office of Long-Term Care to staff the Cabinet, collect and analyze long-term care data and develop comprehensive, coordinated long-term care policies.[17] The creation of the new Office of Long-Term Care within the DHHS and the new Cabinet for Long-Term Care will help reduce the likelihood of overlapping and sometimes conflicting agendas among Divisions of DHHS.

As a corollary to the Department's reorganization, comprehensive long-term care planning should be encouraged at the local level. The North Carolina General Assembly should encourage county commissioners to designate a lead agency to organize a local long-term care planning process at the county or regional level. The Department of Health and Human Services should support these efforts by providing technical assistance and county-level data to assist the communities.[18] In addition, the General Assembly should provide one-time "transition support" to enable counties to implement the recommendations of the Task Force, and additional "capacity building" funds to help small rural counties develop the infrastructure and capacity necessary to implement statewide system changes.[19]

The Task Force also recommends the creation of a uniform portal of entry system.

The Task Force also recommends the creation of a "uniform" portal of entry that would improve the process through which citizens could obtain needed long-term care services. The uniform portal of entry would ensure that multiple agencies serving clients use the same screening and assessment tools, and have information about all the available long-term care resources in their

communities. To make this system work, the Task Force recommends that the state begin using uniform screening, level of service assessment, and care planning instruments; and that the state identify or help develop a computerized information and assistance system that can be used statewide.[20]

Quality: There is a need for a continuing dialogue about the standards of quality for long-term care services in our state. A start in this direction has been taken through the work of the Task Force, but this is an ongoing agenda the Task Force feels best passed on to the new Office of Long-Term Care, with active participation by the long-term care industry, consumer advocacy groups, regulators, and other interested stakeholders.[21] Much is already going on in this area, but the Task Force maintains that an emphasis on "quality improvement" would greatly enhance current efforts. As a beginning, the Office of Long-Term Care should explore methods to improve and reward quality and not limit actions solely to imposing penalties for deficiencies.[22] Similarly, the Department should develop a Quality Improvement Consultation program to assist providers in the development of quality improvement plans for each facility and program offering long-term care services.[23] A partnership arrangement with Medical Review of North Carolina and the state's public and private universities in this regard is also recommended.[24]

The Office of Long-Term Care should work with different stakeholders to improve and reward quality of long-term care services.

Workforce: One of the major challenges facing the state is ensuring an adequate supply of trained professional and paraprofessional staff. With regard to workforce issues in long-term care, the major "crisis" is the current shortage of paraprofessional personnel in these facilities and programs. However, there are also issues related to the preparation of adequate numbers of physicians, dentists, nurses, and other health professionals with the skills and the commitment to work in long-term care. The Task Force recommends that the General Assembly increase appropriations for Medicaid funded in-home and adult care home Personal Care Services (PCS), and nursing home care by increasing the personal care service hourly rate and nursing home daily rate for direct care. This enhancement would be used for wages, benefits, and/or payment of shift differentials (e.g., nights/weekends). Providers would be required to submit additional cost data to ensure that these funds are used for their intended purpose.[25]

The state must act immediately to address the current workforce shortage in long-term care. One of the Task Force's top recommendations is to implement a wage enhancement to increase wages, benefits and/or pay shift differentials for paraprofessional staff in long-term care settings.

In addition to wage enhancements, the Task Force recommends that the General Assembly appropriate funds to develop a continuing education and paraprofessional development initiative,[26] as well as a career ladder for long-term care paraprofessionals.[27] To support these efforts, additional data collection and analysis is needed, for example—to examine the turnover and retention rates, wages and benefits of nurse aides.[28] The state should explore ways to establish a group health insurance purchasing arrangement for long-term care staff.[29] The General Assembly should also establish a Legislative Study Commission to examine long-term care workforce shortages among paraprofessionals and other professionals serving older adults and people with disabilities.[30]

Current efforts made by the long-term care industry to address the long-term care paraprofessional recruitment and retention issues should be applauded and further encouraged. The Task Force recognized that both the state and private industry have a role in addressing the current workforce shortages. Long-term care provider associations should develop plans to improve the recruitment and retention rates among paraprofessionals and professionals in the long-term care

industry. The plans may include mechanisms to improve job satisfaction, increase pay, develop career paths or improve working conditions.[31]

Expanding Access/Financing Long-Term Care Services: One of the first steps the state should take in expanding publicly-financed long-term care services is to remove the current institutional bias in these programs. It is currently easier for older adults or people with disabilities to qualify for publicly-financed long-term care services in a nursing home or adult care home than it is to receive services at home. Two promising means of reducing the current institutional bias would be to increase the Medicaid medically needy income limits up to 100% of the federal poverty guidelines;[32] and to expand the number of people served by the CAP/DA and CAP-MR/DD Medicaid programs. Both of these approaches would enable people to receive long-term care services while living at home or a community setting.[33] In addition, the state should explore ways to support family caregivers, thereby reducing the risk for needing formal, publicly-financed services.[34]

One of the first steps the state should take in expanding publicly-financed long-term care services is to remove the current institutional bias in these programs.

The Task Force recognized the state's strong interest in maximizing the use of federal Medicaid dollars to financing long-term care services, as the federal government pays approximately 62% of all Medicaid service costs. As such, the Task Force recommends that the state explore ways to use existing resources as the state's match in further Medicaid expansions.[35] Another idea, successfully used in other states, is to ensure that Medicare pays for covered long-term care services for Medicare-eligible individuals.[36]

In addition, the state should launch an outreach effort targeted at "baby-boomers," to explain the different long-term care financing and payment options. The outreach effort should include information on what Medicare covers, what Medicaid covers, what individuals must pay on their own, and what private long-term care insurance can cover.

Despite several important limitations of this report (e.g., the limitations of available data on long-term care use, need and demand; the limited information about and attention given to the long-term care needs of persons with mental illness or developmental disabilities; and the inadequate attention given to the housing needs of older adults and people with disabilities), the Task Force hopes that its analyses of these complex issues will provide a framework for forward movement in addressing these issues in the interest of improving the health and well-being of all of North Carolina's citizens, particularly those in need of long-term care.

Due to the importance of the issues described in this report, it is the intention of the Board of Directors of the NC IOM to re-convene the Task Force one year from the date this report is published for the purpose of formulating an assessment of progress in relation to the report's major recommendations. At that time, certain recommendations may need reformulation on the basis of new and emerging data. Others may require extensions or deletions. A "report card" assessment of progress will help to guide further efforts in this area and help the Institute, the General Assembly, and the DHHS evaluate the efforts of the Task Force as a basis for further initiatives.

RECOMMENDATIONS

The following is a summary of the recommendations made by the NC IOM Task Force on Long-Term Care. The priority recommendations are highlighted in boldface type. The full text of the recommendations is contained in the full report (page number cited in the chart below). The chart also indicates whether an appropriation is needed to support the recommendation, and if so, the estimated amount of the appropriation required.

Recommendation	*Report Page*	*Appropriations Required ($)*
Long-Term Care Policy Statement		
#1. North Carolina's policy for long-term care is to support older adults and people with disabilities needing long-term care and their families, in making their own choices with regard to living arrangements and long-term care services that will result in appropriate, high-quality, cost-effective care provided in the least restrictive setting (priority).	**26**	
DHHS Organization for Long-Term Care		
#2. The Secretary of the DHHS should establish a Long-Term Care Cabinet and an Office of Long-Term Care should be created within the Office of the Secretary. The Office of Long-Term Care shall have responsibility for organizing and maintaining a new Forum on Long-Term Care (priority).	**28**	
Entry into the Long-Term Care System		
#3. North Carolina's long-term care system should be accessible and understandable for both public and private pay consumers, and uniform for all in need of long-term care services (priority).	**34**	
#4. The North Carolina DHHS should develop a "uniform portal of entry" system for long-term care services in which confidentiality of information is ensured (priority).	**40**	
#5. The North Carolina DHHS should begin using uniform screening, level of service assessment, and care planning instruments based on the RAI family of instruments (priority).	**40**	
#6. As part of the uniform entry system, the Department should continue the development of a telephone-screening tool that is based on the RAI family of instruments and that can also be used for information and assistance purposes (priority).	**41**	

Recommendation	Report Page	Appropriations Required ($)
#7. To further support the uniform entry system, the Department should develop or identify existing computerized information and assistance systems that can be used statewide. The goal is to have a comprehensive, professionally administered, and computerized information and assistance systems that work together with long-term care telephone-screening tools in local communities (priority).	**42**	SFY 02: $125,000 SFY 03: $125,000
#8. The Department should develop a level of services assessment instrument that is based on the RAI family of instruments that is tailored to North Carolina. The level of services assessment instrument should help consumers and providers determine the level and type of service needed or desired, and eventually be used to substitute for the existing level of services eligibility tools used by the state.	**43-44**	
#9. The Department should develop an assessment process using these new instruments that will help individuals make an informed choice and will assist in determining eligibility for state publicly-funded programs. The Department should develop procedures to ensure the assessments are done in a timely manner so as not to delay the receipt of necessary long-term care services.	**44**	
#10. The North Carolina General Assembly should appropriate funds to provide care management services to non-Medicaid eligible individuals age 18 or older who are at-risk of institutionalization.	**46**	SFY02: $3,888,000 SFY03: $7,128,000
Availability and Need for Long-Term Care Services		
#11. Every North Carolinian should have access, either in the county or within reasonable distance from the county, to certain core long-term care services (priority).	**48**	
#12. The Department's long-term care policies and program activities should be designed to strengthen the capacity of families to perform caregiving functions (priority).	**49**	
#13. The DHHS should explore the possibility of establishing uniform payment rates for in-home aide services across funding streams. The Department should explore the need, if any, for regional variations in reimbursement rates or shift differentials for these workers.	**52**	
#14. If the state establishes more uniform rates, the DHHS should consider requiring all licensed providers of long-term care services that participate in state-funded programs to provide some services to Medicaid clients.	**52**	

Recommendation	*Report Page*	*Appropriations Required ($)*
#15. The Department should collect North Carolina-specific data to determine the need and demand for long-term care services in the state.	**57**	
#16. The NC General Assembly should encourage county commissioners to designate a lead agency to organize a local long-term care planning process at the county or regional level. The Department should develop county data packages and provide technical assistance to the counties to assist them with their long-term planning process (priority).	**58**	
Workforce		
#17. The North Carolina General Assembly should increase appropriations for Medicaid funded in-home and adult-care home Personal Care Services (PCS) and to nursing home care by increasing the personal care service hourly rate and nursing home daily rate for direct care. This enhancement must be used for wages, benefits, and/or payment of shift differentials (e.g., nights/weekends). Providers would be required to submit additional cost data to ensure accountability for use of these funds as intended (priority).	**64**	SFY02: $17,227,597 SFY03: $23,460,713
#18. The North Carolina General Assembly should appropriate funds to develop a continuing education and professional development initiative for long-term care aides (priority).	**64**	SFY02: $1,406,029 SFY03: $2,097,301
#19. The North Carolina General Assembly should appropriate funds to develop a career ladder and associated curricula requirements and job category qualifications for long-term care aide workers (priority).	**64**	SFY02: $100,000 SFY03: $100,000
#20. The North Carolina General Assembly should appropriate funds to support on-going collection and analysis of data related to North Carolina's aide workforce. The analysis should include information on demographics, turnover and retention rates, wages/benefits, comparison of active versus inactive nurse aide registrants with regard to job stability and wages (priority).	**65**	SFY02: $50,000 SFY03: $50,000
#21. The North Carolina General Assembly should establish a Legislative Study Commission to examine workforce shortages among paraprofessionals and other professionals serving the older adults and people with disabilities (priority).	**65**	

Recommendation	*Report Page*	*Appropriations Required ($)*
#22. The DHHS, along with the Department of Insurance, should explore ways to establish a group health insurance purchasing arrangement for staff, including paraprofessionals, in residential and non-residential long-term care facilities and programs (priority).	**65**	
#23. Long-term care provider associations should develop a plan to improve the retention rates among paraprofessional and professionals in the long-term care industry. The plan may include mechanisms to improve job satisfaction, increase pay, develop career paths, or improve working conditions, and should be reported to the NC General Assembly no later than March 15, 2001 (priority).	**65**	
Assuring Quality of Long-Term Care		
#24. Further quality of care initiatives should become a major responsibility of the Department. The Department should convene a Quality Standards Work Group with representatives from providers, consumers, long-term care Ombudsmen, state regulatory agencies, local Departments of Social Services and academics (priority).	**73**	
#25. Initial efforts to address quality issues in long-term care in North Carolina should include initiatives that can build upon the model quality improvement program developed by Medical Review of North Carolina, to include provider/consumer input to problem selection, data analysis, measurements appropriate to particular dimensions of quality (indicators), intervention design, implementation and evaluation. These efforts should utilize the expertise housed in the state's public and private universities and community colleges (priority).	**74**	
#26. The Department should explore methods to improve and reward quality and not limit their actions solely to imposing penalties for deficiencies (priority).	**74**	
#27. The Department should develop a Quality Improvement Consultation Program to assist providers in the development of quality improvement plans for each facility and program offering long-term care services to the public in North Carolina (priority).	**75**	
Financing Long-Term Care		
#28. The North Carolina General Assembly should appropriate funds to increase the Medicaid medically needy income limits up to 100% of the federal poverty guidelines (priority).	**84**	SFY02: $43,151,156 SFY03: $48,674,894

Recommendation	*Report Page*	*Appropriations Required ($)*
#29. The North Carolina General Assembly should expand the number of CAP/DA and CAP-MR/DD allocations to help individuals who would otherwise need institutionalization to remain in their homes or in the community (priority).	**84-85**	*CAP/DA:* SFY02: $ 5,690,691 SFY03: $14,929,109 *CAP-MR/DD:* SFY02: $ 2,976,584 SFY03: $14,402,714
#30. North Carolina should increase the Community Alternative Program (CAP) income eligibility limits to 300% SSI (currently $1,536/month for an individual), and allow the individual to deduct an amount equal to 100% of the federal poverty guidelines to support a spouse living in the community.	**86**	Estimates being developed
#31. If permitted under federal law, North Carolina should increase the Medicaid income guidelines for older adults and people with disabilities up to the State-County Special Assistance income limits.	**86**	Estimates being developed
#32. North Carolina has a strong public interest in maximizing the use of federal dollars to fund long-term care services. The state should ensure that Medicare pays for covered services for Medicare-eligible individuals by appealing the denials of Medicare coverage of long-term care services (priority).	**87**	
#33. The DHHS should explore methods to use existing resources as the state's match in further Medicaid expansion to cover more older adults and people with disabilities, additional long-term care services, or to pay for long-term care administrative costs (priority).	**87**	
#34. The North Carolina General Assembly should appropriate funds to the Division of Aging to expand the availability of home and community services for non-Medicaid eligible older adults.	**87**	SFY02: $10,399,955 SFY03; $10,399,955
#35. The North Carolina General Assembly should appropriate funds to the Division of Social Services to expand the availability of home and community services for non-Medicaid eligible adults with disabilities between 18-59.	**88**	SFY02: $2,500,000 SFY03: $5,000,000
#36. The North Carolina General Assembly should appropriate funds to expand the state Adult Day Services Fund to increase the availability of respite services for family caregivers.	**88**	SFY02: $3,427,622 SFY03: $3,427,622
#37. The Task Force does not recommend that the General Assembly rely on reverse mortgages as a means of financing long-term care services.	**89**	
#38. The North Carolina General Assembly should provide funds for private long-term care insurance outreach efforts.	**91**	SFY02: $268,000 SFY03: $268,000

Recommendation	*Report Page*	*Appropriations Required ($)*
#39. The Task Force does not recommend that the General Assembly rely on Medical Savings Accounts as a means of financing long-term care services.	**92**	
#40. The General Assembly should pass a resolution to encourage the NC Congressional delegation to support federal incentives to purchase private long-term care insurance, such as federal tax credits or deductions, flexible savings accounts or cafeteria plans; and to eliminate the federal barriers to expansion of Medicaid long-term care partnership plans.	**93**	
#41. The Task Force does not support further restrictions in Medicaid through tightening transfer of assets provisions or estate recovery.	**95**	
#42. The Office of Long-Term Care, within the DHHS should establish a sliding scale fee based on an individual's ability to pay.	**96**	
#43. The Department should explore ways to invest in family caregiving so that it can be sustained as the primary resource for long-term care, reducing the risk for needing formal, publicly-financed services (priority).	**96**	
Local Initiatives and Demonstrations		
#44. The General Assembly should provide special funds for one-time county "transition support" to enable counties to implement the recommendations of the Task Force on Long-Term Care and to make needed system improvements (priority).	**97**	
#45. The General Assembly should appropriate one-time "capacity-building" funds for small, rural counties to enable them to develop the infrastructure and capacity to implement statewide system changes (priority).	**98**	
#46. The Department should establish a clearinghouse to gather information on successful initiatives, demonstrations and system improvements in North Carolina and other states; distribute information and provide technical assistance to local communities.	**98**	
#47. Participation in any state-supported demonstration should be open to all counties and/or regions via a competitive RFP (Request for Proposal) process. The State should set parameters required of all participants, but local communities should be allowed to meet specified parameters in a variety of ways. All state-supported demonstrations should be evaluated by an independent outside source, and should include outcome-focused evaluation measures.	**99**	

[1] The NC General Assembly directed the Department to develop a long-term care system that provides a continuum of care for older adults and disabled individuals and their families. Sec. 11.7A of the Session Laws 1999-237. The system was to include:

- a structure and means for screening, assessment, and care management across settings of care;
- a process to determine outcome measures of care;
- an integrated data system to track expenditures, consumer characteristics, and consumer outcomes;
- relationships between the Department and the state's universities to provide policy analysis and program evaluation support for the development of long-term care system reforms;
- an implementation plan that addresses the testing of models, the review of reviewing existing models, the evaluation of components, and the steps needed to achieve the development of a coordinated system; and
- provision for consumer, provider, and agency input into the system design and implementation development.

By January 1, 2001, the Department was to have a system in place that would:

- implement the initial phase of a comprehensive data system that tracks long-term care expenditures, services, consumer profiles, and consumer preferences; and
- develop a system of statewide long-term care services coordination and case management to minimize administrative costs, improve access to services, and minimize obstacles to the delivery of long-term care services to people in need.

The Department was also directed to pursue financing strategies that would shift the balance of financial responsibility for long-term care services from public to private sources by promoting public-private partnerships and personal responsibility for long-term care. Specifically, the Department was directed to explore:

- the flexible use of reverse mortgages;
- private insurance coverage for long-term care;
- tax credits or employment programs, such as medical savings accounts and deferred compensation plans, for long-term care; and
- changes in Medicaid eligibility and asset protection requirements that increase consumers' financial responsibility for their long-term care, such as revising the rules relating to the transfer of assets and estate recovery policies.

[2] The original legislation had a reporting date of April 15, 2000, but this was later extended to January, 2001. Sec. 11b of the Session Law 2000-67.

[3] Initially, the Task Force also tried examining the long-term care needs of people with mental illness or developmental disabilities. However, after the Task Force began its deliberations, two other groups were created that included, as part of its charge, an examination of the long-term care needs of people with mental illness and developmental disabilities: the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities and Substance Abuse Reform and the N.C. Department of Health and Human Services' *Olmstead* planning efforts. The Task Force recognized that there are some people with mental illness and developmental disabilities who enter the long-term care settings discussed in this report; and that there is an ongoing dialogue about the appropriateness of these settings for the MI/DD population of younger adults (18-59). However, given the ongoing work of these other two groups, the Task Force decided to limit most of its focus on long-term care delivery and financing systems for older adults and people with acquired physical and cognitive disabilities.

[4] The Task Force used the long-term care principles enunciated by the North Carolina General Assembly in developing its long-term care policy statement. NCGS §143B-181.6. Specifically, the General Assembly established the following long-term care principles to guide the development of a long-term care system for older adults:

1) Long-term care services administered by the Department of Health and Human Services and other state and local agencies shall include a balanced array of health, social and supportive services that promote individual choice, dignity and the highest practicable level of independence;
2) Home and community-based services shall be developed, expanded or maintained in order to meet the needs of consumers in the least confusing manner and based on the desires of the elderly and their families;
3) All services shall be responsive and appropriate to individual need and shall be delivered through a seamless system that is flexible and responsive regardless of funding source;

4) Services shall be available to all elderly who need them but targeted primarily to the most frail, needy elderly;
5) State and local agencies shall maximize the use of limited resources by establishing a fee system for persons who have the ability to pay;
6) Institutional care shall be provided in such a manner and in such an environment as to promote maintenance or enhancement of quality of life of each resident and timely discharge to a less restrictive care setting when appropriate; and
7) State health planning for institutional bed supply shall take into account increased availability of other home and community-based options.

[5] See Recommendation #1 on page 26 of the full Report.
[6] See Recommendation #12 on page 49 of the full Report.
[7] See Recommendation #11 on page 48 of the full Report.
[8] See Recommendation #3 on page 34 of the full Report.
[9] Sec. 11.7A(a) of the Session Laws 1999-237.
[10] Goins R. Turner and Leak SC. Distribution of Home and Community-Based Long Term Care Services for the Elderly in North Carolina. Occasional LTC Policy Paper Series. Duke Long Term Care Resources 1999 Nov;Program Paper No. 11.
[11] While these utilization data are a useful starting point - they have serious limitations. First, the state collects little information on the use or need for long-term care services in the private market. Second, while the state maintains information about the *use* of some publicly funded long-term care programs, they do not collect similar information on the extent to which these services are needed but not available (i.e. “unmet needs”).
[12] 5,600 have unmet needs related to one or two ADLs; and 5,200 have unmet needs with three or more ADLs
[13] NC Division of Facility Services. Comparing State Efforts to Address the Recruitment and Retention of Nurse Aide and Other Paraprofessional Aide Workers. September 1999.
[14] Kane RA, Kane RL, Ladd RC. 1998:190-195. The Heart of Long-Term Care. Oxford:New York.
[15] Kane RA, Kane RL, Ladd RC. 1998:189.
[16] Kane RA, Kane RL, Ladd RC. 1998:189.
[17] See Recommendation #2 on page 28 of the full Report.
[18] See Recommendation #16 on page 58 of the full Report.
[19] See Recommendations #44-45 on pages 97-98 of the full Report.
[20] See Recommendations #4-7 on pages 40-42 of the full Report.
[21] See Recommendation #24 on page 73 of the full Report.
[22] See Recommendation #26 on page 74 of the full Report.
[23] See Recommendation #27 on page 75 of the full Report.
[24] See Recommendation #25 on page 74 of the full Report.
[25] See Recommendation #17 on page 64 of the full Report.
[26] See Recommendation #18 on page 64 of the full Report.
[27] See Recommendation #19 on page 64 of the full Report.
[28] See Recommendation #20 on page 65 of the full Report.
[29] See Recommendation #22 on page 65 of the full Report.
[30] See Recommendation #21 on page 65 of the full Report.
[31] See Recommendation #23 on page 65 of the full Report.
[32] See Recommendation #28 on page 84 of the full Report.
[33] See Recommendation #29 on pages 84-85 of the full Report.
[34] See Recommendation #43 on page 96 of the full Report.
[35] See Recommendation #33 on page 87 of the full Report.
[36] See Recommendation #32 on page 87 of the full Report.

CHAPTER 1

INTRODUCTION

…Long-term care lurks as the sleeping giant of the health-care system and the stakes are high unless steps are carefully taken to forge a long-term care system in this decade that is accessible to all the citizens of this State.[1]

BACKGROUND

North Carolina is in the midst of a major demographic change that has significant implications for the citizens of the state. The number of older adults in North Carolina is growing faster than in most other states.[2] By 2025, only 10 states will have a greater percentage of older adults age 65 or older. The number of older adults is expected to grow from 12.8% of the state's population in 1998 to 21.4% by 2025.

Sixty percent of persons who live to age 65 will need long-term care sometime in their lives.[3] Long-term care is the sum of health, social, housing, transportation, and other supportive services needed by those with physical, mental, or cognitive limitations that compromise independent living.[4] Long-term care services can be provided in the home, in the community, in residential, or institutional settings.

Most people who need long-term care services rely on family and friends for their support. For many individuals and their families, the need for long-term care can result in financial ruin or hardship.

Older adults are not the only people who need long-term care services. Children as well as other adults with disabilities may need long-term care. National data suggest that children represent about 3.5% of those needing long-term care; adults with disabilities under age 65 represent 46%, and those 65 or older represent 50% of the people needing long-term care services.[5]

The growth in the number of people who will need long-term care services will affect both families and policy makers. Most people who need long-term care services rely on family and friends for their support—generally in the form of unpaid help in meeting daily needs.[6] Individuals and their families also pay a substantial portion of the costs of long-term care services—nationally, out-of-pocket spending accounted for 26% of nursing home and home care expenditures in 1998. For many individuals and families, the need for long-term care can result in financial ruin or hardship.

Government also plays a role in both financing long-term care services and in ensuring minimum levels of quality. Nationally, Medicaid paid approximately 40% of long-term care expenditures for nursing home and home care in 1998.[7] In North Carolina, Medicaid spent more than $1.7 billion in long-term care expenditures for older adults and people with disabilities in SFY 1999. As the number of people who need long-term care services grows, so will the need for additional public expenditures—a trend that has serious financial implications for state, county, and federal governments.

The total population in North Carolina aged 18 and older is projected to grow by 14% between 2000 and 2010, from 5.86 million to 6.69 million. As the data displayed in Table 1.1 indicate, growth rates across different age-sex-race subgroups are projected to range from less than 12% for non-white males aged 18-64 to approximately 28% for white males 65 and older. Of particular interest is the projected increase in persons aged 65 and older, from less than 1 million persons in 2000 to nearly 1.22 million persons in 2010. This large growth among the older adult population of our state has a substantial effect on the projections of persons needing long-term care presented in subsequent chapters of this report.

Table 1.1
Total Persons Aged 18 and Older by Age, Sex, and Race: Projections (2000-2010)[8]

Age-Sex-Race Cohort	2000	2005	2010	*% Change 2000-2010*
Ages 18 to 64	**4,865,700**	**5,199,700**	**5,467,400**	***12.4%***
Female, White	1,678,900	1,795,100	1,888,900	*12.5%*
Female, Non-White	786,300	838,400	882,400	*12.2%*
Male, White	1,662,200	1,779,400	1,870,700	*12.5%*
Male, Non-White	738,300	786,800	825,400	*11.8%*
Ages 65 and Older	**999,200**	**1,082,100**	**1,219,300**	***22.0%***
Female, White	439,000	471,100	522,500	*19.0%*
Female, Non-White	163,500	173,700	191,200	*16.9%*
Male, White	298,000	329,300	381,300	*28.0%*
Male, Non-White	98,700	108,000	124,300	*25.9%*
Ages 18 and Older	**5,864,900**	**6,281,800**	**6,686,700**	***14.0%***
Female, White	2,117,900	2,266,200	2,411,400	*13.9%*
Female, Non-White	949,800	1,012,100	1,073,600	*13.0%*
Male, White	1,960,200	2,108,700	2,252,000	*14.9%*
Male, Non-White	837,000	894,800	949,700	*13.5%*

Table 1, Appendix A

These population changes do not reveal the patterns of population change among persons with low income who may have greater dependency on public funding of long-term care, nor do they indicate the anticipated growth in the numbers of North Carolinians with developmental disabilities or mental retardation who will also present substantial need for residential, in-home- and community-based long-term care services. (See Appendix A for the full report from Millennium Healthcare Solutions, Inc. commissioned as part of the work of the Task Force on Long-Term Care).

Even if public or private financing is available, necessary services may not be. Nationally, one in five adults with long-term care needs reports an inability to obtain the care they need.[9] The shortage of nurse aides and other paraprofessionals makes it particularly difficult for agencies to meet the need for long-term care services.

The growing demand for long-term care services raises concerns about the proper balance between institutional and non-institutional services, assuring quality of care, ensuring an adequate supply of services, and financing. Yet, the 1998 State Auditor's Report on Long-Term Care raised significant questions about the state's ability to meet this challenge.[10] The current system is fragmented and difficult for many people to use. It is for these reasons the North Carolina General Assembly directed the North Carolina Department of Health and Human Services (DHHS) to develop a long-term care plan for the state. This report represents an important step toward the completion of such a plan.

LEGISLATIVE CHARGE

The 1999 General Assembly directed the North Carolina Department of Health and Human Services to develop a long-term care system that provides a continuum of care for older adults, persons with disabilities, and their families.[11] The Department was directed to develop this system in cooperation with other state and local agencies and representatives of consumer and provider organizations. The system was to include:

- a structure and means for screening, assessment, and care management across settings of care;
- a process to determine outcome measures of care;
- an integrated data system to track expenditures, consumer characteristics, and consumer outcomes;
- relationships between the Department and the state's universities to provide policy analysis and program evaluation support for the development of long-term care system reforms;
- an implementation plan that addresses testing of models, review of existing models, evaluation of components, and steps needed to achieve the development of a coordinated system; and
- provision for consumer, provider, and agency input into the system design and implementation development.

The 1999 General Assembly directed the North Carolina Department of Health and Human Services to develop a long-term care system that provides a continuum of care for older adults, persons with disabilities, and their families. The Secretary asked the NC IOM to assist the Department in this effort.

By January 1, 2001, the Department was to have a system in place that would:

- implement the initial phase of a comprehensive data system that tracks long-term care expenditures, services, consumer profiles, and consumer preferences; and
- develop a system of statewide long-term care services coordination and case management to minimize administrative costs, improve access to services, and minimize obstacles to the delivery of long-term care services to people in need.

The Department was also directed to pursue financing strategies that would shift the balance of financial responsibility for long-term care services from public to private sources by promoting public-private partnerships and personal responsibility for long-term care. Specifically, the Department was directed to explore:

- the flexible use of reverse mortgages;
- private insurance coverage for long-term care;
- tax credits or employment programs, such as medical savings accounts and deferred compensation plans, for long-term care; and
- changes in Medicaid eligibility and asset protection requirements that increase consumers' financial responsibility for their long-term care, such as revising the rules relating to transfer of assets and estate recovery policies.

The Department was directed to report its progress to the General Assembly no later than April 15, 2000. The 2000 General Assembly extended the time to complete the development of the new long-term care plan for the state to January 1, 2001 and to implement the initial phase of the comprehensive data system and statewide long-term care service coordination by January 1, 2002.[12]

In the fall of 1999, the Secretary of the North Carolina DHHS, the Honorable H. David Bruton, M.D., asked the North Carolina Institute of Medicine (NC IOM) to convene a statewide task force to assist DHHS in developing a comprehensive long-term care plan. Robert A. Ingram, Chairman of Glaxo Wellcome Inc. agreed to co-chair the Task Force on Long-Term Care along with Secretary Bruton. The full Task Force was appointed in the early fall of 1999, and comprised 49 additional members including representatives of the North Carolina General Assembly, county commissioners, local governments, university and community college experts in long-term care, long-term care providers and industry associations, consumer advocacy groups, and business representatives. In addition, the Task Force included agency directors within DHHS charged with the provision or oversight of long-term care services to older adults or people with disabilities. The Task Force began meeting in November 1999 and met eleven times through December 2000. In addition, the Task Force created two work groups—one for instrument development (Instruments Technical Work Group) and one to examine quality of care issues in more depth (Quality Work Group). These work groups met in the fall of 2000. Their recommendations were considered by the full Task Force and included in this report where appropriate. The NC IOM staff also met periodically with other state agency staff to prepare materials and the agendas for the monthly Task Force meetings.

The Task Force examined long-term care issues for both older adults and persons with physical or cognitive disabilities.

The Task Force examined long-term care issues for both older adults and people with physical or cognitive disabilities. Initially, the Task Force tried to examine the long-term care needs of people with mental illness or developmental disabilities.[13] However, after the Task Force began its deliberations, two other groups were created that included, as part of their charge, an examination of the long-term care needs of people with mental illness and developmental disabilities: the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities and Substance

Abuse Reform and the NC Department of Health and Human Services' *Olmstead*[14] planning efforts. The Task Force recognized that there are some people with mental illness and developmental disabilities who receive services from the long-term care residential and/or community-based facilities discussed in this report; and that there is an ongoing dialogue about the appropriateness of these settings for the population of younger adults (18-59) with mental illness or developmental disabilities. However, given the ongoing work of these other two groups, the Task Force decided to limit most of its focus on long-term care delivery and financing systems for older adults and people with acquired physical and cognitive disabilities. While not focusing on people with developmental disabilities or mental illness, several of the recommendations affect these groups. Therefore, this report will be sent to the Joint Legislative Oversight Committee and the Olmstead planning team within the Department of Health and Human Services.

The Task Force identified eight key areas that needed to be addressed in response to the legislative charge:

(1) DHHS organizational issues;
(2) consumer entry into the long-term care system;
(3) assuring availability of services;
(4) ensuring the quality of services;
(5) workforce issues—particularly the availability of nurse aides and other paraprofessionals;
(6) financing options;
(7) data and data system requirements; and
(8) pilot and demonstration projects.

NORTH CAROLINA'S LONG-TERM CARE POLICY

Ideally, long-term care services would be provided by home- and community-based programs or families on behalf of their loved ones. These services should enable individuals to live as independently as possible without casting them into poverty. Without adequate private long-term care insurance or public funding, some individuals in need of long-term care services are faced with three options: (1) find a family member to provide unpaid care; (2) pay a caregiver out-of-pocket; or (3) enter a long-term care facility (where, as they more quickly use up their resources to pay for institutional care, they are more likely to qualify for public subsidies). This raises questions about the availability of services and financing needed for people to live independently without institutionalization.

Long-term care services should enable individuals to live as independently as possible, without casting people into poverty.

The General Assembly elucidated principles to guide the development of a long-term care system for older adults in the state.[15] These are:

(1) Long-term care services administered by the Department of Health and Human Services and other state and local agencies shall include a balanced array of health, social, and supportive services that promote individual choice, dignity, and the highest practicable level of independence;

(2) Home and community-based services shall be developed, expanded, or maintained in order to meet the needs of consumers in the least confusing manner and based on the desires of the elderly and their families;

(3) All services shall be responsive and appropriate to individual need and shall be delivered through a seamless system that is flexible and responsive regardless of funding source;

(4) Services shall be available to all elderly who need them but targeted primarily to the most frail, needy elderly;

(5) State and local agencies shall maximize the use of limited resources by establishing a fee system for persons who have the ability to pay;

(6) Institutional care shall be provided in such a manner and in such an environment as to promote maintenance or enhancement of the quality of life of each resident and timely discharge to a less restrictive care setting when appropriate; and

(7) State health planning for institutional bed supply shall take into account increased availability of other home and community-based services options.

North Carolina's policy for long-term care is to support older adults and people with disabilities, and their families, in making their own choices with regard to living arrangements and long-term care services that will result in appropriate, high-quality, cost-effective care provided in the least restrictive setting.

In keeping with these principles, the Task Force determined that North Carolina needed an overriding policy statement to guide the future direction of long-term care policy for all individuals in this state. The goal of the Task Force was to design a seamless system of care that promotes individual autonomy, dignity, and choice while providing services to individuals in the least restrictive setting. Specifically, the Task Force recommends:

1. **North Carolina's policy for long-term care is to support older adults and persons with disabilities needing long-term care, and their families, in making their own choices with regard to living arrangements and long-term care services that will result in appropriate, high-quality, cost-effective care provided in the least restrictive setting.**

CHAPTER 2

THE STRUCTURE OF THE NORTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES FOR LONG-TERM CARE

As noted in Chapter 1, the State Auditor's Report on Long-Term Care in 1998 raised questions about the state's ability to meet the long-term care challenge facing the state as the population ages. This challenge is made more difficult by the fragmentation within the Department of Health and Human Services (DHHS) among the different agencies delivering, financing, or regulating long-term care services. For example, within the NC DHHS, there are at least eight Divisions that play a role in the long-term care system:

- *Division of Aging (DOA)*—has the primary planning responsibility to meet the needs of older adults and their family caregivers; promotes and protects the rights of residents in nursing facilities and adult care homes through the Ombudsman program and the local community advisory committees; supports information and education about the provision and financing of long-term care; and with Area Agencies on Aging and Division of Social Services representatives, administers funds and applies standards for home- and community-based services for younger persons with disabilities and people age 60 or older, including the certification of adult day services.

- *Division of Facility Services (DFS)*—licenses nursing facilities, intermediate care facilities for the mentally retarded (ICF-MRs), home health agencies, and adult care homes; establishes need for new beds in nursing facilities and ICF-MRs through the Certificate of Need program; and oversees the quality of care provided by licensed institutional and community-based providers through regulatory oversight and periodic inspections.

- *Division of Information Resource Management*—is developing data systems to collect information about the use of and needs of people using the state-subsidized long-term care system.

- *Division of Medical Assistance (DMA)*—finances health care, personal care services, nursing facility care and intermediate care for the mentally retarded (in ICF-MRs), for older adults, and for people with disabilities; is the primary payer for home and community based and institutional long-term care services in the state; maintains the Community Alternatives Program for Disabled Adults (CAP/DA) waiver; develops and maintains program policies and procedures; and oversees local program operations; develops medical/functional and financial eligibility criteria for Medicaid reimbursement for nursing facility and ICF-MR care.

The multiplicity of Divisions within the North Carolina Department of Health and Human Services charged with financing, delivering, or regulating long-term care services has made it difficult to develop a coordinated long-term care policy for the state.

- *Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS)*—finances, regulates, and provides long-term care services to people with mental illness, developmental disabilities, or substance abuse problems.

- *Division of Public Health*—finances some home health services.

- *Division of Services for the Blind*—finances the costs of residential services provided to people with visual impairments in adult care homes; and finances home management and personal care services for people with visual impairments.

- *Division of Social Services (DSS)*—finances and regulates the costs of residential services provided to persons with disabilities in adult care homes; finances home- and community-based services to adults age 18 or older with disabilities; and provides adult protective services and guardianships to individuals to prevent abuse, neglect, or exploitation.

- *Division of Vocational Rehabilitation*—the Independent Living Rehabilitation Program helps some people with disabilities obtain vocational rehabilitation services and assists individuals who might otherwise require institutionalization remain active in their homes and communities; and helps some individuals transition from nursing homes to the community.

The multiplicity of Divisions at the state level has made it difficult in the past to develop a coordinated long-term care policy for the state. The North Carolina Institute of Medicine (NC IOM) worked with the NC Department of Health and Human Services to develop a plan to enhance communication and coordination among the various Divisions. This plan has been endorsed by Secretary Bruton, DHHS Division Directors, and the NC IOM Task Force. In keeping with this plan, the Task Force recommends:

The Secretary of the North Carolina Department of Health and Human Services should establish a Long-Term Care Cabinet and Office of Long-Term Care to enhance communication and coordination among the various divisions.

2. A new Long-Term Care Cabinet and an Office of Long-Term Care should be created within the Office of the Secretary. The Office of Long-Term Care should have responsibility for organizing and maintaining a new Forum on Long-Term Care.

LONG-TERM CARE CABINET

The Long-Term Care Cabinet should include the Division Directors of all of the DHHS Divisions that affect long-term care policy, including representatives from the Divisions of: Aging; Early Intervention Services; Facility Services; Information Resource Management; Medical Assistance; Mental Health, Developmental Disabilities and Substance Abuse Services; Public Health; Social Services; Services for the Blind; Services for the Deaf and Hard of Hearing; Vocational Rehabilitation; Office of Research, Demonstrations and Rural Health Development; and the Division of Budget, Planning and Analysis. The LTC Cabinet should meet on a monthly basis and should be chaired by the Secretary or his or her designee.

The Long-Term Care Cabinet should:

- Articulate a vision for long-term care in North Carolina and assure that the Department's activities are consistent with it.

- Oversee the development of an *Olmstead* plan that helps ensure that people with disabilities who are institutionalized or at-risk of institutionalization receive care in the most integrated setting appropriate to their needs and preferences.

- Establish a work plan for the Department in the area of long-term care and *Olmstead* that is consistent with the Department's vision, the Governor's priorities, and legislative mandates and intent, and is informed by the input of all participating Divisions and Offices. The initial plan should define short-, intermediate-, and long-range objectives; expected outcomes and products; timetables; and team leaders for priorities established by the Cabinet. The initial plan should also address the recommendations of the North Carolina Institute of Medicine's Task Force on Long-Term Care Final Report that relate to responsibilities of the Department of Health and Human Services and the recommendations of the Department's *Olmstead* plan. The Cabinet should adopt an annual process to review and revise the work plan and assess the effectiveness of the Department's overall coordination and management approach for long-term care. In addition, the Cabinet should write an annual report detailing the progress made on the items contained in the work plan. This work plan and the annual report should be public documents and accessible online.

- Review the functions of each participating Division and Office as they relate to long-term care or *Olmstead* to determine where there are opportunities for improved coordination as well as streamlining and possible integration of policies, programs, and/or material and human resources. The Cabinet should subsequently reexamine its findings and conclusions once a year or whenever there are system changes.

- Review the annual state- and county-level long-term care and *Olmstead* budgets, services, needs, and client demographic data coordinated or produced by the Office of Long-Term Care. The Cabinet should review these data for policy and planning purposes, and to foster long-term care service development at state and local levels.

- Establish Interdivisional/Interoffice Performance Teams to work on specific long-term care issues that cut across DHHS Divisions and Offices and that are priorities as identified in the Long-Term Care Cabinet's work plan. These teams could also include representatives of other state agencies that have an interest or influence related to a particular priority issue (e.g., the Department of Insurance or the Community College System). The Performance Teams should be established at the direction of the Cabinet and shall work on both administrative and programmatic issues as appropriate. (An example of an administrative issue may include assuring the compatibility of

The Long-Term Care Cabinet should articulate a vision for long-term care in North Carolina and assure that the Department's activities are consistent with it.

client information reporting systems so that comparable data are available for planning and management functions. A programmatic issue, for example, could be to improve the recruitment and retention of qualified direct service providers for in-home and residential long-term care.) The Office of Long-Term Care should recommend team leaders and offer advice on team participation. All members of the teams should share responsibility for achieving the expected outcomes/products.

- Have input into the Department and Governor's legislative and budget priorities as they apply to long-term care and *Olmstead*. As part of the planning process, the Long-Term Care Cabinet should identify fiscal implications related to the Department's work plan and the financial resources and legislation needed to implement elements of the plan. The Cabinet should be responsible for approving a long-term care budget package to guide the continuation and expansion budget requests of the Department.

OFFICE OF LONG-TERM CARE

The new Office of Long-Term Care should be responsible for interagency long-term care planning. An expert in long-term care policy should be selected to direct the Office of Long-Term Care. The Director's salary level should be equivalent to that of a Division Director; she or he should report directly to the Secretary and have an adequate number of qualified personnel to help carry out the Office's responsibilities (see Appendix B for a list of possible positions). In addition, the Office should be provided with sufficient resources to contract with consultants or universities to assist in policy development and program evaluation.

The Office should have primary responsibility for the following tasks:

The Office of Long-Term Care would have primary responsibility for interagency long-term care planning, policy analysis, data analysis, evaluation and research, and public communications.

- *Coordination of the Department's Long-Term Care Cabinet*. The Director of the Office of Long-Term Care shall be a member of the Long-Term Care Cabinet and shall work with the Secretary or the designated chair in coordinating the work of the Cabinet and any performance teams established to address particular long-term care issues. The Director should oversee any contractual services secured to assist the Long-Term Care Cabinet or the Office of Long-Term Care.

- *Policy Analysis*. The Office should have responsibility for analyzing long-term care and *Olmstead* policies, identifying emerging issues, and bringing policy issues to the attention of the Long-Term Care Cabinet. The Office should research and propose strategies for addressing areas that are not otherwise receiving sufficient attention from the separate Divisions. In addition, the Office should assist Divisions in preparing required documents that address long-term care or *Olmstead* issues (such as long-term care sections of the State Aging Services Plan).

- *Data Analysis*. The Office should collect, analyze, and periodically update county- and state-level data about the use of and need for

long-term care services across DHHS Divisions. The Office should work with all appropriate state agencies and offices to improve the collection of relevant data that can aid policy and program planning and evaluation. In addition, the Office should have primary responsibility for the analysis of aggregate client assessment data across all settings. The Office should work with the different Divisions to better understand who uses what types of services (e.g., functional abilities, medical needs, and availability of informal support), and what types of events trigger movement from one level or type of service to another.

The Office of Long-Term Care will also have primary responsibility for ensuring the confidentiality of consumer data.

- *Ensure Confidentiality*. The Office should have responsibility for ensuring the confidentiality of consumer data and that the new long-term care system operates in compliance with the Health Insurance Portability and Accountability Act (HIPAA) confidentiality regulations.

- *Evaluation/Research*. The Office should have primary responsibility for coordinating and, if necessary, contracting for or carrying out program evaluation across Divisions. The Office should also work with the Cabinet, performance teams, and appropriate Divisions in establishing demonstration projects to test new long-term care or *Olmstead* programs or policies. The Office should support the efforts of Divisions to secure grants and otherwise undertake activities to evaluate their services and develop new approaches to service delivery, financing, and oversight of services. The Office should coordinate the Department's performance planning for long-term care and *Olmstead*, in conjunction with the State Budget and Planning Offices. The Office should assist Divisions and the Long-Term Care Cabinet in translating goals into measurable outcomes and in developing means to measure these outcomes. The Office should keep abreast of and share new techniques, tools, technologies, and best practices to aid Divisions in their respective work. The Office may conduct customer satisfaction surveys to provide performance feedback to the Long-Term Care Cabinet, and assist in diagnosing problems and issues revealed by this feedback.

- *Collaboration with universities*. The Office should identify public and private university and college faculty with expertise in long-term care issues and collaborate with appropriate faculty around data collection, evaluation and research, quality improvement initiatives, policy, and other areas as appropriate.

- *Public communication*. The Office should be the focal point (primary contact point) for long-term care and *Olmstead* policy in North Carolina. The Office should have primary responsibility for working with stakeholders and the general public to inform them of North Carolina's long-term care and *Olmstead*-specific policies, and to assist them in navigating the system and reaching appropriate contact persons. Specifically, the Office should organize the Forum on Long-Term Care (see below) and should work with the Division of Mental Health, Developmental Disability and Substance Abuse Services *Olmstead* steering committee. The office should provide the Forum, *Olmstead* Steering Committee, legislature, appropriate legislative study commissions, and others in the public with regular

updates and progress reports. In addition, the Office should seek public input into the functioning of the state's long-term care system and *Olmstead* plan from these groups and other interested persons. The Office should also develop and maintain a web site for long-term care and *Olmstead* that builds upon the existing DHHS pages, coordinating and adding content so that the information is of maximum benefit to policymakers, researchers, long-term care providers, consumers, and the general public. Any problems identified from the Forum, Steering Committee, web site, or other medium that cannot be immediately resolved should be brought to the attention of the Long-Term Care Cabinet. The Office should also assist DHHS Divisions with responses to information requests from the media and other sources pertinent to long-term care issues.

- *Development and Coordination of Services Training*. The Office should identify training activities among Divisions that are targeted for professionals and paraprofessionals in long-term care and assist with the development of new training opportunities deemed necessary. The Office should sponsor education, training, and other knowledge-sharing opportunities for Department personnel working in long-term care to build staff capabilities, reduce barriers across Divisions, and disseminate best practices.

The Department should establish a new Forum on Long-Term Care. The Forum will be comprised of consumers, advocates, long-term care industry leaders, and government officials and will provide the state with ongoing feedback into the development of the state's long-term care system.

FORUM ON LONG-TERM CARE

The Office of Long-Term Care should have responsibility for organizing and maintaining a Forum on Long-Term Care. The Forum on Long-Term Care should assist with the functions of informing stakeholders, policy makers, and the general public about the development of long-term care policies and programs in the state. The Department should invite a panel of leading citizens, consumers, advocates, long-term care industry leaders, and legislative and county government officials to be part of a NC Forum on Long-Term Care. This new advisory panel should be constituted in much the same way as the Task Force on Long-Term Care convened by the NC IOM and may include some or all of the members of the Task Force. However, the new Forum would not be limited to the members of the NC IOM Task Force on Long-Term Care. The Forum should replace the current Long-Term Care Roundtable. The Forum should meet at least quarterly and review progress toward the goals and objectives for long-term care developed by the NC IOM Task Force, the Long-Term Care Cabinet and the NC General Assembly (as reflected in legislation and/or the work of relevant legislative study commissions or committees).

CHAPTER 3

ENTRY INTO THE SYSTEM OF LONG-TERM CARE

DEFINITION OF THE PROBLEM

Getting information about long-term care services and gaining access to those services can be a complex process—one that is often confusing to consumers. Some of the difficulties and complexities can best be illustrated by a case example provided by a member of the Task Force.

> *An 83 year old woman living at home with her daughter with disabilities fell and broke her hip. The ambulance took her to the hospital where her hip was pinned. A week later the woman returned home where her daughter with disabilities greeted her. The daughter directed the transporters to her mother's room and bed. Later that day, unable to move her mother or to get her out of bed, the daughter called the police for assistance. A police officer came, and seeing the situation, called the local public health department. The next door neighbor came over, and upset with the situation, went home and called the Senior Citizen's Center, which gave her the Council on Aging phone number. The neighbor also called the Department of Social Services (DSS) to report her concern about the situation.*
>
> *Later that afternoon, a nurse from a home health agency called to schedule an assessment visit for the following day. The home health agency received a referral from the hospital at discharge. An adult protective services social worker from DSS arrived to evaluate the complaint called in by the neighbor and to assess the woman's condition. The social worker found the woman lying on the floor of her bedroom in great pain and called an ambulance and the doctor. The woman was taken back to the hospital for evaluation and another assessment.*

Fragmentation and duplication of services exists in North Carolina's long-tern care system.

The above example is not intended to convey that all attempts to access or provide needed services are fraught with such difficulties. Many people receive the services they need more easily. At the same time, there is fragmentation and duplication in the state's long-term care system. The above example merely illustrates some of the problems that can and do occur all too often as a result of the lack of coordination among agencies and programs providing long-term care services in our state.

THE CURRENT SYSTEM

"Entry into the system" refers to a set of issues surrounding consumer pathways into and through the system and includes the following types of general services: information, referral and assistance; screening; level of service assessment; and care planning. Given the fragmentation and duplication within the current system and resulting confusion it causes for consumers, the Task Force concluded early in its deliberations that one of its goals would be to propose a system that would allow consumers to find their

North Carolina's long-term care system should be accessible and understandable for both public- and private-pay consumers, and uniform for all in need of long-term care services.

way into and through the system with ease, regardless of the consumer's source of payment for long-term care services. Thus, one of the overall recommendations of the Task Force is:

3. **North Carolina's long-term care system should be accessible and understandable for both public- and private-pay consumers, and uniform for all in need of long-term care services.**

Information, Referral, and Assistance

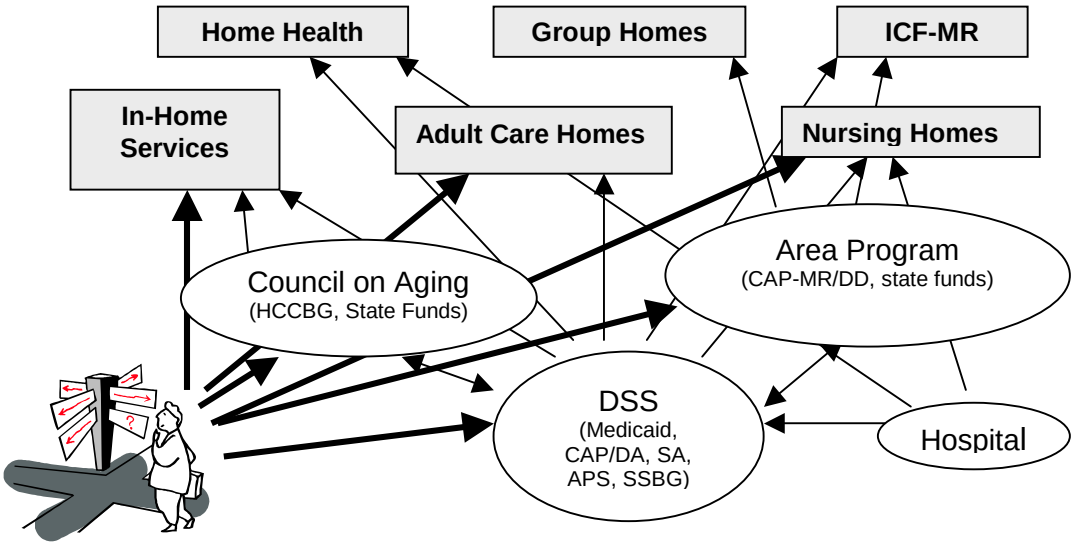
Providing information to individuals in need of long-term care services, with referral to appropriate community resources, is known as "information, referral, and assistance." People needing information about long-term care services find that information in multiple ways. They may telephone an agency requesting information and assistance. Many local agencies and organizations that work with older adults or people with disabilities are knowledgeable about long-term care resources in the community and provide this information free of charge upon request. People may also go directly to an agency and request the service they need. Or, they may go to an agency for a specific service; only to find out that that particular agency does not provide the service they are seeking or need. In this latter instance, the agency contacted by the consumer will try to refer the consumer to the appropriate agency.

The system that people with developmental disabilities use to obtain long-term care services is more clearly established. Individuals with developmental disabilities needing services can obtain referrals through area mental health, developmental disabilities and substance abuse programs. However, some people with developmental disabilities enter the long-term care system through other means. For example, a family member may place another family member in an adult care home without first seeking services through the area mental health, developmental disabilities and substance abuse program. While the system for people with developmental disabilities is more organized, some changes may be needed to ensure that individuals who enter the system through other means are identified and receive appropriate services.

Few individuals understand all the services available in their communities or what agencies can help with payment for these services.

Consumers face an array of agencies purporting to deliver long-term care services (see Chart 3.1). Multiple agencies provide different types of long-term care services. Departments of Social Services, Councils and Departments on Aging, Area Programs on Aging, Health Departments, Area Mental Health, Developmental Disability and Substance Abuse Programs, home health agencies, adult day care and day health centers, adult care homes, assisted living facilities, nursing homes, hospitals, group homes for people with developmental disabilities or mental illness, adult developmental vocational programs, and community respite facilities are some of the major providers of long-term care services. Some of these services are available to both publicly-funded and private-pay individuals; other services are limited to individuals with specific sources of payment. Persons seeking services may know of some of these agencies, but not others. Few individuals understand all the services available in the community, or what agencies can help with payment for these services.

Chart 3.1
The Complex System of Information, Referral, and Assistance



While most communities offer some form of information, referral, and assistance to older adults and their family caregivers, it is also clear that the amount and quality of this help varies enormously around the state. Some communities and agencies have made this a priority while others have not. The Governor's Advisory Council on Aging emphasized the pressing need to develop a comprehensive, professional, and uniform aging information resource system, especially as the older population and fragmented service system continue to grow.[16] Information, referral, and assistance agencies are usually aware of the resources and services provided by other agencies in their communities. Some communities use informal mechanisms to keep appraised of available services. Other counties, approximately 50, have developed formal resource databases. Many of these counties are using a computerized information and assistance system, IRis, but this system is not used uniformly across all counties and may not include all the long-term care resources needed by people with disabilities.

Without a systematic means of providing up-to-date information about available services to all agencies, the likelihood of providing erroneous information to consumers increases. Further, without a systematic information database that is shared among counties, consumers might not be given all the information they need, and/or inappropriate referrals might be made. Given this problem, the Task Force recommended in its interim report that the Department develop a framework for a computerized information and assistance system that can be used statewide and takes advantage of existing systems throughout the state. The Division of Aging has taken the lead in establishing an interagency task force to design a comprehensive and uniform information resource system that includes standardized procedures for the collection, storage, and dissemination of information as well as monitoring and evaluating the information system itself. The Division of

Aging's task force includes state and local agency staff who provide information and assistance to older adults and people with disabilities, their families and caregivers, and providers.

Screening

An initial screening is often conducted as part of the information and assistance process. When services are requested, an individual is screened to gather basic information about the type of services needed, his or her potential level of care needed, and financial eligibility for publicly-funded programs and services. Screening helps to determine which individuals may potentially need long-term care services and which individuals need a referral to other types of services. The goal of screening is to direct individuals to appropriate resources and agencies.

Level of Service Assessment

A more in-depth information gathering process is needed to determine an individual's need for long-term care services. Information on physical health, mental health, functional status, amount of available informal support, condition of the home, and financial ability to meet day-to-day needs must be collected. This assessment is conducted with the goal of determining what types of services are appropriate for an individual based on his/her functional and health status and available informal support. Some assessment instruments also obtain information on the client's goals and preferences. The level of service assessment may be done as part of an eligibility determination for publicly-subsidized long-term care programs (see level of service eligibility below) or may be done for private-pay consumers to identify the appropriate services based on the person's needs and preferences.

Eligibility Determination

Agencies that help pay for long-term care services use two types of criteria for determining eligibility for services—level of service need and financial status.

(1) *Level of Service Eligibility*: To be eligible for services, a consumer must meet a level of service need that is based on the complexity or intensity of a person's chronic care needs. Level of service need is based on an assessment encompassing clinical, psychosocial, and functional criteria. Information gathered during the assessment is used to match the consumer's particular needs and preferences with an appropriate category or level of service. Data from this level of service assessment are used to determine whether a person qualifies for public funding for a certain level of service.

(2) *Financial Eligibility*: Eligibility for some publicly-funded long-term care services is based on an individual's financial status. For example, eligibility for assistance in paying for adult care home services (through State-County Special Assistance) or for nursing home care (through Medicaid) is based not only on level of service need criteria, but also financial criteria, such as income and assets. In Medicaid, the financial eligibility guidelines differ depending on the level of service need (see Chapter 7, Table 7.5).

Care Planning

Once a person's level of service needs and personal preferences are determined and the person is referred to the appropriate agency, a care plan must be developed. Care planning is the development of a package of services that meet an individual's long-term care needs, based on a more thorough assessment of the individual's functional and health status. Assessors in the long-term care arena for older adults and people with disabilities are usually nurses and social workers. The individual in need of care, the individual's family, the assessor(s) and the person's physician generally have input and reach consensus on the plan of care.

Individuals and families are often subjected to multiple assessments, and coordination of services between agencies may be lacking.

Different agencies use different screening, level of service assessment and care planning instruments. When the client is eligible for Medicare reimbursement, the federal government, through the Health Care Financing Administration (HCFA), requires that nursing homes use specialized instruments for care planning purposes (Minimum Data Set - MDS 2.0) and to determine whether residents with mental health problems or developmental disabilities are appropriate for nursing home placement (Preadmission Screening and Annual Resident Review - PASARR). Home health agencies are required to use a different tool (Outcome and Assessment Information Set - OASIS) to obtain information on the client's functional and medical status. In addition to the tools required by the federal government, different state agencies require different forms for care planning processes. For example, some agencies provide specialized long-term care services such as ICF-MR and CAP-MR/DD for persons with developmental disabilities, or specialized long-term psychiatric care in hospital and community settings for persons with severe and persistent mental illness. These services require specialized care planning tools that address habilitation and treatment needs. Other agencies require different forms for level of service and care planning assessments. The following table (Table 3.1) shows the various assessment tools currently in use by different agencies for different services. In some cases there may not be a standardized form that is required for screening by an agency.

The use of multiple, and often incompatible, screening and assessment instruments by different agencies causes problems:

- There is little or no sharing of client assessment information across multiple agencies working with an individual and his or her family. Thus, individuals and families are often subjected to multiple assessments, and coordination of services between agencies may be lacking.
- Coordinated and continuous care planning and care management is limited. Care managers cannot monitor changes in functional or health status as individuals move throughout the long-term care system.
- It is difficult for public programs to plan for long-term care services because the state lacks data about the use of long-term care services and the functional or health status of people using different types of services.

The state lacks data about the use of long-term care services and the functional or health status of people using different types of services.

- The state cannot easily monitor outcomes for long-term care services other than nursing home services because the state does not collect baseline or on-going functional and health status information about persons using other types or levels of long-term care services.

Table 3.1
State or Federally Required
Level of Service and Care Planning Instruments

Service	Level of Service Assessment	Care Planning Assessment
Nursing home	• Medicaid: FL-2	• MDS 2.0 (federally required) • PASARR to determine if a resident who has a mental illness or developmental disability is appropriate for nursing facility care (federally required)
CAP/DA*	• Medicaid: FL-2	• Medicaid: DMA 3012 (care planning) • Medicaid: DMA 3011 (assessment to determine specific services needed)
Adult Care Home	• State-County Special Assistance (SA): FL-2 • Medicaid: DMA 3050 (for personal care services)	• Current: DMA 3050 • Future (SB10): RAI-ACNC
Home Health	• OASIS (federally required)	• HCFA 485 (federally required)
In-Home Services	• SSBG: DSS 6220 (adult services assessment)	• SSBG: DSS 6220 • Medicaid: DMA 3000
ICF-MR**	• Medicaid: MR-2	• Medicaid: DMA 3012 (care planning) • MHDDSAS: NC SNAP
CAP-MR/DD***	• Medicaid: MR-2	• Medicaid: CAP-MR/DD treatment/habilitation plan • MHDDSAS: NC SNAP
Other long-term care services offered by DMHDDSAS****	• DMHDDSAS: NC SNAP for all MR/DD clients • CAFAS for children • GAF for adults	• No instrument is used

* CAP/DA — Community Alternatives Program for Disabled Adults
** ICF-MR — Intermediate Care Facility for the Mentally Retarded
*** CAP-MR/DD — Community Alternatives Program for persons with Mental Retardation or Developmental Disabilities
**** DMHDDSAS — Division of Mental Health, Developmental Disabilities and Substance Abuse Services

COMMON SCREENING, LEVEL OF SERVICE ASSESSMENT, AND CARE PLANNING INSTRUMENTS

North Carolina's situation is not unique; other states have similar long-term care systems. A few states, however, have begun to address the problem of duplicative screening and assessment processes. *Inter*RAI, a nonprofit corporation, developed a series of Resident Assessment Instruments (RAI) to be used as assessment and care planning instruments for long-term care services. These instruments include:

Other states have used Resident Assessment Instruments (RAI) for care planning, case-mix reimbursement, and to monitor the quality of care.

- MDS 2.0 for nursing home services (mandated for use nationally by HCFA);
- RAI-AL, referred to as RAI-ALNC (Assisted Living North Carolina) in North Carolina, for assisted living and adult care home services;
- RAI-HC for home care services;
- RAI-AC for acute care services;
- RAI-MH for mental health services; and
- RAI-PAC for post-acute care.

Currently there is no RAI-type instrument to assess people with developmental disabilities, but *inter*RAI is contemplating the development of such an instrument.

Each instrument in the RAI family is a standardized assessment tool that measures common dimensions of functional and health status, such as cognition, communication, physical activity, continence, and mood and behavior. While each of the instruments has certain similarities, they also differ in that they reflect the more common care needs associated with specific types of settings. Many of the RAI instruments used in care planning also include 'triggers' for changes in status, which signal a need for a more thorough assessment and protocols for assessing and planning care.

As noted above, the RAI instruments are commonly used for care planning and care management. However, they are also used for other purposes. The demographic information about the users of long-term care services are used by states for planning purposes, and to monitor outcomes of care and performance of providers. Some states have used this information to establish a case-mix reimbursement methodology for long-term care services. Additionally, an RAI level of service assessment instrument has been used in at least one state to conduct level of service need assessments to determine eligibility for public payment of services (see Chart 3.2).

Chart 3.2
Applications of RAI-based Assessment Tools

A UNIFORM PORTAL OF ENTRY SYSTEM WITH UNIFORM ASSESSMENT

In order to reduce fragmentation, multiple assessments, and confusion on the part of consumers, the NC IOM Task Force on Long-Term Care recommends:

4. **The North Carolina Department of Health and Human Services should develop a "uniform portal of entry" system for long-term care services, in which confidentiality of information is ensured, in accordance with the Health Insurance Portability and Accountability Act (HIPAA) confidentiality regulations.**

   The uniform portal of entry system should be defined by *functions*, as opposed to *place or agency*. Uniform portal of entry characteristics include:

   - **common information and assistance, screening, level of service, and care planning assessment tools;**
   - **automated information sharing between agencies (local to local and local to state) that meet specified confidentiality protections;**
   - **entry functions (information and assistance, screening, initial level of service assessment, and financial eligibility determination) as readily accessible and understandable to consumers as possible; and**
   - **simplification of the financial eligibility determination process. The state should develop mechanisms to simplify the application process, for example, by outstationing Division of Social Services Medicaid eligibility workers; collecting the financial information by other agencies; and transmitting it to DSS, or where possible, having the same agency that conducts the initial level of service assessment conduct the financial eligibility determination.**

   The state should provide guidelines and parameters for the uniform portal of entry system, but which agency provides what services should be determined locally. In designing the uniform portal of entry, DHHS should examine whether this system should be expanded to include long-term care services for people with developmental disabilities, or if not, how the uniform portal of entry can be coordinated with the existing system for people with developmental disabilities.

DHHS should develop a uniform portal of entry to reduce fragmentation and confusion for individuals and their families needing long-term care services.

In order to move forward with a uniform portal of entry system, the NC IOM Task Force on Long-Term Care recommends:

5. **The North Carolina Department of Health and Human Services should begin using uniform screening, level of service assessment, and care planning instruments based on the RAI family of instruments. These instruments should be used by the Division of Social Services (DSS), Division of Aging (DOA), and Division of Medical Assistance (DMA) for all long-term care services.**

While some standardized assessment instruments are fully developed (e.g., the Resident Assessment Instrument [RAI] for nursing homes and home care), other screening and assessment instruments are not fully developed. In addition, existing tools and yet-to-be-developed tools need to be modified to meet North Carolina's system requirements. Thus, a work group inclusive of technical experts and provider and state agency representatives was necessary. In the interim report, the NC IOM Task Force on Long-Term Care recommended the formation of an Instruments Technical Work Group, which would include state and local government agency representatives, care providers, consumers, and academics experienced in tool development and outcome measurement. The Instruments Technical Work Group was given the responsibility for identifying or developing a RAI-compatible telephone screening tool and level of service assessment instrument. The Instruments Technical Work Group was asked to develop the level of service assessment instrument, but was not charged with determining the medical and functional status criteria to be used in determining eligibility for public payment of services. The medical and functional level of service eligibility criteria will continue to be set by state agencies.

The Instruments Technical Work Group began its work in August 2000 and met on a monthly basis through December (See Appendix C for a list of Work Group members). The Work Group focused initially on developing a telephone-screening tool that could be used for both information and assistance and screening for long-term care services. Ideally, telephone screening would be conducted as part of the information and assistance provided by various agencies. There may be multiple agencies in a community that provide these services, but all of the agencies will be required to use the same long-term care screening instrument. Offering information and assistance and long-term care screening through multiple agencies allows individuals greater ability to access needed services. Requiring the use of the same screening instrument ensures that individuals will be provided consistent information regardless of how or where they enter the system.

The Work Group will continue its effort to develop a telephone-screening instrument. The new Office of Long-Term Care will coordinate this ongoing effort. The Task Force on Long-Term Care recommends:

6. **The Office of Long-Term Care, within the Department of Health and Human Services, should work with the Instruments Technical Work Group to complete the development of a telephone-screening tool that is based on the RAI-family of instruments and that can also be used for information and assistance purposes. The telephone-screening tool shall also include questions to identify people with mental health, developmental disabilities, or substance abuse problems in order to refer them to appropriate area programs. Telephone screening and/or information and assistance can be provided by multiple agencies in communities, as long as they use the same telephone screening protocol.**

The Task Force recognizes the leadership that counties have demonstrated in developing information and assistance systems across the state. Some of these systems are quite sophisticated, and allow individuals to access information about local resources on-line as well as by contacting the information and assistance agency directly. Just1Call, an innovative program of the Mecklenburg County DSS, is an example of a model information and assistance system. The system was designed to provide assistance for all seniors and adults with disabilities. The system collects background information, how the person learned about the agency, why the person called, financial status, as well as information about activities of daily living, health, and functional status. Just1Call also has information and assistance capacity, so it can identify appropriate referrals based on the client's needs and preferences (for example, it can narrow down the referrals to a certain part of town). The Just1Call software was developed with public funds, so it can be shared with other communities.

DHHS should continue its work to develop or identify existing computerized information and assistance systems that can be used statewide to help individuals who need long-term care and their families obtain up-to-date information about available resources.

The Task Force wanted the Department of Health and Human Services to take the lead in helping other counties develop similar systems. It is for this reason that the Task Force recommends:

7. **The North Carolina Division of Aging, in conjunction with the Office of Long-Term Care, should continue its work to develop or identify existing computerized information and assistance systems that can be used statewide. This system should include long-term care resources for both older adults and other people with disabilities. The goal is to have comprehensive, professionally administered, and computerized information and assistance systems that work together with long-term care telephone-screening tools in local communities. The Office of Long-Term Care, within the Department of Health and Human Services, should work with the Division of Aging to assure adequate support for development and maintenance of this system. The General Assembly should appropriate $125,000 both years of the biennium to the Division of Aging to facilitate the development of this information and assistance system statewide.**

The Instruments Technical Work Group also began work on a level of service assessment tool, although more work is needed. The goal of this assessment is to determine an individual's need for long-term care services. As noted earlier, the level of service assessment will ultimately serve two functions:

- to provide information to individuals about the range of long-term care services that would be appropriate based on their functional, cognitive, mental health, health care needs, informal support, and environmental conditions; and
- to determine functional and medical eligibility for publicly-subsidized long-term care programs.

Once a person has been identified as a potential candidate for state publicly-funded long-term care services (through the telephone screening tool), the person would be assessed using a RAI-based level of service assessment (see Chart 3.3). The assessment should be conducted by a

registered nurse or social worker. If a social worker conducts the level of service assessment, the agency that conducts the assessments will have access to a registered nurse on staff or by contract who can assist the social work assessor in the completion of more complex clinical questions.

Ideally, the level of service assessment would be conducted in a face-to-face interview with the person in their own home, so the assessor could also examine whether home modifications would be needed to enable the person to reside at home, and to assess the adequacy of a person's informal support system. However, many people first enter the long-term care system after a hospital admission. In these instances, the hospital discharge planner would be involved in the level of service assessment.

DHHS should continue its work to develop a level of service assessment instrument. This assessment will help provide individuals with information about the full range of long-term care services that would be appropriate based on their individual circumstances. The assessment can also help the state determine eligibility for publicly-subsidized long-term care programs.

The Task Force *suggests e*ach county designate a lead agency that will conduct the in-home assessments. The lead agency would have the following responsibilities:

(a) ensuring that assessments are conducted in a timely fashion;
(b) helping individuals complete financial eligibility applications, if needed, for publicly-funded services;
(c) working with clients to explain the full range of service options so that clients and their families can make an informed choice of appropriate services based on their level of need.

The Task Force recognized that more work was needed to develop the level of service assessment instrument. Therefore, the Task Force recommends that:

8. The Office of Long-Term Care, in conjunction with the Instruments Technical Work Group, should develop a level of service instrument based on the RAI family of instruments. The level of service assessment instrument should be less detailed than the care planning instrument; help consumers and providers determine the level and type of service needed or desired; and eventually be used to substitute for the FL-2 and other level of service eligibility tools used by the state.

Everyone seeking state publicly-funded out-of-home services in a long-term care facility or state publicly-funded in-home or community-based long-term care services would be required to use the level of service assessment instrument to determine what level and types of services are needed. For this purpose, state publicly-funded in-home services include: home delivered meals, adult day care, adult day health, care management, ongoing respite services, in-home aides, home health care, and durable medical equipment (if an assessment is already required for the service). Individuals who are seeking privately-funded or Medicare-funded long-term care services shall be advised about the opportunity to obtain a full level of service assessment on a private-pay basis.[17] Individuals not currently seeking publicly-funded long-term care services shall be informed that eligibility for publicly-funded services is based on a person's functional and medical needs and may also include financial eligibility requirements. Exhaustion of private or third-

party payment sources for long-term care services does not guarantee public-funding.

In addition to developing a level of service assessment instrument, the Office of Long-Term Care, in conjunction with the Instruments Technical Work Group, should:

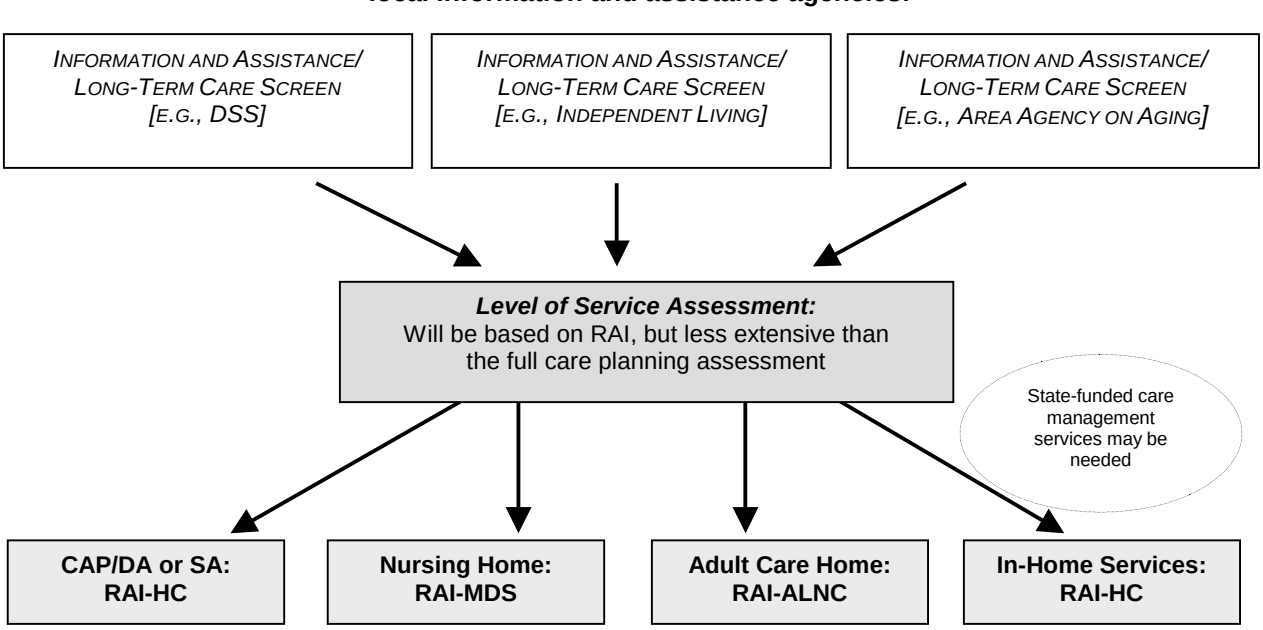
- **develop consumer preference items, if needed, for the RAI family of instruments;**
- **explore whether to use the RAI family of instruments for long-term care services provided by the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS), or whether the specialized assessment tools used by DMHDDSAS can be coordinated with the use of the RAI family of instruments for long-term care services;**
- **explore whether to use the RAI family of instruments for long-term care services provided by the Division of Vocational Rehabilitation and/or Services for the Blind;**
- **review RAI generated information to use in measuring outcomes and setting outcome goals for both individuals and the system;**
- **develop training protocols and work with people in the field to garner support for the use of the new tools;**
- **evaluate the cost of universal screening and assessment across the whole system; and**
- **set a timetable for developing, modifying, and testing instruments in the field.**

9. **The Office of Long-Term Care, within the NC Department of Health and Human Services, should develop an assessment process that will help individuals make an informed choice and will assist in determining eligibility for state publicly-funded programs. The Office should develop procedures to ensure that assessments can be conducted in a timely manner so as to not delay placement in long-term care facilities or delay the provision of needed in-home and community-based services. The Office should develop procedures to ensure that assessment agencies that provide long-term care services directly do not inappropriately self-refer. In addition, the Department should contract to conduct "look-behind" assessments of a randomly selected subset of the assessments to assure the reliability of the assessment instrument. The Office of Long-Term Care should explore possible Medicaid funding to help pay for the costs of the level of service assessment.**

   The Secretary of DHHS should offer the public an opportunity for public comment on the tools and the assessment process before implementing the new system statewide.

Once the screening and assessment instruments for all levels of the long-term care system are developed, individuals will progress through the system as illustrated in Chart 3.3. After information, assistance, and screening, individuals needing more extensive long-term care services will proceed to the level of service assessment.

Chart 3.3
Entry into the System of Long-Term Care:
Sequence of Assessments



Most individuals will then receive a full care planning assessment once they begin receiving long-term care services (see Chart 3.3). For example, nursing homes are required by federal law to administer the RAI-based Minimum Data Set (MDS 2.0) to develop a care plan for individuals entering a nursing home; the Division of Medical Assistance has started to use the RAI-HC for CAP/DA clients on a demonstration basis; the Division of Social Services requires county Departments of Social Services to use the RAI-HC for the State-County Special Assistance (SA) demonstration pilot. The Medical Care Commission has mandated that adult care homes begin using the RAI-based ACNC for care planning purposes beginning in 2002.

Under the current system, some individuals who are at-risk of institutionalization may not receive a full care planning assessment. These are individuals who access services through the Home and Community Care Block Grant or State In-Home Funds programs. Many of these individuals have complex medical needs or limitations with multiple activities of daily living or instrumental activities of daily living. The Task Force recognized that these individuals would benefit from the receipt of a full care planning

assessment along with care management services. Based on the Millennium data, there are 32,400 persons in North Carolina, who are: 18 years of age and older; with 3+ impairments in carrying out activities of daily living in North Carolina; with long term care needs living in the community; and with income between 100-200% of the federal poverty level. These individuals would benefit from care management to coordinate the services needed to live in the community. This service would be available to non-Medicaid eligible individuals with incomes below 200% of the federal poverty level (FPL). Individuals with incomes between 150% and 200% of FPL would be charged a co-payment of $50 per month. The cost of the program would be $3,888,000 in SFY 2002 and $7,128,000 in SFY 2003.[18] To facilitate this, the Task Force recommends:

10. **The North Carolina General Assembly should appropriate $3,888,000 in SFY 2002 and $7,128,000 in SFY 2003 to the NC Department of Health and Human Services to provide care management services to non-Medicaid eligible individuals age 18 or older with incomes below 200% of the federal poverty guidelines who are at-risk of institutionalization. Individuals who are eligible for these care management services are those who require on-going care coordination of in-home and community-based long-term care services.**

Once a person is in the long-term care system, the care planning assessment tools can be used for level of service assessment purposes if the person wants to change the level of publicly-funded services received. In other words, once in the state-subsidized long-term care system, the state can use the care planning assessment to determine eligibility for other state publicly-funded services. Therefore, a separate level of service assessment would be unnecessary if the person needed to change the type of long-term care services received.

CHAPTER 4

AVAILABILITY AND NEED FOR LONG-TERM CARE SERVICES

The NC General Assembly directed the NC Department of Health and Human Services (DHHS) to develop a system that provides a continuum of long-term care services for older adults and people with disabilities.[19] To address this requirement, the North Carolina Institute of Medicine (NC IOM) Task Force on Long-Term Care examined three issues:

(1) What core long-term care services should be available to all North Carolina citizens?

(2) How available are these core services, and does availability vary by geography?

(3) How can North Carolina project the need for long-term care services? What is the appropriate availability of services now? And in the future?

CORE LONG-TERM CARE SERVICES

North Carolina currently offers an array of services to individuals needing long-term care. They range from institutional services offered in a hospital or nursing home, to services provided to enable a person to live at home. These services include:

Institutional Care:
- State mental hospitals
- State Intermediate Care Facilities for the Mentally Retarded (ICF-MR)
- Acute care hospitals
- Rehabilitation hospitals
- Skilled nursing facilities

Residential Care:
- Adult care homes
  - assisted living facilities
  - homes for the aged
  - family care homes
  - multi-unit assisted housing with services
- Continuing care retirement communities
- Retirement villages
- Congregate housing for older adults
- Group homes for people with mental illness
- Group homes for people with developmental disabilities

Community-Based Care:
- Adult day care/day health centers
- Community mental health centers
- Senior centers
- Congregate nutrition/meals

In-Home Services:
- Home health
- In-home aides
- Home delivered meals
- Respite care
- Sitter services
- Home modifications and repairs
- Medical alert services

Other Services Necessary to Support Older Adults and People with Disabilities:
- Information and Assistance
- Medical services
- Mental health and services for people with developmental disabilities
- Dental, vision, and hearing services
- Transportation
- Legal services
- Adult protective services including Guardianship

Ideally, every individual should have a choice of long-term care services that would best meet their needs and would result in high-quality, cost-effective care provided in the least restrictive setting possible. However, the Task Force recognized that it was not realistic to expect all of these services to be readily available throughout the state. Instead, the Task Force identified the "core services" that should be available and accessible to consumers both geographically and economically. The Task Force recommends:

The Task Force identified the core long-term care services that should be available and accessible to all North Carolinians.

11. Every North Carolinian should have access, either in the county of residence or within reasonable distance from the county, to the following long-term care services:

- **Long-term care information and assistance services**
- **Transportation**
- **Housing and home repair and modification assistance**
- **Home delivered meals**
- **Durable medical equipment and supplies**
- **Medical alert or related services**
- **Nursing services**
- **Respite care, adult day care/day health, or attendant care**
- **In-home aide services**
- **Home health care**
- **Adult care homes (various types)**
- **Nursing homes**
- **Care management for high-risk or complex conditions**

In addition to the long-term care services listed above, older adults and people with disabilities need other medical, mental health, dental, vision, and hearing services to meet specific health and functional needs. Individuals who have functional, medical, or cognitive impairments may also need guardianship services or protective services to ensure that their long-term care needs are being met.

AVAILABILITY OF CAREGIVER SUPPORT

According to a study commissioned for the NC IOM Task Force on Long-Term Care by Millennium Healthcare Solutions, 57% of older adults who have problems with one to two activities of daily living (ADLs)[20], and 49% of those who have problems with three or more ADLs rely on informal (unpaid) support as their sole source of care (see Table 4.3). Another 23% and 46%, respectively, rely on both formal (paid) and informal support. The state has a critical interest in supporting family and informal caregivers so that they can continue to provide care to older adults and people with disabilities who need long-term care services.

The state provides a number of services that help provide caregiver support through Medicaid, the Home and Community Care Block Grant program (HCCBG), the Social Services Block Grant program (SSBG), and other state or local appropriations. Some of these services substitute formal state-subsidized services for services that could otherwise be provided by the caregiver; others are designed to provide temporary relief or respite services to the caregiver. Respite services are provided to caregivers through adult day care or day health

programs, institutional or group respite services (offered through adult day care/day health centers, adult care facilities, nursing homes or hospitals), or through the use of in-home aides. The Home and Community Block Grant program also gives provider agencies the flexibility to pay family members to serve as in-home aides if they give up employment or the opportunity for employment in order to care for the frail older adult. A number of local communities offer information and assistance services that help caregivers identify local resources. In addition to publicly-subsidized caregiver support services, a number of disease-specific associations offer peer counseling groups that provide information, counseling, training, and other supports to family caregivers.

Congress recently reauthorized the Older Americans Act. In this legislation is a new provision to create a Family Caregiver Support Program. The state will receive approximately $3 million in new funds to work in partnership with Area Agencies on Aging, community-service providers, and consumer organizations to:

The state has a critical interest in supporting family and informal caregivers so they can continue to provide care to older adults and people with disabilities who need long-term care services.

(1) provide information on resources that will help families in their caregiver roles;
(2) assist families in locating services from a variety of private and voluntary agencies;
(3) provide caregiver counseling, training, and peer support to help them better cope with the emotional and physical stress of dealing with the disabling effects of a family member's chronic condition;
(4) provide respite services in the home, adult day care center, or over a weekend in a nursing home or residential setting such as an assisted living facility; and
(5) provide limited supplemental services to fill a service gap that cannot be filled in any other manner.

Given the important role that caregivers play in providing services to family members with functional, mental health, cognitive, or health care needs, the Task Force recommends:

12. The Office of Long-Term Care, within the Department of Health and Human Services, should assure that all policy and program development activities consider and respect the importance of family caregiving and examine how to further strengthen the capacity of families to perform their caregiving functions.

HOUSING

One of the major barriers to successfully maintaining frail older adults in home and community settings is the lack of affordable housing, especially for North Carolina's older adults living at or below the poverty level (13.8% in 1999). Finding affordable housing is a critical need.[21] Yet, there are currently only 673 subsidized housing projects for older adults in North Carolina, offering 34,303 subsidized housing units.[22]

Most housing subsidy programs are federally supported. The state does not usually subsidize residential costs, unless those costs are included as part of the

costs of a medical institution (e.g., nursing facility, ICF-MR, state psychiatric hospital, rehabilitation or acute-care hospital). The State-County Special Assistance (SA) program is an exception. SA payments are used to support the residential costs of people who live in adult care homes. The state recently began a pilot program to use SA funds to support up to 400 people in their homes as an alternative to out-of-home placement. These funds can be used to help pay for residential costs or services, depending on the needs of the client.

The North Carolina Housing Finance Agency also offers three primary resources to assist in the production of affordable rental housing for low and moderate income households across North Carolina: federal low-income tax credits, state low-income housing tax credits, and below-market-rate loans. These rental housing production programs are awarded annually through the Multifamily Rental Development program.

While the state does not typically help subsidize the costs of housing, limited state funding is available to help with the costs of home modifications to make existing housing accessible to people with disabilities. These funds are available through the Housing Trust Fund, administered by the NC Housing Finance Agency, the Home and Community Care Block Grant program and the Division of Vocational Rehabilitation Independent Living Program.

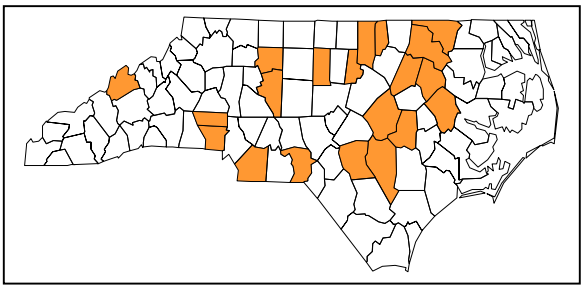
AVAILABILITY OF LONG-TERM CARE SERVICES

The availability of long-term care services varies greatly by county.

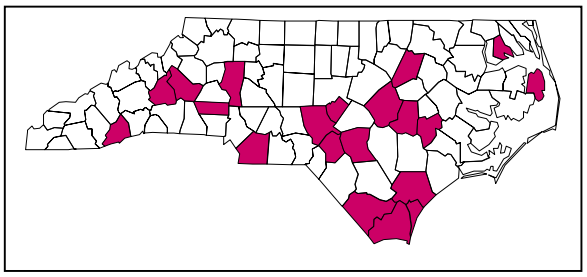
The Task Force tried to determine the availability of existing long-term care services. Limited data are available for this purpose. Specifically, the state collects data on nursing home and adult care home bed capacity, as well as expenditures and utilization of some long-term care services funded by Medicaid, the Home and Community Care Block Grant program, the Social Services Block Grant program, and programs funded through Public Health. Building on an earlier study,[23] the Task Force obtained utilization data for Medicaid personal care services (PCS), Community Alternatives Program for Disabled Adults (CAP/DA), and HCCBG and SSBG in-home aides, adult day care/adult day health and home delivered meals. While these utilization data are a useful starting point—they have serious limitations. First, the state collects little information on the use or need for long-term care services in the private market.[24] Second, while the state maintains information about the use of some publicly-funded long-term care programs, similar information on the unmet need for these same services does not exist.

The Task Force used the data the state does collect to estimate the relative availability of long-term care services.[25] (See Appendix D). The availability of long-term care services varies greatly by county. For example, the rate of licensed nursing home beds per 1,000 older adults ranged from 25.4 in Brunswick county to 89.1 in Hyde county (state average: 42.2/1,000). There was even greater variation in utilization of CAP/DA services. Utilization varied from 8.39 individuals per 1,000 Medicaid aged and disabled in Johnston county to 200 per 1,000 in Avery county (state average: 36.0/1,000). The Task Force was unable to identify any consistent pattern of service availability across multiple types of long-term care services. Generally, counties offered more of some types of services and less of others (in proportion to their population).

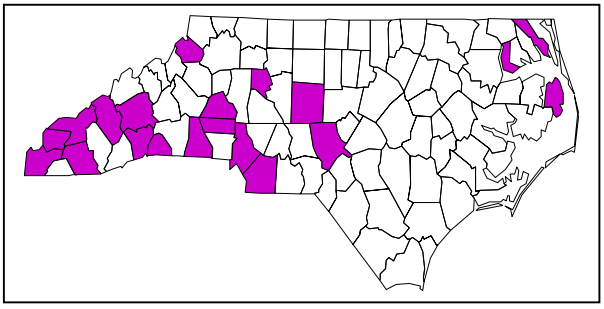
Counties with the CAP/DA ratios in the lowest twenty percent



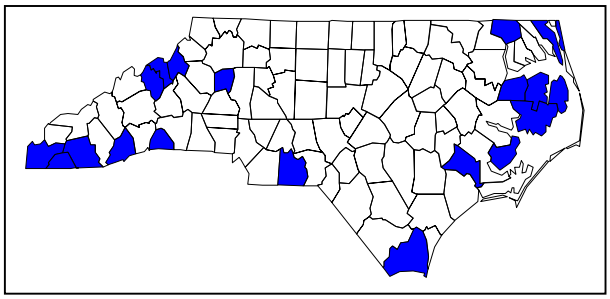
Counties with the Nursing Home Bed Supply in the lowest twenty percent



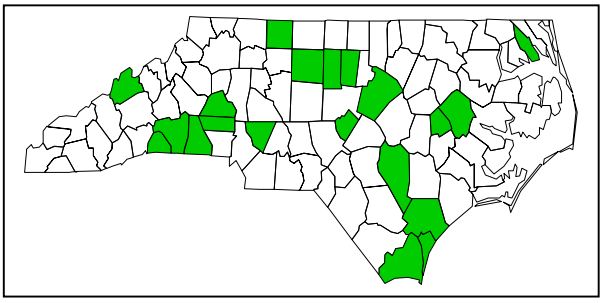
Counties with Medicaid Personal Care Services in the lowest twenty percent



Counties with the Adult Care Home Bed Supply in the lowest twenty percent



Counties with HCCBG In-Home Aide Services in lowest twenty percent



Some of the counties that were low in the provision of in-home services among some funding streams were the same counties that were higher in the provision of in-home services among other publicly-funded programs. The Task Force heard testimony that some providers were willing to participate in certain publicly-funded programs, but not in others. There were 112 agencies that provided in-home aide services through the HCCBG program in State Fiscal Year 1999 (SFY99). Sixty of these agencies were either not enrolled as Medicaid

providers, or were enrolled but did not bill Medicaid for any personal care services.[26] Medicaid establishes a fixed reimbursement rate that applies to all personal care providers, whereas each county has the flexibility of negotiating reimbursement rates for services provided through the HCCBG. The Medicaid PCS reimbursement rate was $12.32 per hour, compared to the average HCCBG rate for in-home aide services of $12.92. The adequacy of the Medicaid reimbursement rate was an issue for some, but not all providers. Half of the 60 providers that did not bill Medicaid for personal care services had average reimbursement rates that were equal to or less than the Medicaid PCS rate. In follow-up interviews with the HCCBG providers with higher reimbursement rates, the state found that many of these providers were offering their staff retirement and health insurance benefits.

There are different reasons why agencies do not participate in Medicaid, such as low reimbursement rates or a lack of capacity to accept additional clients. However, the failure of these agencies to participate in all publicly-funded programs causes problems. First, individuals who are receiving services from one provider may be forced to switch to another provider if they change their source of public subsidy (for example, when a person who was receiving HCCBG or SSBG services becomes eligible for Medicaid). This shift in providers causes a disruption in the client's continuity of care. In addition, this system is an inefficient way to provide long-term care services, as the HCCBG and SSBG have federal spending caps. In contrast, the federal government pays approximately 62% of all Medicaid service costs—the more funds the state and county put into the Medicaid program, the more federal dollars the state draws down.

The Task Force recognized that some people who are Medicaid-eligible may still legitimately use HCCBG or SSBG services. For example, Medicaid does not pay for adult day care, so if a Medicaid-eligible person wants adult day care, he or she would have to be covered through the HCCBG program. However, the Task Force wants to ensure that Medicaid-eligible individuals obtain covered Medicaid services through the Medicaid program rather than through limited HCCBG or SSBG funds wherever possible.

13. **The NC Department of Health and Human Services should explore the possibility of establishing uniform payment rates for in-home aide services across funding streams. The Department should explore the need, if any, for regional variations in reimbursement rates or shift differentials among long-term care facility or program staff.**

14. **If the state establishes more uniform rates, the Department of Health and Human Services should consider requiring all licensed providers of long-term care services that participate in state-funded programs to provide some services to Medicaid clients. The goal of this recommendation is to ensure that consumers can continue to be served by the same provider if they change their source of public financing for these services, and to maximize the use of federal Medicaid funds.**

NEED FOR LONG-TERM CARE SERVICES

While the Task Force was able to get some information about the existing array of services, it did not initially have any data to determine whether the existing array of services was adequate to meet the long-term care needs of older adults or people with disabilities today or in the future. The Task Force recommends further study to determine the appropriate array of long-term care services that should be available to all North Carolinians.

The North Carolina Institute of Medicine contracted with a private consulting firm, Millennium Healthcare Solutions of Edison, New Jersey, to obtain projections of the need for in-home, community and residential long-term care services. The full report received from the consultants is appended to this document, along with county-specific estimates of need for long-term care services. We offer only a brief summary of this report here, but direct the reader to Appendix A for further details on the estimation procedures and detailed results.

The Task Force contracted to obtain an estimate of the need for different long-term care services in North Carolina.

Demand for long-term care can be expressed in numerous ways. Different population characteristics and circumstances act in combination to affect demand for long-term care services. Measures of need for publicly-supported long-term care are typically expressed in terms of functional impairments in ADLs and Instrumental Activities of Daily Living (IADLs). ADL impairments relate to daily personal tasks such as bathing, dressing, toileting, transferring from bed to chair, personal grooming, and eating. IADL impairments relate to tasks such as preparing meals, using the telephone, managing finances, doing light housework, transportation outside the home, etc. ADL and IADL impairments are intended to capture the functional impact of disease, cognitive deficits and/or physical disabilities in everyday life. Both ADL and IADL measures help identify persons who need assistance with long-term care services, as well as gauge the severity of need and determine what type or level of service may be needed.

The methodology for the Millennium analyses draws on ADL and IADL impairment rates derived from national longitudinal surveys that are adjusted based on demographic estimates for the North Carolina population age 18 and over, on a county-by-county basis. Once the number of persons needing long-term care were estimated for each county, additional factors that may affect the nature of the demand for long-term care services were considered, such as income levels and availability of informal (unpaid) support. Lastly, a separate set of projections was prepared for North Carolinians with Mental Retardation or Developmental Disability (MR/DD) impairments.

It is important to note that findings from the National Long-Term Care Survey (NLTCS) of the National Center for Health Statistics have shown generally declining rates of both ADL/IADL impairment and institutionalization among older adults. However, there are differences in this trend between the sexes and across different levels of impairment, with prevalence and/or severity of long-term care needs appearing to be increasing among certain groups.[27]

Given their prominent role in North Carolina's current service environment for long-term care, a separate set of projections was developed for adult care homes. Adult care homes are classified as "group quarters" rather than as "institutions," and thus the estimated number of adult care home residents with long-term care needs (e.g., at least one ADL or IADL impairment) is included in the Millennium estimates in the "community dwelling" category. Persons residing in intermediate care facilities for the mentally retarded with more than 40 beds are automatically included in the "institutional" category.

Projections of demand for long-term care were first developed for the year 2000. Additional projections for the years 2005 and 2010 were then prepared, using a similar base methodology as was developed for the year 2000 projections and incorporating certain assumptions regarding trends in population growth and impairment levels in future years.

Table 4.1 presents the projected number of persons aged 18 or older needing long-term care for the years 2000, 2005, and 2010 for the State of North Carolina as a whole, by level of functional impairment and setting of care.

Table 4.1
Projected Number of Persons Aged 18 or Older
With Long-Term Care Needs

Level of Impairment and Care Setting	2000	2005	2010	*Change 000-2010*
Community-Dwelling	**308,800**	**337,500**	**366,700**	***18.8%***
(includes adult care home residents)				
IADL Impairments Only	123,600	134,400	143,500	*16%*
1-2 ADL Impairments	105,400	114,800	124,800	*18%*
3+ ADL Impairments	79,800	88,400	98,400	*23%*
Institutional Residents	**42,700**	**45,500**	**51,700**	***21.1%***
(includes all nursing facilities and intermediate care institutions with more than 40 beds)				
Total Long-Term Care	**351,600**	**383,100**	**418,400**	***19.0%***

Table 2, Appendix A

The estimates of the population 18 and over by both institutional and non-institutional (e.g., community-dwelling) settings do not imply or reflect changes in current long-term care policies. They are based on current use of institutional and non-institutional services adjusted for potential changes in functional status and other demographic trends. These projections would need to be adjusted for any policy changes that impact on utilization rates for nursing home care, residential care, and home/community-based services.

Table 4.2 presents projections of the total number of adult care home residents (including homes for the aged, family care homes, homes for the developmentally disabled, and non-institutional intermediate care facilities for the mentally retarded) for the years 2000, 2005, and 2010, regardless of level of impairment among the resident population.

Table 4.2
Projected Number of Persons Aged 18 or Older
Residing in Adult Care Homes

Adult Care Home Category	2000	2005	2010	*% Change 2000-2010*
Homes For The Aged	23,800	26,500	29,600	*+24%*
Family Care and Developmentally Disabled Homes	3,900	4,100	4,400	*+15%*
Intermediate Care Facilities For The Mentally Retarded *(less than 40 beds)*	1,900	2,000	2,100	*+11%*
Total Adult Care Home Population	**29,600**[28]	**32,700**	**36,100**	***22.0%***

Table 3, Appendix A

NOTE: Since many adult care home residents do not have IADL or ADL impairments, not all persons projected as adult care home residents in Table 4.2 are included in Table 4.1 above.

Unlike the projections developed for numbers of community-dwelling persons and institutional residents with long-term care needs, the projections for the number of adult care home residents shown in Table 4.2 do not account for declining rates of impairment among older adults. They assume the same rates of utilization of adult care homes by age-sex-race cohort for the years 2005 and 2010 as estimated for 2000. They do not account for any planned policy or regulator changes governing adult care homes, such as the current State-County Special Assistance demonstration to allow potential adult care home residents to remain at home. For these reasons, they should be considered as an estimated "upper bound" of likely demand, based on current occupancy rates and prior studies of resident characteristics.

Table 4.3 presents projections of utilization of formal and informal support among community-dwelling persons aged 65 or older, based on level of functional impairment, where "formal support" is defined as receiving "paid assistance" and "informal support" as receiving "unpaid assistance." Table 4.3 also includes projections of the number of persons aged 65 or older who have unmet ADL needs, defined as requiring human assistance to perform an ADL task, but not receiving the assistance that is required.[29]

Table 4.3
Projected Number of Community-Dwelling Persons Aged 65 or Older with Long-Term Care Needs by Source of Care

Level of Impairment and Source of Care	2000	2005	2010
Community-Dwelling, 65 or Older, 1-2 ADL Impairments			
Total *(100%)*	66,500	71,800	78,900
Formal (Paid) Support Only *(8%)*	5,500	6,000	6,600
Informal (Unpaid) Support Only *(57%)*	37,600	40,600	44,600
Both Formal And Informal *(23%)*	15,500	16,700	18,300
Neither Formal Nor Informal *(12%)*	7,900	8,500	9,400
Persons With Any Unmet ADL Needs (8.4%)	*5,600*	*6,000*	*6,600*
Community-Dwelling, 65 or Older, 3+ ADL Impairments			
Total *(100%)*	64,900	72,000	80,800
Formal (Paid) Support Only *(4%)*	2,400	2,700	3,000
Informal (Unpaid) Support Only *(49%)*	31,700	35,100	39,400
Both Formal And Informal *(46%)*	29,800	33,100	37,100
Neither Formal Nor Informal *(1%)*	1,000	1,100	1,300
Persons With Any Unmet ADL Needs (8.0%)	*5,200*	*5,800*	*6,500*

Table 5, Appendix A

Approximately 8% of older North Carolinians with functional impairments have needs for long-term care services that are going unmet.

Very few persons with MR/DD are older adults, with just 0.1% of those 70 or older classified as MR/DD.[30] Therefore, the projections in this report for the MR/DD population will focus on those under age 65. From the 1990 Survey of Income and Program Participation (SIPP), an estimated 0.7% of the working-age non-institutionalized adults have some form of MR/DD, and of these, 63.2% have long-term care needs (defined as needing assistance with at least one ADL or IADL). In addition, the overall prevalence rate of MR/DD appears to be higher among males (0.8%) than among females (0.6%), and among non-whites (1.1%) than among whites (0.6%).

Using these findings from the 1990 SIPP, the number of non-institutionalized persons in each county aged 18 to 64 with some form of MR/DD and the number with MR/DD requiring long-term care were projected for 2000, 2005, and 2010, adjusting for differences in sex/race population composition. Table 4.4 presents corresponding statewide projections of working-age adults with any MR/DD and those with MR/DD that require at least some ADL or IADL assistance.

Table 4.4
Projected Numbers of Persons Aged 18 to 64
with Mental Retardation or Developmental Disability

Measure of Impairment	2000	2005	2010
Persons Aged 18-64 with Disabling MR/DD Condition	34,300	36,600	38,600
Persons Aged 18-64 with Disabling MR/DD Needing Assistance With At Least 1 ADL or IADL	21,700	23,200	24,400

Table 6, Appendix A

As a final word of caution in reading and interpreting these data on projected need and demand for long-term care services in our state, the Task Force hastens to point out that these estimates are only as good as the demographic statistics and the set of assumptions from which these estimates were made. Some of these projections are based on national studies, which may or may not mirror the experience of North Carolinians. Other studies are old, and may not reflect recent changes in functional status or preferences in the use of long-term care services. These estimates are in constant need of revision in light of new information, as well as careful analysis of changes in the way in which long-term care services are organized and provided in North Carolina.

The Department should collect North Carolina specific data to get a better understanding of the need for long-term care services in the state.

The Task Force recognized the need to have North Carolina-specific data to drive state policies. Therefore the Task Force recommends:

15. The Office of Long-Term Care, within the Department of Health and Human Services, should collect North Carolina-specific data to determine the need for long-term care services in the state.

LOCAL PLANNING

As noted in Chapter 2, long-term care services are often fragmented, duplicative, complex, and not consumer-friendly. Further, many counties lack needed core long-term care services. Most, if not all, counties in the state have planning bodies that are charged with developing plans for specific long-term care services. Under state law, county commissioners must designate lead agencies for the Home and Community Care Block Grant (HCCBG) and the Medicaid Community Alternatives Program for Disabled Adults (CAP/DA). In all but about 20 counties, these lead agencies are separate organizations. A small number of counties have initiated a more comprehensive and inclusive planning process to identify needed long-term care resources and to reduce fragmentation.

A comprehensive planning process is needed statewide to encourage capacity building for long-term care services and the development of a consumer friendly system of care and services. Local or regional planning bodies could promote the development of a consumer-centered system of care and services with highly visible entry points, encourage the “balanced” development of core services in counties or regions, and develop the readiness to work with standardized instruments and data sharing across agencies. The NC IOM Task Force on Long-Term Care recommends:

A comprehensive local planning process is needed to identify unmet needs, encourage the development of appropriate long-term care services, and create a consumer-centered system of care and services.

16. The NC General Assembly should encourage county commissioners to designate a lead agency to organize a local long-term care planning process at the county or regional level.

The local planning initiative should broadly represent agencies involved in the provision of long-term care services, including: representatives of local social service departments, health departments, area mental health programs, aging councils and departments, HCCBG and CAP/DA lead agencies, hospitals, home health and home care agencies, nursing homes, assisted living facilities, adult day care/adult day health agencies, group homes for people with mental illness or developmental disabilities, independent living programs and facilities, area agencies on aging, long-term care ombudsman programs, community advisory committees, older adults and persons with disabilities and their caregivers, advocates for older adults and persons with disabilities, and representatives of county government. The local planning committee should be required to:

- **review and analyze service utilization data through county data packages;**
- **track the flow of consumers from referral to disposition through core service agencies;**
- **identify barriers to a comprehensive system of care and services;**
- **determine how to design the uniform portal of entry;**
- **determine the need for additional core long-term care services; and**
- **communicate findings to local, state, and federal policymakers.**

To facilitate these local-planning efforts, DHHS should:

- **develop county data packages that include information on the number of people age 18 or older using publicly-funded long-term care services at the county level, and expenditures for these services;**
- **provide information on the availability and need for core services in each county and the balance of different services needed; and**
- **provide technical assistance to counties to assist them with their long-term planning process.**

CHAPTER 5

LONG-TERM CARE WORKFORCE

North Carolina is in the midst of a long-term care workforce crisis. Efforts to design a long-term care system that ensures the availability of services and high-quality care are somewhat meaningless, absent a supply of trained professional and paraprofessional staff—including nurse aides, nurses, physicians, dentists, and allied health professionals.

NURSE AIDES

Nurse aides and other paraprofessionals provide most of the direct long-term care services to individuals, whether at home or in a residential facility. These workers help individuals with their most basic needs—including bathing, dressing, eating, and toileting. In addition, paraprofessionals often help with housekeeping tasks, and may help administer medications, change bandages, or monitor changes in a person's health status.

North Carolina is in the midst of a long-term care workforce crisis—particularly as it relates to nurse aides and other paraprofessionals.

North Carolina, like the rest of the nation, is experiencing a severe shortage of paraprofessionals trained and willing to work in the long-term care industry. Between 1990 and 1998, there were almost 180,000 North Carolinians trained to work as nursing assistants.[31] Yet, less than half of these trained personnel are currently certified to work as nurse aides. The annual turnover rate among aides who worked in nursing homes exceeded 100% in 1999. The annual turnover rate was even higher among aides who worked in adult care homes (140%). North Carolina will need more than 21,000 additional nurse aides and other paraprofessionals to meet the long-term care needs of older adults and people with disabilities over the next five years.

Nurse aides and other paraprofessionals provide most of the direct long-term care services to individuals, whether at home or in residential facilities.

There are a number of reasons for the problems in recruiting and retaining paraprofessionals: low wages, few benefits, no career path, physically demanding work, lack of opportunity for meaningful input into client care, inadequate recognition and appreciation, and inadequate exposure to "real life" job demands during training.[32] The state's low unemployment rate (3.7% in October 2000 compared to 3.9% nationally[33]) further exacerbates the current paraprofessional shortage in long-term care.

A recent study examining the job history of nurse aides who stayed in the field compared with those who left the industry showed that people who left the industry are more likely to have higher wages and to work for one employer (versus multiple part-time jobs).[34]

Table 5.1
Comparison of Nurse Aides Currently Working versus Not Working in the Long-Term Care Industry

	Currently working in the long-term care industry	Not working in the long-term care industry
Median wages from all sources	$11,358	$14,425
Wages for the highest 20% of earners from all sources	$18,369	$25,505
Average number of sources of income	1.89 employers	1.05 employers

One caveat to these data is that they include individuals who were certified as nurse aides during their training as nurses—that is, some of the people who are no longer working in the industry may be individuals who were being trained as nurses and who could command higher salaries than nurse aides. The state's database of nurse aides does not distinguish between those nurse aides who received training and intended to work as aides, versus those who were certified as nurse aides during their nursing education.

Most states around the country are struggling with the same problem. The NC Division of Facility Services (DFS) conducted a study of other state's responses to this problem in 1999.[35] The study identified a number of different policy responses to try to increase paraprofessional recruitment and retention, including:

States around the country have tried different policy approaches to increase paraprofessional recruitment and retention.

- *Wage and benefit pass throughs*: these pass-throughs require that increased reimbursement be used to enhance paraprofessional salaries. Some of the states implemented wage pass-throughs based on a set dollar amount per worker per hour or per client day; other states established a wage pass through as a percentage of the increase in the Medicaid reimbursement rate.
- *Enhancement incentives*: tying reimbursement increases to increased performance by providers and staff. For example, Rhode Island is offering enhanced reimbursement based on shift differentials, client satisfaction, level of client acuity, level of provider accreditation, continuity of care, and level of worker satisfaction.
- *Higher reimbursement for shift differentials*: some states have addressed the problems agencies and facilities experience recruiting evening and weekend staff by paying higher reimbursement rates for in-home aide services provided during non-traditional work hours.
- *Transportation reimbursement*: the state of Washington passed legislation requiring home care providers to pay aides for the time spent in their cars traveling from one location to another.
- *Career ladders*: several states passed legislation creating career ladders for nurse aides. For instance, a separate set of standards for homemaker and personal care positions was legislated in Mississippi. In Missouri, the Advanced Personal Care Unit, which allows an aide with advanced training to serve consumers who need more complex care (this is an exception to the Nurse Practice Act) has had the unintended effect of

serving as a career ladder for aides. There is also provision of more training and salary advancements for the aides, creating a step up within the home care industry. There is a higher reimbursement rate for clients served by aides with advanced training, which leads to higher aide wages.[36]

- *Training*: some states are developing additional training requirements for nurse aides; either as part of the minimum training or through continuing education requirements.
- *Training former welfare recipients*: some states are encouraging welfare recipients to enter into nurse aide training programs.
- *Training volunteer populations*: some states have explored the idea of using volunteers to provide some in-home aide services.

The Division of Facility Services updated this survey in November 2000, focusing its analysis on states that implemented wage supplements.[37] The DFS report indicated that 16 states had approved or implemented some form of wage supplement, although most states had done so too recently to assess the impact of this policy on recruitment and retention. However, Michigan, which implemented a wage pass-through provision in 1990, was able to show a drop in the overall turnover rates for aides working in nursing facilities (74.5% in 1990 to 67.45% in 1998). The “wage pass through” and market forces increased the average starting wages for lower-level long-term care employees.

The NC Division of Facility Services obtained a grant from the Kate B. Reynolds Charitable Trust to work with the UNC Institute on Aging to identify strategies to address the nurse aide workforce shortage. Part of the grant was used to study the differences in demographics, salaries, benefits, and job stability among certified nurse aides who are actively employed in health care facilities compared to those who left the field (described previously). The grant was also used to test seven new training programs developed by the NC DFS to address gaps in initial training identified by the aides and their supervisors, and to test the impact of financial and other incentives given for completion of this training on overall aide retention rates. Funds were also used to develop a mentoring program for nurse aides working in long-term care settings, and to develop public education and awareness efforts regarding the importance of the aides in the delivery of long-term care services.

The North Carolina General Assembly also appropriated $500,000 to the State Board of Community Colleges in SFY 2001 to develop innovative training programs to improve recruitment and retention of nurse aides who work in nursing facilities. The Community College System Office is directed to work with the North Carolina Health Care Facilities Association to plan and develop the components of the project. The appropriation will be used to develop at least two new training curriculums to enhance the work environment of the nursing assistant; test the effect of hiring bonuses, stipends, and length of service bonuses on retention; and create recruitment and educational tools.

OTHER HEALTH PROFESSIONALS

Registered and Licensed Practical Nurses

Registered nurses (RNs) have the day-to-day responsibility for overseeing the health care needs of nursing home residents. While supported by on-call physicians, nurses are the first point of contact when residents have a health care problem. Most RNs working in the long-term care industry are graduates of two-year associate degree programs rather than four-year baccalaureate nursing programs.[38] There were 10,568 registered nurses in 1999 that listed their primary specialty as geriatrics, or their primary practice as long-term care or home care/hospice.[39]

A study of newly registered nurses in North Carolina in 1997 showed that new RNs were given very little orientation or training once entering the long-term care industry. On average, these nurses were given only two and a half weeks of orientation in nursing homes, compared to a six-week hospital orientation in rural areas, or a nine-week hospital orientation in urban areas.[40] Further, RNs in nursing home settings were asked to take on full resident loads more quickly than nurses in other settings. Nurses in long-term care settings are also more likely to have supervisory responsibilities—supervising licensed practical nurses (LPNs) or nurse aides. This may create problems, as few nursing programs offer extensive management training.

The state is also experiencing a shortage of trained nurses, geriatricians, and other allied health professionals with specific geriatric expertise or training in long-term care issues.

The UNC Institute on Aging, along with the NC Division of Facility Services, is in the process of surveying nursing administrators of long-term care facilities and agencies. They are gathering information on salaries, benefits, turnover, and job satisfaction. The preliminary results of this survey are being reviewed.

Licensed practical nurses also play a critical role in the care for older adults and people with disabilities in long-term care settings. In nursing home settings, LPNs often have direct supervisory responsibility for nurse aides. Like RNs, LPNs have little opportunity for management training in their educational curricula. In home care settings, LPNs perform duties within their scope of practice; however, they cannot perform supervisory visits for home health aides, nor can they provide case management of clients. While they may not perform independent assessments, they do gather and document client information. In 1999, there were 5,748 LPNs in North Carolina with their primary employment in long-term care facilities; another 654 were serving in home care and hospice settings.[41]

Geriatricians and Geriatric Nurse Practitioners

There is also a dearth of physicians who have specific geriatric expertise or training in long-term care issues. In North Carolina, there are only 20 physicians who list a primary specialty in geriatrics on their medical licenses; 65 physicians list their primary practice location as a nursing home or extended care facility.[42] Approximately half of the physicians who listed their primary practice location as a nursing home or extended care facility listed their primary specialty as family practice, internal medicine, general practice, or psychiatry.[43] While this is not the universe of physicians caring for older adults or people with disabilities in long-term care settings, it does indicate a lack of specially trained physicians with expertise in meeting the needs of the frail older adults or people with physical or cognitive disabilities. All four of the medical schools in North Carolina offer

geriatric fellowships; but these programs only graduate approximately 10 to 12 fellows per year and not all of these physicians enter clinical practice in the state. This problem is not unique to North Carolina. In 1998 Medicare helped to support nearly 100,000 residency and fellowship positions, of which 324 were in geriatric medicine and geriatric psychiatry. In 1998 there were 8,000 geriatricians and geriatric psychiatrists practicing in the US.[44] The estimated population of people 65 or older in the United States in 1998 was 34.4 million.[45]

In addition to the geriatricians or physicians with specific geriatric expertise, there are 68 geriatric nurse practitioners in North Carolina. The communities with the highest concentration of specially trained physicians and nurse practitioners are those with major hospitals or medical schools. Twelve geriatricians practice in Durham, Forsyth, or Orange counties. Twenty-five geriatric nurse practitioners are located in Forsyth and Guilford counties. Eighty-nine counties are without geriatricians and 74 counties are without nurse practitioners with specific geriatric or long-term care expertise.

Physical Therapists and Physical Therapy Assistants

Physical therapists also play a critical role in addressing the long-term care needs of older adults and people with disabilities. Physical therapists are used in home care to provide services similar to those provided in out-patient settings or in the hospital. Clients of physical therapists have usually suffered paralysis, weakness, and/or decreased endurance due to an acute episode that required hospitalization, joint replacements, etc. Physical therapy services are usually of short duration, no more than 60 days and often from three to six weeks.[46] In 1998, there were 301 physical therapists employed by nursing homes in North Carolina, and another 440 employed by home health agencies.[47] In addition to the physical therapists, there were 332 physical therapy assistants who worked for nursing homes, and 323 employed by the home health industry. Physical therapists and physical therapy assistants are located throughout North Carolina; however, ten counties have no physical therapist employed in nursing homes or home health agencies; two counties have no physical therapy assistants employed in nursing homes or home health agencies; and two counties, Washington and Yancey, lack both physical therapists and physical therapy assistants in nursing home or home health settings.

Clearly more should be done to address the shortage of trained paraprofessional and professional staff to provide long-term care services. The Task Force recommends that the state implement policies that would improve the training, salaries, and benefits offered to these staff. In addition, the industry has the challenge of improving the work environment and increasing the job satisfaction of these long-term care workers. The North Carolina Legislative Study Commission on Aging has also examined this issue and developed proposed legislation which will be introduced into the 2001 General Assembly. The draft bill is included in Appendices E.

The state must act immediately to address the current workforce shortage in long-term care. One of the Task Force's top recommendations is to implement a wage enhancement to increase wages, benefits, and/or pay shift differentials for paraprofessional staff in long-term care settings.

17. **The North Carolina General Assembly should appropriate $17,227,597 in SFY 2002 and $23,460,713 in SFY 2003 for Medicaid-funded in-home and adult care home Personal Care Services (PCS), and nursing home care by increasing the PCS hourly rate and nursing home daily rate for direct care. This enhancement must be used for wages, benefits, and/or payment of shift differentials (e.g., nights/weekends). Providers should be required to submit additional cost data to ensure accountability for use of these funds as intended. The Division of Medical Assistance should institute a cost-settlement process to ensure that funds are expended on labor enhancements for direct care providers. Personal care services providers should be required to submit audited cost data (as is currently required of nursing homes and adult care homes). The Division of Medical Assistance should study the PCS rate-setting methodology to determine whether the rate should be adjusted to reflect costs unique to this care setting, such as the travel time/mileage between clients. See Appendix E, Sec. 1 for proposed legislation recommended by the Aging Study Commission.**

18. **The North Carolina General Assembly should appropriate $1,406,029 in SFY 2002 and $2,097,301 in SFY 2003 to the Division of Facility Services to develop a continuing education and professional development initiative for long-term care aides. The initiative should be modeled after the TEACH program for child care workers. Funding should be used to develop the continuing education program, and to provide bonuses, tuition, and other financial assistance and incentives to support continuing education and professional development for long-term care aides. See Appendix E, Sec. 2(a)-(c) for proposed legislation recommended by the Aging Study Commission.**

19. **The North Carolina General Assembly should appropriate $100,000 in SFY 2002 to the Division of Facility Services to develop a career ladder and associated curricula requirements and job category qualifications for long-term care aide workers. The purpose of the career ladder is to provide a career path for aide workers that recognizes the attainment of additional skills and broadens the pool of potential workers by providing additional job opportunities. The Department should work with the North Carolina Board of Nursing, the NC Center for Nursing, the North Carolina Community College System, long-term care provider organizations, and other appropriate organizations to consider the need to re-engineer current job categories of aide workers to meet the current and future needs of long-term care clients and patients. See Appendix E Sec. 2(d)-(e) for proposed legislation recommended by the Aging Study Commission**

The state and long-term care industry should take additional steps to increase training opportunities, establish career paths, and improve working conditions.

20. **The North Carolina General Assembly should appropriate $50,000 in SFY 2002 and $50,000 in SFY 2003 to the Division of Facility Services to support on-going collection and analysis of data related to North Carolina's aide workforce. The analysis should include information on demographics, turnover and retention rates, wages/benefits, and comparison of active versus inactive nurse aide registrants with regard to job stability and wages. The Division may contract with the UNC Institute on Aging to collect and analyze these data. See Appendix E, Sec. 3(a)-(b) for proposed legislation recommended by the Aging Study Commission.**

21. **The North Carolina General Assembly should establish a Legislative Study Commission to examine workforce shortages among paraprofessionals and other professionals serving the population of older adults and persons with disabilities. See Appendix E, Sec. 4, for proposed legislation recommended by the Aging Study Commission.**

22. **The NC Department of Health and Human Services Office of Long-Term Care, along with the NC Department of Insurance, should explore ways to establish a group health insurance purchasing arrangement for staff, including paraprofessionals, in residential and non-residential long-term care facilities and agencies.**

23. **The NC Healthcare Facilities Association, NC Association of Long Term Care Facilities, NC Association of Nonprofit Homes for the Aging, NC Assisted Living Association, NC Association for Home and Hospice Care, NC Family Care Facilities Association, NC Adult Day Services Association, NC Association on Aging, Mental Health Association of North Carolina, Developmental Disabilities Facilities Association, and the NC Center for Nursing should develop a plan, either together or independently, to improve the retention rates among paraprofessional and professional staff in the North Carolina long-term care industry. These plans should include mechanisms to improve job satisfaction, increase pay, develop career paths, or improve working conditions. Report(s) should be presented to the NC General Assembly no later than March 15, 2001.**

CHAPTER 6

ASSURING THE QUALITY OF LONG-TERM CARE

Since the publication of the Interim Report of the North Carolina Institute of Medicine (NC IOM) Task Force on Long-Term Care in June, 2000, a special technical work group convened by the Institute undertook to explore specific ways in which issues of quality of care in the state's long-term care arena could be addressed through a collaborative effort involving all interested stakeholders. The work group on quality of long-term care met for two, day-long meetings in the fall of 2000, in October and again in December (see Appendix F for a list of members). The deliberations of this technical work group are reflected in revisions and extensions of this chapter, based on the original work of the full Task Force.

DEFINING QUALITY OF LONG-TERM CARE

Though it is assumed that any service provided by a health care organization or professional licensed to provide that service will meet minimum standards of quality, steps to assure that this is the case are not always taken. Often complaints, or more serious legal actions, by clients of these services bring shortcomings and deficiencies of care to light. Any responsible public or private system of care must include reliable and effective procedures for monitoring and assuring that services offered meet accepted standards, that clients of these services are not put in harm's way from having used these services, and that the expected outcomes of care are realized.

The long-term care system should ensure that services offered meet accepted standards, that clients are not put in harm's way, and that the expected outcomes of care are realized.

In order for such goals to be realized in long-term care, there must first be consensus regarding the definition of quality of care, whether in residential or in home- and community-based settings. Given the diversity of facilities, programs, and services that are conventionally subsumed under the rubric of "long-term care," the definition of what is meant by "quality" is not a straightforward concept.

The North Carolina Institute of Medicine Task Force on Long-Term Care began its consideration of issues related to quality assurance with a discussion of the "hierarchy of needs" promulgated by Abraham Maslow.[48] From this conceptualization, Maslow postulated a series of five levels of need every person attempts to meet in various ways, regardless of their residential or general life situation. These are: physiological needs, security and freedom, social needs, self-esteem, and self-actualization. If these different levels of needs are applied to the field of long-term care, the following considerations may be identified:

- *Physiological needs*: nutrition, hydration, sleep, freedom from pain and discomfort.
- *Security and freedom*: freedom from hazards, outdoor access, privacy.
- *Social needs*: companionship, respect from others, affection, family relationships and social support.
- *Self-esteem*: independence, personalization, meaningful activities.
- *Self-actualization*: optimal quality of life.

Long-term care has a number of characteristics that differentiate it from other levels and types of health care services. First of all, the *goals* of care may be very different than in other types of health care services. Second, the goals of long-term care may lack *clarity* or *societal consensus* because of the conjunction of both therapeutic/clinical and social purposes of these services and programs. Many of the goals of long-term care may conflict with one another (as in the case of prolonging life *vs.* controlling pain; freedom of movement *vs.* safety). Some of the trajectories of physical or mental health among long-term care consumers may be inevitable and irreversible, therefore making conventional health outcomes largely irrelevant to the evaluation of long-term care quality. The measure of success may not necessarily include the goal of "improvement;" rather, "delaying decline" may be a significant achievement.[49]

The Task Force confronted the difficulty of addressing issues of quality in long-term care in a way that would be inclusive of the structure, process, and outcome dimensions. Following Kane, Kane, and Ladd, the Task Force concluded that quality of care, to the client of these services, "…combines a *personal* and *internal* response to the events and conditions they experience with a basic expectation that the *technical quality* meets some standard."[50] It is for this reason that Kane, Kane, and Ladd make such a strong plea for the inclusion of measures of consumer satisfaction in any effort to address quality of long-term care, although they hasten to point out that consumer satisfaction is "an insufficient test of quality," since there are some technical aspects of care consumers may be incapable to judge.

One of the most challenging aspects of quality assurance, especially in long-term care, is the necessity of making "trade-offs" among different aspects of daily living arrangements, some having positive and some negative influence on the overall quality of life.

One of the most challenging aspects of quality assurance, especially in long-term care, is the necessity of making "trade-offs" among different aspects of daily living arrangements, some having positive and some negative influence on the overall quality of life. For example, there is often a real dilemma in long-term care as decisions are made about the relative allowable freedom of movement for frail older adults who are at risk of falls. While overall quality of life may be enhanced through allowing such persons to be mobile on their own, perhaps with the aid of a walker or the use of handrails instead of using a wheelchair or other mobility assistive technology, the risk of falls may be measurably increased. There are few issues in long-term care as sensitive as the issue of use of physical or pharmacological restraints. Here the trade-offs are between the relative values of physical comfort and sedation used to protect an individual from self-induced risk or potential harm to others. Though less use of restraints may lead to greater individual autonomy in many aspects of daily living, this may also increase the possibility of falls and therefore decrease safety. Likewise, there are complex ethical and care management issues surrounding the prescription of "therapeutic diets" through home-delivered meals when patients simply refuse to eat foods they do not like.

The fact that such trade-offs are an unavoidable aspect of quality of care decision-making in long-term care is well recognized, but there are often insufficient arrangements for the inclusion of clients/residents/families in making such decisions. When shared decision making occurs, there can be a mutual understanding of the difficulty of achieving goals that may seem diametrically opposed, but also an appreciation of the unfairness of judging quality from one side or the other of such decision dilemmas.

The Task Force found the following from Kane, Kane, and Ladd a good summary of the dilemmas posed by quality improvement efforts in long-term care:

> Long-term care is a continuing, and sometimes a lifelong process, rather than a product of discrete events. It is also a pervasive phenomenon; having an impact on many areas of life… Different aspects of quality may take precedence, even in the mind of the consumer, at different times. Because of the long time horizon…(i)n the name of quality, long-term care consumers are often asked to forego present comfort or contentment in order to forestall accidents or dangers that could (lead to further disability).[51]

It is tempting to make quick and sporadic judgements of long-term care providers when one observes a choice has been made (either consciously or unintentionally) to opt for one side or another of these very complex trade-off situations. It is therefore useful to work toward the use of conceptual frameworks like the one developed by Maslow in evaluating overall strategies for the assurance of quality in long-term care. However, when one is faced with the task of measuring the on-going level of quality in a given facility or program of care, it is obviously difficult to select the most salient and valid indicators of quality of care.

ESSENTIAL STEPS TOWARD QUALITY ASSURANCE

The Task Force on Long-Term Care chose to make a distinction between two separate steps in the effort to assure quality of care in the state's long-term care arena. The first of these is quality assessment (or measurement). The second is quality assurance (or improvement). While the former gives emphasis to technical issues related to the measurement of critical dimensions of health care quality, beginning with efforts to define those dimensions to be measured, the latter involves the implementation of a system of planned measurements and follow-up correctional/care improvement strategies that are intended to ensure accepted standards of care are met on a day-to-day basis by those offering these services. Both rely on the existence of consensus with regard to the standards by which quality will be defined.

Consumers, industry providers, regulators, and payers/purchasers may all have different definitions of good quality long-term care.

Definitions of good quality long-term care may vary depending on whether quality is being defined by consumers (including residents, clients, and families), industry providers, regulators, or by payers/purchasers/insurers. The effort to agree on so-called "gold standards" of care is not an insignificant or easily attainable goal. Consumers (or their families) may wish to see evidence that day-to-day life in a residential care facility closely approximates the autonomy and range of activities that one might have enjoyed while living in more conventional home- and community-based settings. Industry providers face the difficult task of offering a similar level of nursing/medical/assistive and personal care for all residents for whom they are responsible while attempting to allow for individual differences in preferences and capacities. There will always be issues of relative deprivation, attention, acuity of needs, and preferences where multiple residents, often of different ages, genders, and levels of functional capacity and health status, coexist in the same facility. Choosing either generic categories of service or outcomes within which to measure quality of care, or specific measures to reflect these broad categories, can be difficult. Providers have to face another

major criterion in making such decisions that consumers rarely consider—the relative cost-efficiency of elements of care that might be offered to clients.

The Task Force expresses a preference for what might be called "mixed approaches" to quality assurance in long-term care. This would include consumer initiatives (e.g., the Ombudsman program), regulatory approaches, provider-initiated approaches, educational efforts, and system change approaches (e.g., those involving case management, financial incentives, etc.). Quality of long-term care is such a complex, yet critical, element of an overall system of care that it needs to be addressed on many different levels with broad participation from all stakeholders.

As it addressed these issues, the Task Force asked its members: what is missing in quality assurance efforts in our state? Among the observations advanced by Task Force members were the following:

Quality of long-term care is such a complex, yet critical, element in an overall system of care that it needs to be addressed on many different levels with broad participation from all stakeholders.

- There is insufficient dialogue among long-term care industry segments with regard to quality of care and efforts to achieve quality improvements.
- There is only minimal public understanding of quality of care issues in long-term care.
- There is a lack of consensus on the dimensions of quality that need to be addressed in any statewide quality assurance or improvement initiative.
- It is not clear that data systems exist by which to pinpoint problems related to long-term care quality needing attention.
- There is no discussion of how these issues might be addressed outside of the conventional regulatory process.
- It is unclear that these issues can be addressed effectively on a voluntary basis, and if addressed voluntarily, what sort of technical assistance will be required.

With these issues as background the Task Force undertook to formulate a reasonable approach toward quality assurance for North Carolina that would build on current efforts in both the public and private sectors, while exploring new opportunities for change.

ASSIGNING RESPONSIBILITY FOR QUALITY ASSURANCE IN LONG-TERM CARE

It is important that both quality assessment and assurance not be seen as solely the responsibility of regulators, but as useful tools of long-term care providers and as integral components of facility and program management. The criteria used for the assessment of quality of care ideally should be the same quality indicators whether being used by provider organizations or by agencies of county, state, or federal government responsible for monitoring and regulating the provision of such care to the general public.

The Task Force on Long-Term Care takes the view that both sanctions and rewards are required to assure good quality of care. Whereas agencies of government charged with regulatory responsibilities have the task of monitoring quality and imposing penalties when deficiencies are observed in order to motivate quality-oriented change, the efforts of these agencies are usually

mounted only in relation to minimal standards of care. These standards are ones for which readily available, reliable measures are obtainable by on-site inspectors in relatively short periods of observation or information collection. Regulatory agencies, like the Division of Facility Services (DFS) of the North Carolina Department of Health and Human Services (DHHS), are delegated the responsibility under federal law for collecting survey data pertinent to criteria prescribed by the Health Care Financing Administration (HCFA) from every nursing home approved for Medicare reimbursement in the state.

All facilities licensed as nursing homes are surveyed at least annually by DFS personnel unless there are extenuating circumstances that require re-surveying more frequently. [52] Periodic look-behind surveys are conducted by HCFA to determine the adequacy of DFS survey methods and assessment results. Criteria specified by HCFA for the assessment of nursing home quality of care include measures in each of the following categories: accidents, behavior/ emotional patterns, clinical management, cognitive patterns, elimination/incontinence, infection control, nutrition/eating, physical functioning, psychotropic drug use, quality of life, and skin care.[53]

The state has multiple systems to assess and monitor quality of care provided by long-term care facilities and agencies.

There are 631 adult care homes in North Carolina with seven or more beds, 801 family care homes with six or fewer beds, 217 facilities (nursing homes and hospitals) that have adult care beds, and 233 homes for adults with developmental disabilities (licensed under N.C.G.S. §131D),[54] and 1,216 facilities providing long-term care services to people with mental illness or developmental disabilities that are licensed under N.C.G.S. §122C.[55] The responsibility for monitoring the quality of care of these institutions is split between the NC Division of Facility Services and county Departments of Social Services (DSSs). The Division of Facility Services has the responsibility for monitoring group homes for people with developmental disabilities or mental illness licensed under N.C.G.S. §122C, and for inspecting the adult care home beds in nursing homes and hospitals. County DSSs have responsibility for monitoring free-standing adult care homes, family care homes, and group homes for persons with developmental disabilities that are licensed under N.C.G.S. §131D.[56] DFS specifies the criteria to monitor these facilities,[57] but the Adult Care Home Specialists within county Departments of Social Services are responsible for the routine inspections, and also investigate most specific complaints.

Some, but not all, of the information collected at the county level is reported to the state. For example, DFS collects reports that require the imposition of a fine and any inspection with DFS involvement (e.g., for facilities that have serious or repeated violations). In addition, the counties are required to forward corrective action plans to the state. However, inspection reports that do not require the imposition of a penalty or a corrective action plan are not routinely reported to the state. This makes it difficult for the state to determine (as it does for nursing homes and home health agencies) the extent to which quality varies by county or region of the state, across different types of facilities (non-profit vs. for-profit), or by corporate ownership.

The Division of Facility Services does the assessment and monitoring of quality of care in home health agencies.[58] There are 186 agencies providing federally certified home health care in North Carolina; another 899 agencies provide home care (usually personal care services) but are not federally certified. All home health services in North Carolina are monitored by DFS,[59] except in the case of complaints or issues related to adult protective services, which are

handled by county Departments of Social Services. Twenty percent of all home health agencies are surveyed by DFS personnel on an annual basis, with the total number of such programs surveyed once every five years, unless reasons for more frequent surveys occur. The Division of Facility Services receives few client/family complaints about the quality of services provided by home health agencies in our state, but quality of care concerns and conflicts between in-home consumers and providers do occur. Assuring the quality of care provided to individuals in their home is difficult, because of the numerous sites of care, the vulnerability, and isolation of the person receiving care, and the lack of knowledge about the relationship between the care provided and outcomes.[60]

Another important program addressing quality of care concerns in North Carolina long-term care facilities is the state's Ombudsman Program. North Carolina has a statewide Ombudsman Program, along with 26 regional Ombudsmen. The regional Ombudsmen work with over 1,500 community advisory member volunteers who work at the county level. The purpose of the long-term care Ombudsman program is to address complaints about long-term care facilities, to intervene where possible to work out understandings and mutually acceptable resolutions of identified problems arising between clients and staff in these facilities, and to report patterns of deficiencies to the state DFS or county Departments of Social Services where warranted. These complaints can come from anyone including families, residents, caregivers, or the general public. The regional long-term care Ombudsmen are required to participate in a certification process, which includes a four-day orientation, four internships (one each in a nursing home, adult care home, family care home, and home for adults with developmental disabilities), and review of extensive materials provided by the state and federal government. Additionally, in North Carolina there is mandatory training on a quarterly basis to ensure that the regional long-term care Ombudsmen are updated on regulations and processes. The community advisory committee volunteers are trained by the regional long-term care Ombudsmen, using a curriculum provided by the NC Division of Aging.[61]

The availability of long-term care Ombudsmen and community advisory committee volunteers with appropriate training across the state varies from county-to-county, yet the service provided by the long-term care Ombudsmen has been considered valuable by both clients and families and by providers of care.[62] Prior to entering a nursing home, DFS calls on the appropriate regional long-term care Ombudsman regarding any complaints or concerns that have been filed for that facility. The inspection system for adult care homes does not routinely utilize reports from the community advisory committee volunteers or information from the regional long-term care Ombudsman.

Past efforts at ensuring quality have been largely punitive, focusing on imposing penalties and correcting deficiencies among the few "bad" facilities, rather than trying to raise the level of quality among all facilities.

In all of these on-going governmental efforts toward the monitoring of quality of care in North Carolina's long-term care facilities and programs, there is a need to standardize the definitions of the dimensions of quality to be assessed, the measurement of each dimension, and the collection and use of reports from inspections by both state and county officials.

The Task Force recognized that past efforts at ensuring quality have been largely punitive, focusing on imposing penalties and correcting deficiencies among the few "bad" facilities; rather than trying to raise the level of quality among all facilities. More emphasis should be placed on providing incentives to all facilities to improve quality, and to remove regulatory and other barriers that impair these efforts. This effort should be a joint project among regulatory

agencies, the long-term care industry, consumers and other interested parties. In addition, as the growth of home- and community-based services and consumer-directed care is encouraged, adequate attention to defining and measuring quality for these services must be addressed. For these reasons, the Task Force recommends:

24. Quality of care initiatives should become a major responsibility of the new NC Office of Long-Term Care within the NC Department of Health and Human Services. Steps undertaken under the rubric of "quality" of long-term care should be coordinated by the Office of Long-Term Care with the direct involvement of the different Divisions involved in facility or program regulation.

Quality of care initiatives should become a major responsibility of the new North Carolina Office of Long-Term Care.

The North Carolina Office of Long-Term Care should convene a Quality Standards Work Group with representatives from provider groups (nursing homes, adult care homes, and home care agencies), consumer groups, long-term care Ombudsmen, state regulatory agencies, local Departments of Social Services, and academics. The purpose of this Quality Standards Work Group will be to:

- **(a) reach consensus around interpretations of current rules and quality measures;**
- **(b) develop broad multi-perspective definitions of quality for nursing homes, adult care homes, and/or home care and hospice agencies, including a consideration of resident case-mix in long-term care facilities;**
- **(c) facilitate separate discussions of quality of care for each of the three broad segments of the state's long-term care industry (viz., nursing homes, adult care homes and assisted living facilities, home health/home care/hospice)**
- **(d) explore what aspects of the quality assessment/monitoring process can be changed and/or modified under state authority, and make recommendations to the appropriate authority accordingly;**
- **(e) explore ways in which the standards and criteria for establishing the thresholds for key aspects of long-term care quality can be defined (e.g., for behavioral disruptions, gastric feeding, intractable incontinence);**
- **(f) explore those aspects of the quality assessment/ monitoring process that require HCFA approval, and then, possibly in conjunction with North Carolina's Congressional delegation or with other states, request a HCFA waiver to demonstrate a quality indicator approach or some such innovative approach to assuring and monitoring quality; and**
- **(g) assure that state and county regulatory agencies are enabled to incorporate measures of consumer satisfaction with care and consumer choice in the quality assessment process for long-term care programs and facilities.**

25. **Initial efforts to address quality issues in long-term care in North Carolina should include initiatives that can build upon the model quality improvement (QI) program developed by Medical Review of North Carolina (MRNC), to include provider/consumer input to problem selection, data analysis, measurements appropriate to particular dimensions of quality (indicators), intervention design, implementation and evaluation. These quality improvement efforts should assure access for participants in these initiatives to the expertise housed in the state's public and private universities and community colleges.**

THE USE OF QUALITY MEASURES IN LONG-TERM CARE MANAGEMENT AND REGULATION

The Task Force on Long-Term Care focused much of its attention on the way in which standards of quality are used in North Carolina, by county and state inspectors and by the long-term care industry itself, to monitor and encourage quality performance in these facilities and programs. In consideration of these issues, the following recommendation is offered:

26. **The Office of Long-Term Care, within the NC Department of Health and Human Services, should explore methods to improve and reward quality (and not limit their actions solely to imposing penalties for deficiencies) through such mechanisms as:**

    (a) extending the licensure period from one to two years or extending the survey period from two to six months for adult care homes with a good track record and in the absence of complaints;

    (b) increasing the reimbursement rate for long-term care providers that consistently perform over and above the minimum standard of care;

    (c) providing financial rewards for long-term care providers that demonstrate innovation in problem areas, such as maintaining low staff turnover and handling difficult behavior problems, as examples;

    (d) providing financial rewards for long-term care providers that seek and gain accreditation from nationally recognized bodies, attesting to performance above the minimum standards of care;

    (e) considering a cap on allowable indirect costs for adult care homes similar to that imposed on nursing homes, but allowing a higher capped, direct rate of reimbursement, so as to incentivize the provision of higher quality, direct care to residents of these facilities; and

    (f) consider a different approach to setting reimbursement rates for adult care homes that would replace the current "state average" method in current use so that those facilities that operate more efficiently have some incentive to do so and can then reinvest these resources in higher quality care.

The Office of Long-Term Care should explore methods to improve and reward quality, and not limit their actions solely to imposing penalties for deficiencies.

In an effort to reinforce the notion that long-term care programs and facilities in our state should be encouraged to work toward quality of care goals, the Task Force recommends the following steps be taken:

The Department should develop a Quality Improvement Consultation program to assist providers in the development of quality improvement plans for long-term care facilities and agencies.

27. The Office of Long-Term Care, within the NC Department of Health and Human Services, should lead in the development of a Quality Improvement Consultation Program to assist providers in the development of quality improvement plans for each facility and program offering long-term care services to the public in North Carolina.

HCFA restricts the extent to which DFS may offer consultation to nursing homes and home health agencies regarding quality improvement strategies using federally-funded staff during surveys and inspections; therefore, DHHS may need to operationalize the proposed Quality Improvement Consultation Program within another division of the Department or use non-federal dollars in the Division of Facility Services.

Finally, the Task Force took note of the fact that the financial penalties imposed on North Carolina long-term care programs and facilities that fail to meet established standards of care are not always used to any purpose that would further enhance the quality of care rendered to residents or clients of these programs or facilities. Under federal rules and regulations, fines levied against North Carolina nursing homes (amounting to approximately $300,000 per year) are placed in a fund administered by the Division of Facility Services for the benefit of residents of these facilities. As a result, DFS has initiated the Eden Alternatives Program, which offers small animal and horticultural therapy services in nursing homes statewide through a grant-in-aid program to which individual facilities may apply. Unfortunately, the state does not have the same authority to use the fines imposed under state law to address quality improvement initiatives. Under the North Carolina State Constitution, fines collected by state agencies are to be used to benefit the state's public schools.[63] Hence, none of these fines can be reinvested in improving the long-term care services for residents of these facilities where quality was found to be deficient.

CHAPTER 7

FINANCING LONG-TERM CARE SERVICES

The North Carolina General Assembly directed the NC Department of Health and Human Services (DHHS) to explore different ways to finance long-term care services. This chapter is divided into three sections: public expenditures for long-term care services; methods to expand public financing of long-term care services; and methods to expand private financing of long-term care expenditures.

PUBLIC EXPENDITURES FOR LONG-TERM CARE SERVICES

The exact amount of money spent in North Carolina for long-term care services is unknown. Some data are available on the amount of money spent for publicly-funded long-term care services; however, few data are available on private financing of long-term care services.

The total amount of public and private funds spent in North Carolina for long-term care services is unknown.

Long-Term Care Expenditures for Adults Age 18 or Older

North Carolina spends more than $1.7 billion dollars for individuals age 18 or older on publicly-funded long-term care services within programs operated out of the NC Department of Health and Human Services.[64] The exact amount spent is difficult to determine because some of the Divisions do not keep data on long-term care users and expenditures. Most of these services are financed through the Division of Medical Assistance (DMA), although some long-term care services are financed through the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS), Division of Social Services (DSS), Division of Aging (DOA), Division of Vocational Rehabilitation, Division of Services for the Blind, and Division of Public Health.

- *Division of Medical Assistance*. In State Fiscal Year 1999 (SFY 99), DMA spent approximately $1.7 billion on long-term care services from federal, state, and county funds for adults age 18 or older:[65]

Table 7.1
Division of Medical Assistance Long-Term Care Expenditures for SFY 99

Services	Older Adults	Persons with Disabilities	Total
Mental Hospital	$8,068,047	$27,488	$8,095,535
Skilled Nursing Facility	378,378,032	55,121,283	433,499,315
Intermediate Nursing Facility	327,321,715	30,112,197	357,433,912
ICF-MR	16,747,921	353,841,244	370,589,165
CAP/DA	115,954,074	34,638,242	150,592,316 [66]
CAP-MR/DD	3,115,567	130,539,808	133,655,375 [67]
Home Health[68]	21,029,352	68,599,600	89,628,952
Hospice	3,677,382	4,594,051	8,271,433
Personal Care	52,456,974	21,043,332	73,500,306
Adult Care Home	44,072,402	28,243,836	72,316,238
Total	$970,821,466	$726,761,081	$1,697,582,547

North Carolina is spending close to $2 billion in federal, state, and county funds for long-term care services.

Medicaid service expenditures are split between the federal government (62.5%), state (31.9%), and counties (5.6%). Medicaid is an entitlement program, so federal, state, and county governments must match any expenditures for eligible individuals.

- *Division of Mental Health, Developmental Disabilities and Substance Abuse Services*. The total funding for the DMHDDSAS system was $1.6 billion in SFY 99. This includes funds for general administration, child mental health, adult mental health, developmental disabilities, and substance abuse services at the state- and county-level. In SFY 99, $1.2 billion in state and federal funds were spent on mental health services for adults (aged 18 and older) and on developmental disability services for adults and children. It is unclear how much of these funds were spent on long-term care services versus those services that address more acute or short-term needs. It is also unclear how much of the funds were spent on services to adults versus children in North Carolina. DMHDDSAS is in the process of developing a new integrated payment and reporting system. Once developed, this system will capture and track individual specific service unit reporting and payment by type of funding source.

  DMHDDSAS receives some of its funds for long-term care services from Medicaid, for Medicaid eligible clients. To serve non-Medicaid eligible clients, the Division relies on federal block grant and other state or federal appropriations. Unlike Medicaid, these funds are limited—so that funding is not assured for all people with mental illness or developmental disabilities who are in need of long-term care services.

- *Division of Social Services*. DSS administers two programs that provide long-term care services to older adults and people with disabilities: State-County Special Assistance and the Social Services Block Grant.

  - *State-County Special Assistance (SA)*. In SFY 99, SA expenditures equaled approximately $111.8 million. Funding for SA is 50% state and 50% county. About 22,000 people received SA last year. SA is an entitlement program, so the state and county government must appropriate the necessary funds to pay for the residential care of any eligible individual.

  - *Social Services Block Grant (SSBG)*. North Carolina's share of the SSBG is $47 million. About $14 million of the SSBG funds are spent on services to older adults and persons with disabilities. Most, but not all, of this $14 million is spent on long-term care services.[69] Approximately 9,000 services, including adult day care, home delivered meals, case management, home based services, and special services for adults with disabilities, were provided to North Carolinians. Counties are required to match federal SSBG funds. For most services, the matching rate is 75% federal, 25% county; although some services, such as adult day care/day health or meals have a higher federal match rate: 87.5% federal, 12.5% county. Unlike SA, the SSBG program is a block grant, which means that services can be limited to available funding.

- *Division of Aging*. DOA administers the Home and Community Care Block Grant (HCCBG). This program includes funding from the Older Americans Act, Social Services Block Grant, state appropriations, and local match. The HCCBG program had a budget of $30,821,941 in SFY 99. Thirty-six percent of the funds are federal (Older Americans Act and SSBG), 54% state, and 10% local. The Older Americans Act only requires a 15% non-federal (state and/or county) match; but the state and counties' match rate exceeds this federal requirement. These funds are used for long-term care services including: in-home aides ($16 million), adult day care/adult day health ($2.8 million), home-delivered meals ($9 million), and care management ($0.9 million). In SFY 99, there were 10,396 people served by in-home aide services, 1,034 people served by adult day care/adult day health, 21,400 people served by meals, and 301 people who received care management services.[70]

- *Division of Vocational Rehabilitation*. The Division of Vocational Rehabilitation's Independent Living Rehabilitation program offers an array of services, including part-time, consumer-managed personal assistance services, rehabilitation engineering for the design and purchase of transportation and home modifications, medical and non-medical equipment, counseling and guidance, independent living skills training, community re-integration or recreation therapy services, and a community networking system of services to facilitate independence within and outside the home. In SFY 99, the Division spent $2.2 million for reimbursement of personal assistance services, and approximately $4.5 million on home modifications, technology, and other equipment needed to help eligible clients achieve their independent living goals. Most of the program's funding comes from state appropriations (97%); the federal government contributed approximately $364,000 of which $330,000 was used for independent living evaluations or reimbursement of personal care services. In SFY 1999, 4,421 people received equipment and supports, and 294 people received reimbursement for personal care services.[71] There continues to be a long waiting list of eligible individuals for the limited funds available.

- *Division of Services for the Blind*. The Division of Services for the Blind operates three long-term care programs for people with visual impairments. The total amount spent in these programs in SFY 99 was $1.8 million.

    - *Home management services* (Level I in-home aides). Home management services for people with visual impairments are funded through the Social Services Block Grant. The home management program is funded with 75% federal, 12.5% state, and 12.5% county funds. In SFY 1999, the Division of Services for the Blind provided home management services to 575 people;
    - *Personal care services*. An entitlement program funded through Medicaid, 48 people were served in SFY 99; and
    - *Special Assistance for the Blind (SAB)*. SAB helps low-income people with visual impairments pay for the cost of adult care homes. The costs are split 50% state, 50% county. Special Assistance for the Blind, like SA, is an entitlement program so it provides services to all in need. In SFY 99, 142 people received SAB.

- *Division of Public Health*. In SFY 99, the Division of Public Health paid $1.3 million for home health services for 2,717 adults.[72]

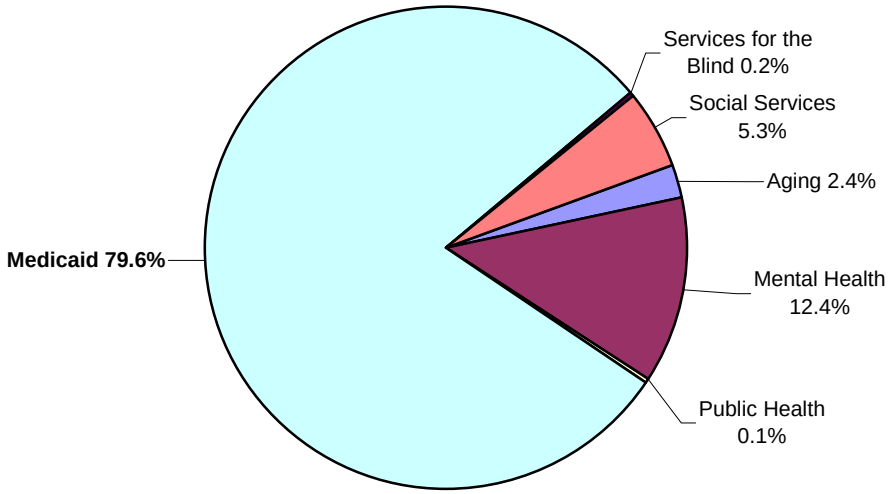
In addition to the funds spent by state and local governments on long-term care, Medicare also pays for some home health and nursing home services. There were approximately 1.1 million Medicare recipients in North Carolina in 1998.[73] Medicare pays for up to 100 days of nursing home care. If a person is homebound and needs intermittent care, Medicare will pay for home health services. Payment is made on a per episode basis. While Medicare does not explicitly limit the number of home health visits, the reimbursement level effectively limits the ability of home health agencies to provide long-term care. In addition, Medicare's coverage of nursing home and home health services is typically limited to individuals who need acute or rehabilitative care. Medicare is an entitlement program and is financed 100% by the federal government. In fiscal year 1998 (FY 98) Medicare paid approximately $329.9 million for North Carolinians on skilled nursing facility stays.[74] In FY 98 the total Medicare Home Health expenditure was $281,460,811.[75]

North Carolina spent $1.3 billion in SFY 99 on publicly-funded long-term care services for older adults.

Long-Term Care Expenditures for Older Adults

The Division of Aging is required by statute to maintain information about services provided to older adults.[76] Since 1991, the Division of Aging has produced a state/county expenditure profile of services provided to persons 60 and older. North Carolina spent $1.3 billion in SFY 99 on publicly-funded long-term care services for older adults.[77] This is an increase of 8% over SFY 98, and a 173% increase since 1990. Over this same ten-year time period the population of older adults in North Carolina increased by 19.4%.

Chart 7.1
Percentage of Long-Term Care Expenditures by Source



Medicaid finances almost four-fifths of the long-term care expenditures for older adults (see Chart 7.1 and Table 7.2).[78]

Table 7.2
Long-Term Care Expenditures for Older Adults, SFY 99

Division	Expenditure
Medicaid	$1,043,583,993
Social Services	69,216,453
Aging	30,821,941
Mental Health	162,162,742
Public Health	1,836,848
Services for the Blind	2,889,408

More than two-thirds of the long-term care expenditures for older adults are spent on institutional care (70.4%), which includes nursing homes, intermediate care facilities for the mentally retarded (ICF-MRs), mental health/substance abuse inpatient care, and mental retardation centers. Over the last nine years, some of the financing has been shifted away from institutional care, such as from nursing homes, ICF-MRs, mental health/substance abuse inpatient care, and mental retardation centers, to adult care homes and home and community care services (see Table 7.3).

More than two-thirds of long-term care expenditures for older adults are for institutional care; but in the last nine years, some of the financing has shifted from institutional care to adult care homes and home and community care.

Table 7.3
Financing Changes in Long-Term Care Expenditures 1990 - 1999

Category	1990	1999
Home and Community Care	16.0%	20.8%
Institutional Care	76.2%	70.4%
Adult Care Homes	7.7%	8.7%

Long-Term Care Expenditures for Adults with Disabilities

Similar trend data about publicly-financed long-term care services for younger adults with disabilities (18-59) are not routinely collected or reported. One of the Task Force's recommendations is to ensure that these data are collected at the state and county level and shared with the counties for local planning purposes. To facilitate local-planning efforts, the Division of Aging should develop county data packages that include information on the number of people age 18 or older using publicly-funded long-term care services at the county level, and expenditures for these services (see Recommendation 16).

The Task Force recommends expanding Medicaid coverage, since the federal government pays almost two-thirds of the long-term care costs for all Medicaid eligible individuals.

METHODS TO EXPAND PUBLIC FUNDING OF LONG-TERM CARE SERVICES

The Task Force explored different options to expand public funding of long-term care services. Medicaid appears to be one of the most viable options since the federal government will pay approximately 62.5% of long-term care costs for Medicaid-eligible individuals. Medicaid is an entitlement program unlike the HCCBG and SSBG programs. That means that the federal government will continue to pay 62.5% of all long-term care expenditures made on behalf of Medicaid-eligible individuals. In contrast, federal contributions for long-term care services covered through the HCCBG and SSBG programs are fixed. No other significant federal funding sources were identified.

In contrast, the other major public programs are block grants—that is, they have fixed federal funding. Funding for these programs can be exhausted, leaving eligible individuals without assistance with services.

In addition to drawing down federal funds, expanding Medicaid offers another advantage to counties—the Medicaid county match rate is lower than under other programs. County match rates by program are listed in Table 7.4.

Table 7.4
County Match Rates by Funding Sources, SFY 99

Funding Source	County Match Rate
Medicaid	5.6%
Mental Health and Developmental Disabilities	5.6% for Medicaid funded inpatient and outpatient hospital services and ICF-MR
	2.0% for outpatient services provided by area programs
	No set rate for non-Medicaid funded services[79]
State-County Special Assistance	50%
Social Services Block Grant	25%
Home and Community Care Block Grant	10%

Medicaid Expansion Options

There are currently inequities in Medicaid eligibility rules which make it easier for people to qualify for assistance if they enter an institution than if they remain at home. Further, not all individuals living at home are treated equitably.

The Task Force recognized that there are current inequities in Medicaid income eligibility rules (see Table 7.5). Individuals can qualify for institutional nursing home care or residential care with higher income limits than can individuals living at home. Further, not all individuals living at home are treated equitably. As a general policy, the Task Force wanted to strive towards more equitable treatment of all Medicaid eligible individuals, whether living at home or in an institution. As the state expands Medicaid eligibility, it should first move to eliminate inequities in the treatment of individuals living at home and then move to eliminate any potential institutional bias.

Table 7.5
Monthly Income Eligibility Requirements for Individuals (2000)

	Countable monthly income limits
Medicaid eligibility for nursing home[80]	$2,289 (skilled nursing) $1,608 (intermediate care)
Medicaid eligibility for ICF-MR	$5,480
State-County Special Assistance for adult care home	$1,098
Medicaid eligibility for people living in their homes[81]	$ 696
Medicaid medically needy income limits	$ 242

Increase Medicaid medically needy income limits

The Task Force discussed ways to expand Medicaid eligibility for long-term care services. Under current eligibility rules, individuals living at home with income in excess of $696 countable monthly income limit may still be able to qualify for Medicaid under the medically needy program if they have high medical expenses.

The Task Force's top financing recommendation is to increase the Medicaid medically needy income limits.

The medically needy income limits are $242/month for an individual or $317 for a couple. To qualify, a person must incur medical bills equaling or exceeding the difference between their countable income and the medically needy income limits called a "deductible" or "spend down."

Example: Older adult woman living on own with $742 in Social Security retirement benefits.

$742	-countable income (too high to meet $696 income limit for person living at home)
- 242	-current medically needy income limits
500	-consumer monthly "deductible" or "spend-down"
x 6	-six month prospective eligibility determined
$3,000	-deductible or spend-down for 6 months

The individual would have to incur medical bills equaling $3,000 before Medicaid would begin covering medical bills.

In the past, the state's medically needy income limits were linked by federal Medicaid law to the state's welfare payments under North Carolina's prior Aid to Families with Dependent Children program (AFDC). Under federal Medicaid law, the medically needy income limit could not be greater than 133% of the highest AFDC cash payment for a family of the same size with no income. However, the Health Care Financing Administration (HCFA) recently issued a new guideline that gives states the flexibility to increase the Medicaid medically needy income limits for older adults and people with disabilities.

The Task Force strongly urges that the state take advantage of this new flexibility. The Task Force's top priority to expand the availability of state-financed home- and community-based services was to increase the Medicaid medically needy income limits up to 100% of the federal poverty guidelines. Raising the medically needy income limits would increase the number of older adults and people with disabilities who are eligible for Medicaid while living at home to cover an additional 35,366 people in SFY 2002 with average home and community care costs of $316.92 per person per month.[82] Individuals could receive needed services in their home or community, rather than in a more costly institutional setting. If the state increased the medically needy income limits, individuals would have much lower deductibles or "spend-downs." In the example given above, the elderly woman with $742 would have her spend-down reduced from $3,000 over a six-month period to $276. Medicaid would begin paying for her medical and personal care services once she incurred $276 in medical bills.

Example: Older adult woman living on own with $742 in Social Security retirement benefits.

$742	- countable income
-696	- Medically needy income limits (based on 100% of the federal poverty guidelines)
$ 46	- consumer monthly "deductible" or "spend-down"
x 6	- six month prospective eligibility determined
$276	- deductible or spend-down for six months

28. The North Carolina General Assembly should appropriate $43,151,156 in SFY 2002 and $48,674,894 in SFY 2003 to the Division of Medical Assistance to increase the Medicaid medically needy income limits up to 100% of the federal poverty guidelines.

In addition, the state should expand the number of people served through the Community Alternatives Program (CAP). CAP provides services and supports to enable people who would otherwise need institutionalization to remain in their home. There are two primary programs serving older adults and people with disabilities: CAP/DA (for adults with disabilities), and CAP-MR/DD (for people with mental retardation or developmental disabilities).

Unlike the regular Medicaid program, the Community Alternatives Programs are not entitlements. That means that the state can limit the number of people served through CAP by limiting the state appropriations.[83] The Task Force recommends that the state increase the number of people served through the Community Alternatives Programs.

The state should expand the number of people served through the Community Alternatives Program. CAP provides services and supports to enable people who would otherwise need institutionalization to remain in their homes.

29. The North Carolina General Assembly should expand the number of CAP/DA and CAP-MR/DD allocations to help individuals who would otherwise need institutionalization remain in their homes or in the community. Expanding the number of CAP allocations would also assist the state in meeting *Olmstead* planning requirements.

***CAP/DA:* to increase the number of people served by CAP/DA from 12,234 in SFY 2001 to 13,750 in SFY 2002 and to 15,125 in SFY 2003:**

Projected allocations used in SFY 2000-01	**12,234**
Projected new allocations in SFY 2001-02	**1,516**
Projected new allocations in SFY 2002-03	**1,375**

	2001-02	2002-03
Total Requirements	**17,665,230**	**46,163,851**
Federal Receipts	**10,986,381**	**28,616,693**
County Receipts	**988,159**	**2,618,048**
State Appropriation	**5,690,691**	**14,929,109**

***CAP-MR/DD*: to increase the number of people served by CAP-MR/DD from 6,527 in SFY 2001 to 7,527 in SFY 2002 and to 8,527 in SFY 2003:**

Projected allocations in SFY 2000-01	**6,527**
Projected new allocations in SFY 2001-02	**1,000**
Projected new allocations in SFY 2002-03	**1,000**

	2001-02	2002-03
Total Requirements	**9,273,652**	**44,552,275**
Federal Receipts	**5,772,243**	**27,610,260**
County Receipts	**524,825**	**2,539,302**
State Appropriation	**2,976,584**	**14,402,714**

The Division of Medical Assistance should ensure the equitable distribution of any new "allocations" funded by the NC General Assembly in order to address some of the variations in the utilization of CAP allocations across the counties (See Chapter 4 and Appendix D). The Division of Medical Assistance, which has state oversight for local management of CAP/DA, will work closely with local governments and lead agencies to ensure there is the capacity to utilize additional service allocations from the NC General Assembly. In addition, DMA will work closely in this same capacity with the Division of Mental Health, Developmental Disabilities and Substance Abuse Services, the agency charged with state oversight of the management of CAP-MR/DD by area mental health programs.

Removing the institutional bias in Medicaid eligibility rules

Institutional services account for the largest share of publicly-funded expenditures. Institutional care is usually more expensive than home and community based care, which explains part of the reason why the state spends so much of its resources on institutional care. For example, the average annual cost per nursing home recipient was $21,656 in SFY 99.[84] This includes both the residential and acute care costs. In contrast, the average cost for a Community CAP/DA recipient was $19,171, including CAP services, acute care, and other home care costs. CAP/DA recipients typically receive services for longer periods of time (278 days versus 242 days for the average nursing home resident). The average daily cost for a nursing home resident is $89 compared to $69 for a CAP/DA recipient.

Another reason that public funding is weighted toward institutional care is that Medicaid and other public program rules make it easier for people to qualify for financial assistance with institutional or residential care than for services provided at home or in the community. Under existing laws, individuals can qualify for either nursing home care or State-County Special Assistance for adult care homes with higher monthly incomes than they can if they want to obtain Medicaid coverage for health services provided in their own home (see Table 7.5).

With these different income eligibility limits, individuals living at home who may have too much income to qualify for Medicaid coverage as long as they remain in their home, may qualify if they move into a more costly institutional or

residential setting. Home and community based services under the SSBG and HCCBG are available without regard to a person's income; but the availability of these services is severely limited by the lack of program funding. Rather than expand SSBG and HCCBG programs—which would be funded through 100% state and county funds—the Task Force sought ways to expand Medicaid eligibility to draw down additional federal funds.

To minimize the program bias toward institutionalization, the Task Force recommends two options:

30. North Carolina should increase the Community Alternatives Program (CAP) income eligibility limits to 300% SSI (currently $1,536/month for an individual), and allow the individual to deduct an amount equal to 100% of the federal poverty guidelines to support the community spouse. See Appendix G for proposed legislation recommended by the Aging Study Commission.

Federal law allows states to increase the Medicaid income limits for people under the Community Alternatives Programs. The maximum the state can increase the Medicaid income limits for this population is to 300% of SSI (currently $1,536 per month). Under this option, the state can determine a "reasonable amount" that the person can deduct from their income to use to maintain a home and meet the needs of a spouse. The remaining income must first be spent on long-term care services before the state will begin paying. The Task Force recommends the state use the same maintenance amount as allowed for individuals in the community (100% of the federal poverty guideline).

31. If permitted under federal law, North Carolina should increase the Medicaid income guidelines for older adults and people with disabilities up to the State-County Special Assistance income limits (currently $1,098/month for an individual).

Under current Medicaid rules, an individual living at home can qualify for Medicaid if his or her income is no greater than $696/month. However, if their income is less than $1,098/month, they can qualify for State-County Special Assistance to pay for the cost of residential care in an adult care home. Individuals who qualify for SA are automatically eligible for Medicaid to pay for their health care and personal care services. The higher Medicaid income eligibility limits for SA than for individuals living at home may force some individuals to move into adult care homes rather than stay at home and receive in-home services.[85]

Other Public Funding Options

The Task Force recognized the state's strong interest in maximizing the use of federal dollars to pay for long-term care services. Medicare, which is funded in whole by the federal government, will pay for some home health services and nursing home care for Medicare-eligible individuals. Coverage for these services may be denied if they do not meet federal requirements for coverage. However, denials of coverage can be appealed, and some states have been very effective in overturning initial Medicare denials of covered services. Before using state resources to pay for long-term care, the state should ensure that all federal funds are explored.

Another way to maximize federal revenues is to leverage federal Medicaid dollars. The state and county governments currently appropriate funds that are

not being matched by the federal government—for example, through State-County Special Assistance and in the provision of other long-term care services to non-Medicaid eligible individuals. To the extent possible, North Carolina should explore ways of using existing state and county funds to leverage federal Medicaid funds.

The Task Force recommends:

32. **North Carolina has a strong public interest in maximizing the use of federal dollars to fund long-term care services. The NC Department of Health and Human Services should ensure that Medicare pays for covered services for Medicare-eligible individuals by appealing the denials of Medicare coverage of long-term care services, including home health care. North Carolina should also maximize the use of Medicaid funds for long-term care services prior to using other more limited sources of state funds.**

The Task Force lacked the information to determine whether there were other ways to leverage existing funds to expand services and eligibles. Therefore, the Task Force recommends:

33. **The new Office of Long-Term Care, within the NC Department of Health and Human Services, should explore methods to use existing resources as the state's match in further Medicaid expansion to cover more older adults and people with disabilities, additional long-term care services, or to pay for long-term care administrative costs. As part of its analysis, the Department should:**
    - **identify possible sources of state funds (e.g., state funds not required as federal match for HCCBG, SA); and**
    - **determine whether the Medicaid expansion would cover the same eligibles and services as covered by the other programs.**

In addition to the expansion of Medicaid and the exploration of ways to leverage federal monies, the Task Force identified a need to expand state funding of home- and community-based services for those individuals who are not Medicaid eligible. Expansion of the Medicaid medically needy income limits will release some resources to use for the non-Medicaid eligibles. However, additional resources are still needed. The Task Force recommends:

The Task Force also recognized the need to expand state funding of home and community-based services for those individuals who are not Medicaid eligible.

34. **The North Carolina General Assembly should appropriate $10,399,955 in both years of the biennium to the Division of Aging to expand the availability of home and community services for non-Medicaid eligible older adults. In December 2000, there were 8,126 identified service needs on the waiting list for services funded through the HCCBG. This includes people waiting for in-home aide services (3,729), and home delivered meals (2,920). The new appropriation would be used to meet the needs for additional in-home services, home delivered meals, and increased transportation services.**

35. **The North Carolina General Assembly should appropriate $2.5 million in SFY 2002 and $5 million in SFY 2003 to the Division of Social Services to expand the availability of home and community services for non-Medicaid eligible persons with disabilities between 18-59. These new funds would provide services to an additional 3,322 adults with disabilities in SFY 2002, and 6,644 in SFY 2003 through the State In-Home Funds program.**

36. **The North Carolina General Assembly should appropriate $3,427,622 in both years of the biennium to the Division of Aging to expand the state Adult Day Services Fund to increase the availability of respite services for family caregivers. The new appropriations would cover an expansion of both the daily rate to cover the cost of daily care and transportation as well as a 45% increase in the number of people served (up to 1,923 people).**

PRIVATE FINANCING OF LONG-TERM CARE SERVICES

The NC General Assembly also directed the Department of Health and Human Services to examine ways to expand private financing of long-term care services. Specifically, the Department was directed to examine:

- reverse mortgages;
- private long-term care insurance;
- tax credits or employment programs such as medical service accounts and deferred compensation plans; and
- changes in Medicaid eligibility and asset protection requirements that increase consumers financial responsibility for long-term care.

In addition, the Task Force examined the idea of charging mandatory sliding scale fees for long-term care services provided through the SSBG or HCCBG programs.[86]

Reverse Mortgages

The Task Force explored the concept of using reverse mortgages to finance long-term care services. A reverse mortgage is a type of loan that is secured by a person's house.[87] Proceeds of the loan may be paid in a number of different ways, including tenure payments, term payments, line of credit (may be a one time lump sum), or a combination of tenure or term, with a line of credit. At the end of the loan period, the loan is paid with proceeds from the sale of the borrower's house. Generally, the loan is not paid back until the person dies, sells the house, or moves.

To be eligible for a reverse mortgage, the borrower must be at least 62 years old; live in the home as their permanent residence; and own the home outright or be able to pay the balance of the mortgage with the proceeds of the reverse mortgage. Before a borrower can obtain a reverse mortgage loan, they must receive face-to-face counseling by a certified reverse mortgage counselor in a U.S. Housing and Urban Development approved non-profit counseling agency.[88] Counselors provide information about reverse mortgages, as well as other options that may be available to assist the borrower (including property tax exemptions, Medicaid, and home repair programs).

The typical borrower is an older person who gets a reverse mortgage to prevent foreclosure by paying outstanding mortgage payments, taxes, insurance, or other creditors, or to make home repairs. Many borrowers use the money to pay outstanding health bills—for example, to buy prescription drugs or pay the balance of medical expenses. Some also use proceeds of the money to pay for services that would not be covered under a long-term care insurance policy, such as shopping, chore services, or yard maintenance.

While reverse mortgages are available throughout the state, few borrowers choose this option. Centura Bank provides most of the reverse mortgages in North Carolina. Centura Bank closed 123 reverse mortgage loans in 1999 and 144 loans in 1998. Reverse mortgages have fluctuating interest rates, and are very expensive loans. Typically, borrowers do not have money to pay origination fees, closing costs, and/or appraisal fees, so these costs get folded into the cost of the loan. If the borrower's house is in disrepair, this will lower the value of the loan. Further, the amount of the loan relative to the property value is less for younger borrowers, since the bank will have to wait longer, actuarially, to have the loan paid back.

Under specific circumstances, reverse mortgages could be used to finance long-term care services. However, it is not a viable method of financing long-term care services or insurance for most people. For many, the amount of the monthly payment is relatively small so the payments would not be sufficient to pay for extensive in-home long-term care services. The option to take the payment in a one time lump sum may be sufficient for financing long-term care services in the short-run but not over a longer period of time. Also, many borrowers are required to use part of proceeds to pay off the existing mortgage, pay for repairs, or pay off other debts before they can use income for other services. For some, a better option may be to move out of a larger house and into smaller house, and use the proceeds of the sale to help pay for supportive services.

Given these caveats, the Task Force recommends:

37. The Task Force does not recommend that the General Assembly rely on reverse mortgages as a means of financing long-term care services.

Reverse mortgages are appropriate for a small segment of the older population to pay for some in-home services. However, reverse mortgages are not appropriate or available for most older adults as a means of paying for long-term care services. Additionally, reverse mortgages are generally not useful as a source of payment to purchase private long-term care insurance. By the time a person is eligible for a reverse mortgage (62 or older), the cost of private long-term care insurance may be prohibitive. One of the primary goals of private long-term care insurance is to protect personal assets. Reverse mortgages may be counterproductive in that instance, as the older adult would need to mortgage their primary asset in order to obtain long-term care insurance.

Private Long-Term Care Insurance

Private long-term care insurance can help pay for the costs of long-term care.[89] Most long-term care policies provide coverage for home health, adult day care, and assisted living facilities in addition to nursing home care. Some policies also provide coverage of alternative benefits—for example, if the insurer can maintain a person in the home cheaper than by putting him or her in an institution, then they will pay to keep the person in the home if the provider,

insurer, and insured agree. The primary reason to buy long-term care insurance is to preserve assets. However, long-term care policies offer another important benefit—people with private long-term care policies will have more choice of providers than do people who rely on Medicaid or other public sources to pay for services.

There are currently about 67 companies selling long-term care insurance in North Carolina. North Carolina's penetration rate based on covered lives is 1% of adults age 35 and older.[90] The state ranks 21st in terms of long-term care insurance policies sold. Information from the National Association of Insurance Commissioners show that there were 41,469 individuals covered by private long-term care insurance in North Carolina in 1998.[91] Insurers incurred $57,081,808 in long-term care claims and earned $200,487,055.

Long-term care insurance typically pays a certain amount per day. The standard daily benefit is $100/day. Long-term care products have different elimination periods (like deductibles). For example, if a policy has a 60-day elimination period, the insured must pay for the first 60-days of long-term care services before the policy begins paying. Companies also offer different inflation protection options, which increase the dollar amount of coverage to keep pace with inflation. People can purchase inflation options that will increase on a simple or compound basis over five year intervals. Inflation policies are particularly important for young purchasers (including those who are 60 or 70 years old). Policies also have non-forfeiture benefits. Individuals who cannot afford to pay premiums (after paying for a certain length of time) can stop paying premiums and maintain some coverage (or can get some reimbursement if the policy is dropped). Another common protection is a waiver of premium feature. An insured may stop paying premiums after he or she becomes eligible for long-term care services.

North Carolina offers a tax credit of 15% of the premium cost, up to $350/year, for people who purchase long-term care policies.

Long-term care policies are deductible from federal income taxes if the policy is federally qualified and the premiums and other unreimbursed medical expenses exceed 7.5% of the adjusted gross income. To be federally qualified, the policy must provide coverage if the insured needs assistance with two of the five activities of daily living.[92] In addition, North Carolina offers a tax credit of 15% of the premium cost up to $350/year to people who purchase long-term care insurance for themselves, spouses, or dependents. Both of these provisions make the purchase of private long-term care insurance products more attractive.

Because of the multiplicity of products, it is difficult for consumers to go into the market to find the product that is best for them. The NC Department of Insurance offers independent counseling about long-term care policies through the Seniors Health Insurance Information Program (SHIIP). While SHIIP was originally set up to help seniors understand private Medicare supplemental policies, it has been expanded to provide information to individuals of all ages about private long-term care policies.

Long-term care insurance is not always easy to get. Companies are very selective in who they will cover. Insurers typically examine a person's health status (medical underwriting) before offering coverage to individual non-group purchasers. Insurers generally do not require medical underwriting if offered through a group plan (if the person purchases the policy during the group's open enrollment period). If a person tries to purchase the group long-term care policy outside of the open enrollment period, then they may be subject to medical underwriting.

The cost of long-term care policies varies with the age of the purchaser and the benefits package chosen.[93] Policies are much more expensive for older purchasers than for younger purchasers. For example, the cost of a policy with a 60-day elimination period and daily benefit of $100 for nursing homes, assisted living facilities, or home care, with different benefit options, is listed in Table 7.6.

Table 7.6
Average Annual Long-Term Care Insurance Premiums in North Carolina (1999)[94]

Benefit Plan	50	60	70	80
Lifetime coverage*	$1,680	$2,203	$4,306	$9,205
6 year coverage*	1,226	1,670	3,378	7,345
4 year coverage**	420	743	1,891	4,990

*5% compound inflation adjustment annually
**No inflation adjustment

The Task Force recognized that private long-term care insurance is not a significant financing source for long-term care services in the immediate future, nor is private long-term care insurance a panacea for everyone. If a person already has health problems that are likely to mean they will need long-term care, they may not be able to buy a policy. Also, long-term care policies are expensive, especially for people who are already older adults. Many older adults and people with disabilities cannot afford to purchase Medicare supplemental policies or prescription drugs, much less be able to afford private long-term care insurance. For these reasons, private long-term care insurance will never be a viable option for certain segments of the population.

The Task Force supports efforts to expand the purchase of private long-term care insurance, especially among younger "baby boomers."

While private long-term care insurance is not viable for everyone, and may not be a significant source of financing of long-term care services in the immediate future, it may be a more viable financing source over the longer-term. Therefore, the Task Force recommends:

38. The North Carolina General Assembly should appropriate $268,000 in each year of the biennium to the NC Department of Insurance for private long-term care insurance outreach efforts. The NC Department of Insurance in conjunction with the NC Division of Aging; NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services; and other appropriate groups should develop an outreach strategy to inform the public about long-term care funding or payment options. The outreach effort should include information on what Medicare covers, what Medicaid covers, what individuals must pay on their own, and what private long-term care insurance can cover. Public education efforts should target employers, "baby-boomers," financial advisors, CPAs, banks, and the legal community. The state should develop multiple outreach strategies including community education, the Internet, and mass media. Further information on the long-term care options could be incorporated into the curricula of courses offered in the community college system on estate and financial planning. Also the outreach should include information about the impartial counseling services offered by the NC Department of Insurance's SHIIP program. See Appendix H for proposed legislation recommended by the Aging Study Commission.

Tax Credits or Employment Programs such as Medical Savings Accounts and Deferred Compensation Plans

The Task Force explored the possibility of using Medical Savings Accounts (MSAs) to finance long-term care services or insurance premiums. Federal law currently allows two groups of people to establish Medical Savings Accounts: individuals who work for small employers (under 50 employees) and Medicare recipients. Medical Savings Accounts are high deductible health insurance policies combined with pre-tax medical IRAs. Funds can be withdrawn from the medical IRA to pay for health care costs to meet the deductible. In addition, the medical IRA funds can be used to pay for long-term care costs or insurance premiums.

Many people argue about the merits of MSAs as a mechanism to pay for health care costs or long-term care. Concerns have been expressed about whether MSAs will attract the healthy and wealthy, leaving those who are sicker in the traditional health insurance pool. Regardless of the merits of MSAs as a means of providing health insurance or paying for the costs of long-term care, these policies are not currently a viable option of paying for long-term care costs. There are few, if any, insurers selling MSAs to the small group market in North Carolina.[95] The federal law that established the MSA demonstration project for small employers will expire in 2001, absent reauthorization. In addition, nationally there are no insurers selling MSAs to the Medicare population.

For these reasons, the Task Force recommends:

39. The Task Force does not recommend that the General Assembly rely on Medical Savings Accounts as a means of financing long-term care services.

The Task Force also examined the possibility of using other methods to encourage people to purchase long-term care insurance. State law already gives individuals a 15% tax credit up to $350/year for the purchase of long-term care insurance. Federal law allows a tax deduction if medical expenses (including long-term expenses) exceed 7.5% of income. However, there are currently bills in Congress that would provide additional financial incentives to encourage people to purchase private long-term care insurance policies.[96] These bills generally fall into four areas:

- federal tax deduction for long-term care insurance (not tied to medical expenses);
- group coverage option for federal employees and certain family members;
- use of funds in flexible spending accounts; or
- allow long-term care insurance coverage in cafeteria plans.

The Task Force was supportive of enacting further financial incentives to encourage more people to purchase private long-term care insurance. Additionally, the Task Force recommends that Congress give states additional flexibility to implement Medicaid long-term care partnership plans. Partnership plans were created to encourage people to purchase private long-term care insurance. If a person purchases a private long-term care insurance policy that meets certain coverage criteria and meets other requirements, then they can later qualify for Medicaid if their private coverage is exhausted. Individuals are still expected to contribute their income toward the cost of Medicaid covered

long-term care services, but could retain some or all of their assets. Federal laws limit these partnership programs to four states: California, Connecticut, Indiana, and New York. Task Force members thought this was another viable way to encourage individuals to purchase long-term care insurance policies. Therefore, the Task Force recommends:

40. The General Assembly should pass a resolution to encourage the NC Congressional delegation to support federal incentives to purchase private long-term care insurance, such as federal tax credits or deductions, flexible savings accounts or cafeteria plans; and to eliminate federal barriers to expansion of Medicaid long-term care partnership plans.

Changes in Medicaid Eligibility to Increase Personal Responsibility for the Payment of Long-Term Care Services

There are two federal Medicaid laws that try to increase personal responsibility for the payment of long-term care services: (1) transfer of assets disqualification periods, and (2) estate recovery rules. Federal laws establish requirements that states must implement, and gives states the flexibility of imposing more stringent requirements. North Carolina has implemented these basic federal requirements, but has not taken the option to implement more stringent laws.

Transfer of assets penalties

Under federal law, nursing home residents or individuals receiving Community Alternatives Program (CAP) services may be subject to a Medicaid disqualification period if they give away or dispose of certain countable assets without receiving fair market value in return.[97] The transfer of assets provision applies if an applicant, an applicant's spouse, or legal representative transfers or gives away assets, or if these individuals eliminate or reduce ownership interest in the assets. Individuals are subject to disqualification periods if they transfer assets within 36 months of applying for Medicaid (or 60 months if the transfer was into a trust).

The disqualification period is determined based on the amount of the uncompensated value divided by the average nursing home costs ($3,000).

> *Example:* In November 1999, a person transferred $10,000 in stock to an adult child. In March 2000, the person enters the nursing facility and applies for Medicaid. There is a three-month period of ineligibility ($10,000/$3,000 = three months). The disqualification period begins in the month of transfer—so in this instance, the penalty would begin in November and last through January. The person would be eligible for Medicaid when they applied in March. The "sanction" period ended before Medicaid was needed.

Under federal law, individuals can transfer certain assets without being subject to a disqualification period. For example, an individual can transfer his or her home to a spouse or, under certain circumstances, a child. Individuals are also allowed to create trusts for "sole benefit" of spouse or child with a disability. Federal law only allows states to apply transfer of assets provisions to individuals who are institutionalized or using long-term care services. States may not impose transfer of assets penalties to individuals living at home who transfer assets to qualify for Medicaid for non-long term care services.

The state also allows transfer of other assets without applying the transfer of assets penalty. Individuals can transfer any asset that would not be counted in determining Medicaid eligibility if the person still retained the asset. One of these allowed transfers revolves around home sites. An individual can convert a former home site into "income producing" property. The value of income producing property is not counted in determining Medicaid resource eligibility (although the income is counted in the calculations of income eligibility). Because the property is exempt from consideration in determining Medicaid eligibility, it can be transferred with no penalty.

Individuals can also transfer property owned by many people (tenancy-in-common). Individuals can "convert" fee-simple ownership to tenancy in common by transferring a small percentage of ownership to another person. This transfer of ownership may create a small disqualification period. However, the individual is then free to transfer the remaining property without being subject to a transfer of assets disqualification penalty because the value of tenancy-in-common property is not counted in determining Medicaid eligibility.

The Division of Medical Assistance also exempts the value of household goods and personal property. Thus, a person is free to transfer these assets without being subject to a disqualification period.

Task Force members considered different ways to tighten these provisions. For example, the Task Force considered whether to apply a penalty for transfers of:

- *Income producing property*. Federal law permits the state to impose a penalty if the equity value in the property is greater than $6,000 and the property is transferred. If the person retains the home site and it produces income, there would not be a penalty.
- *Tenancy by the entirety property*. North Carolina could impose a penalty on the remaining share "owned" by the recipient if part of the fee-simple property was transferred.
- *Household goods and personal effects*. North Carolina could count any transfer of property if the value exceeds $2,000.

The state conducted a study to determine the prevalence of transfer of assets to qualify for Medicaid.[98] In a 1996 study of 194 nursing home residents, DMA found that 35% of nursing home residents had given away assets prior to applying for Medicaid. Transfers usually involved the person's home site. Of those who gave away property, 44% waited to apply for Medicaid until the penalty period had expired, and 55% applied within 36 months after the transfer. Less than 7% of individuals were subject to a disqualification period.

Estate recovery

Under the federal Medicaid statute, states must attempt to recover some of the Medicaid costs for individuals who are in a nursing home, ICF-MR, or from those who receive CAP services.[99] The estate recovery rules apply differently, depending on the person's age and the services that were covered by Medicaid:

- *Individuals who are under age 55*: The state must attempt to recover the costs of institutionalization (nursing home or ICF-MR) and CAP services to individuals who enter long-term care facilities—if the individuals are expected to permanently reside in the facilities. Individuals who have short-stays in long-term care facilities (e.g. for rehabilitative purposes) are not subject to estate recovery.
- *Individuals who are 55 or older*: The state must attempt to recover the costs of institutionalization, CAP services, prescription drugs, and inpatient hospitalization for any individual who enters a long-term care institution (whether for a short rehabilitative stay or a long-term-stay).

Medicaid is currently seventh in the state's priority list of claims in the estate settlement process. Recovery can be waived in certain circumstances:

- real property in the estate if it is the residence of spouse or child under certain conditions;
- Medicaid paid less that $3,000 in claims;
- the estate is valued at less than $5,000;
- there is surviving spouse or dependent; or
- undue hardship.

North Carolina has a number of different options to expand estate recovery:

- The state can change state laws to give Medicaid a higher priority in the estate settlement process.
- The state could expand the types of services that are subject to estate recovery. For example, the state can attempt to collect all of the costs of medical and long-term care services provided to individuals who receive long-term care services (regardless of the age of the individual).
- The state could require that a lien be imposed on the property of the surviving spouse or dependent, to ensure recovery at their death or when the property is sold.

North Carolina does not collect significant funds through the estate recovery process. In SFY 99, North Carolina collected $1.2 million. In SFY 2000, the state expected to collect $1.4 million. These are gross receipts and do not include the costs incurred in collecting funds from decedents' estates. The funds collected through estate recovery are split between the federal, state, and county government—which means that the state effectively recoups little from current estate recovery efforts.

In general, the Task Force did not support further restrictions in Medicaid through tightening transfer of assets provisions or estate recovery. Fear of estate recovery is already a barrier for some older adults who are afraid to apply for Medicaid, CAP, or other long-term care services. Further, people who have a lot of assets can afford to buy legal advice about how to shelter the assets. The only people who are likely to be "caught" in the transfer of assets provisions are those with fewer resources. Therefore, the Task Force recommends:

41. The Task Force does not support further restrictions in Medicaid through tightening transfer of assets provisions or estate recovery.

Sliding Scale Fees for Long-Term Care Services

In general, the Task Force supports the concept that individuals should be required to contribute to the cost of long-term care services when they can afford to do so. In the past, there were legal barriers that prevented the state from mandating that individuals contribute toward their long-term care services. First, the past Older Americans Act prohibited states from mandating that older adults (60 or older) contribute to the cost of their long-term care services. The Division of Social Services used to require fees for younger individuals needing in-home aide services under the Social Services Block Grant. However, the state changed this provision after a complaint was filed with the US Department of Justice over the discriminatory treatment of younger individuals with disabilities versus older adults needing similar long-term care services. The state changed its regulations to remove all mandatory fees for long-term care services, replacing them with a voluntary fee schedule.[100]

The newly authorized Older Americans Act gave the states more flexibility to impose some cost sharing, therefore the Task Force recommends:

42. The Office of Long-Term Care, within the NC Department of Health and Human Services, should explore the possibility of establishing a sliding scale fee based on an individual's ability to pay. This sliding scale fee should be imposed on long-term care services provided under the HCCBG and SSBG programs. If a sliding scale fee is imposed, the Department should establish a mechanism to waive the fees for people who are unable to pay.

The Office of Long-Term Care should explore ways to invest in family caregiving so that it can be sustained as a primary resource for long-term care, reducing the need for formal, publicly-financed services.

Support of Family Caregiving

Because the contributions of family caregiving are so essential to the viability of North Carolina's long-term care system, the state and nation must look seriously at how to further support this informal service network. Some options include additional income tax relief for long-term care responsibilities and expenses, reform of Social Security to credit family caregiving, incentives for businesses to offer elder care, subsidized elderly care for low-income persons going from welfare to work, and direct cash payments or vouchers for use by family caregivers instead of receiving formal services. Some of these supports are state options; while others require policy changes at the federal level. Because of the complexity of this issue, the Task Force recommends:

43. The Office of Long-Term Care, within the NC Department of Health and Human services, explore ways to invest in family caregiving so that it can be sustained as a primary resource for long-term care, reducing the risk for needing formal, publicly-financed services.

CHAPTER 8

LOCAL INITIATIVES AND DEMONSTRATIONS

LOCAL INNOVATION

Local communities and regional coalitions have been leaders in the effort to reform the long-term care delivery system. Throughout its study of these issues, the Task Force learned about the efforts of many local communities to improve long-term care systems across the state. In fact, many of the Task Force recommendations derive from the experiences of local communities.

Local communities and regional coalitions have been the leaders in the effort to reform the long-term care delivery system.

Many local initiatives address the same or similar system problems—such as confusing and fragmented consumer access to information and assistance; obsolete, incomplete, and difficult to use resource information; and multiple and duplicative assessment forms and procedures. While the state has supported pilot projects through public and private resources to advance and test concepts and approaches, some local communities have taken their own initiatives to build on lessons learned and to tackle issues that the state has not yet resolved. Consequently, local communities have developed their own unique programs and systems. Some of the initiatives begun by local communities are listed and described in Appendix I. The list and descriptions do not include all the initiatives in long-term care started by local communities. They are intended to provide *examples* of the many innovations that have been and continue to be implemented locally.

Local initiatives in long-term care were implemented with full knowledge of the risk of doing so. Once state government decides what direction it is going to take, some local communities may discover their initiatives to be in conformity with new state policies and guidelines. Other local communities, however, may not be so fortunate; they may have to make additional investments to bring their programs in line with new state requirements. For example, many counties developed electronic resource databases and screening tools; various software programs were used to support these electronic applications—e.g., IRis, Elder Care, and Duke's SOS. Depending on which software program the state adopts for a statewide electronic resource database and screening tool, some counties will be well positioned and others will have to change.

Despite the risk, counties have taken their own initiatives because they could no longer wait to address system problems, improve services, and meet consumer demand. At the same time they are eager for the state to provide decisive leadership and coordination so that future changes made locally will be in conformity with state policy. However, during the transition period, counties will need support to convert their existing systems and programs. The Task Force recommends:

44. Special funds should be earmarked for one-time county "transition support" to enable counties to implement the recommendations of the Task Force on Long-Term Care and to make needed system improvements to conform to policies and procedures implemented by the new DHHS Office of Long-Term Care.

While some counties were able to move forward and implement needed improvements, others were limited to involving themselves in regional planning discussions. These latter counties sometimes lacked the resources to implement agreed upon system changes. For example, in the eastern part of the state, 23 counties have participated with the Mid-East Commission Area Agency on Aging to plan for coordinated services, but Pitt county is the only one that has been able to implement changes. The same is true in the western part of the state where 26 counties have plans to eventually participate in an electronic information and assistance network. Currently only Buncombe county has been able to implement the electronic network; twelve other counties expect to have their operational networks in early 2001. These counties have the will to make changes, but lack sufficient resources to invest in an electronic infrastructure, technical assistance, and staff training. The Task Force recommends:

The state should provide counties with transition support as well as capacity-building funds to help make the changes necessary to bring their programs in line with new state requirements.

45. Special one-time "capacity-building" funds should be made available to small, rural counties to enable them to develop the infrastructure and capacity to implement statewide system changes.

While county and regional planners, providers, and consumers across the state were involved in planning different innovations and improvements, they learned from the each other's experiences. However, no one in the state has the responsibility to gather, analyze, and disseminate information on local initiatives. Therefore, the Task Force recommends:

46. The Office of Long-Term Care should establish a clearinghouse to:

- **Gather information on the success and failure of long-term care initiatives, demonstrations, and system improvements in North Carolina and other states;**
- **Distribute such information to all local areas in North Carolina;**
- **Provide technical assistance for implementation of system improvements to counties that are not well-resourced; and**
- **Provide a neutral forum for state and local leaders to come together to discuss continuous system improvement.**

STATEWIDE DEMONSTRATIONS

In order to implement some of the Task Force recommendations and newly adopted state policies, demonstration projects may be needed. Further, future system improvements and innovations may best be evaluated by using a demonstration project methodology (see description of current state demonstration projects in Appendix I). In its deliberations over the last year, the Task Force identified a number of issues or problems worthy of special demonstration or pilot project effort. These include designing a uniform portal of entry, county comprehensive planning efforts, care management initiatives for non-Medicaid eligibles, and implementing the Resident Assessment Instrument (RAI)-based level of service and care planning assessment tools. The Task Force adopted the following recommendations to ensure that demonstration project involvement is available to all counties and that the state takes a decisive leadership role in setting policy and parameters necessary for statewide coordination. The Task Force recommends:

47. **Participation in any state-supported demonstration should be open to all counties and/or regions via a competitive RFP (Request for Proposal) process.**

    In any state-supported demonstration, the state should set parameters required of all participants in the demonstration; however, local communities should be allowed to meet specified parameters in a variety of ways that reflect differences in local agency structure, patterns of interaction, service, and governance.

    In addition to demonstration project-specific guidelines and/or parameters, any state-supported demonstration should include the following features:

    - **a clearly identified locus of county or regional leadership;**
    - **minimal local level infrastructure; and**
    - **local and/or regional potential for sustainability after the demonstration support.**

    All state-supported demonstrations should be evaluated by an independent outside source, and should include outcome-focused evaluation measures.

CHAPTER 9

NEXT STEPS TOWARD THE IMPROVEMENT OF LONG-TERM CARE FOR NORTH CAROLINIANS

TOP PRIORITIES FOR POLICY AND PROGRAM DEVELOPMENT

Long-term care involves an important and complicated set of issues critical to the overall health of North Carolina's population. The North Carolina Institute of Medicine's Task Force on Long-Term Care has sought to understand and to communicate, through the chapters of this report, its analysis of the current and likely future issues facing our state with regard to this vital aspect of health and human services needed by our older adults and persons with disabilities.

The Task Force has conducted lengthy discussions and analyses regarding entry into the long-term care system, the availability of and need for long-term care services (now and over the coming decade), pressing workforce issues facing the long-term care industry of our state, efforts to assure quality in long-term care, financing options, and the need for local demonstration and pilot efforts addressing critical issues for which there is inadequate current information for guiding social policy in long-term care.

The Task Force identified the most pressing recommendations—those that require immediate action. These fall into four areas: (1) infrastructure, (2) quality, (3) workforce, and (4) access/ financing.

The Task Force made a total of 47 recommendations to improve North Carolina's long-term care delivery, financing and regulatory systems. Some of these recommendations require immediate action; others can wait and/or are contingent on the prior implementation of other recommendations. To help guide the work of the state's policy makers, the Task Force identified the most pressing recommendations—those that require more immediate action. These recommendations fall into four areas: (1) infrastructure; (2) quality; (3) workforce; and (4) access/financing.

Infrastructure: Early in its deliberations, the Task Force recognized the fragmentation that exists at the state level among the different agencies charged with delivering, financing or regulating long-term care. Thus, one of the Task Force's top recommendations is for a more cohesive process to establish state-level long-term care policies and programs. The Task Force recommends the creation of a Cabinet for Long-Term Care within the Department of Health and Human Services comprised of all the Division Directors charged with financing, regulating or providing long-term care services. In addition, the Secretary of the Department of Health and Human Services should create a new Office of Long-term Care to staff the Cabinet and develop comprehensive, coordinated long-term care policies.[101] The creation of the new Office of Long-Term Care within the DHHS and the new Cabinet for Long-Term Care, will help reduce the likelihood of overlapping and sometimes conflicting agendas among Divisions of DHHS.

As a corollary to the Department's reorganization, comprehensive long-term care planning should be encouraged at the local level. The North Carolina General Assembly should encourage county commissioners to designate a lead agency to organize a local long-term care planning process at the county or regional level. The Department of Health and Human Services should support

these efforts by providing technical assistance and county-level data to assist the communities.[102] In addition, the General Assembly should provide one-time "transition support" to enable counties to implement the recommendations of the Task Force, and additional "capacity-building" funds to help small rural counties develop the infrastructure and capacity necessary to implement statewide system changes.[103]

The Task Force also recommends the creation of a "uniform" portal of entry that would improve the process through which citizens could obtain needed long-term care services. The uniform portal of entry would ensure that multiple agencies serving clients use the same screening and assessment tools, and have information about all the available long-term care resources in their communities. To make this system work, the Task Force recommends that the state begin using uniform screening, level of services assessment and care planning instruments; and that the state identify or help develop a computerized information and assistance system that can be used statewide.[104]

Quality: There is a need for a continuing dialogue about the standards of quality in the long-term care field in our state. A start in this direction has been taken through the work of the Task Force, but this is an ongoing agenda the Task Force feels best passed on to the new Office of Long-Term Care, with active participation by the long-term care industry, consumer advocacy groups, regulators, and other interested stakeholders.[105] Much is already going on in this area, but the Task Force maintains that an emphasis on "quality improvement" would greatly enhance current efforts. As a beginning, the Office of Long-Term Care should explore methods to improve and reward quality and not limit actions solely to imposing penalties for deficiencies.[106] Similarly, the Department should develop a Quality Improvement Consultation program to assist providers in the development of quality improvement plans for each facility and program offering long-term care services.[107] A partnership arrangement with Medical Review of North Carolina and the state's public and private universities in this regard is also recommended.[108]

Workforce: One of the major challenges facing the state is ensuring an adequate supply of trained professional and paraprofessional staff. With regard to workforce issues in long-term care, the major "crisis" is the current shortage of paraprofessional personnel in these facilities and programs. However, there are also issues related to the preparation of adequate numbers of physicians, dentists, nurses, and other health professionals with the skills and the commitment to work in long-term care. The Task Force recommends that the General Assembly increase appropriations for Medicaid funded in-home and adult care home Personal Care Services (PCS), and nursing home care by increasing the personal care service hourly rate and nursing home daily rate for direct care. This enhancement would be used for wages, benefits, and/or payment of shift differentials (e.g., nights/weekends). Providers would be required to submit additional cost data to ensure that these funds are used for their intended purpose.[109]

In addition to wage enhancements, the Task Force recommends that the General Assembly appropriate funds to develop a continuing education and paraprofessional development initiative,[110] as well as a career ladder for long-term care paraprofessionals.[111] To support these efforts, additional data collection and analysis is needed, for example—to examine the turnover and retention rates, wages and benefits of nurse aides.[112] The state should also

explore ways to establish a group health insurance purchasing arrangement for long-term care staff.[113] The General Assembly should also establish a Legislative Study Commission to examine long-term care workforce shortages among paraprofessionals and other professionals serving older adults and people with disabilities.[114]

Current efforts made by the long-term care industry to address the long-term care paraprofessional recruitment and retention issues should be applauded and further encouraged. The Task Force recognized that both the state and private industry have a role in addressing the current workforce shortages. Long-term care provider associations should develop plans to improve the recruitment and retention rates among paraprofessionals and professionals in the long-term care industry. The plans may include mechanisms to improve job satisfaction, increase pay, develop career paths or improve working conditions.[115]

Expanding Access/Financing Long-Term Care Services: One of the first steps the state should take in expanding publicly-financed long-term care services is to remove the current institutional bias in these programs. It is currently easier for older adults or people with disabilities to qualify for publicly-financed long-term care services in a nursing home or adult care home than it is to receive services at home. Two promising means of reducing the current institutional bias would be to increase the Medicaid medically needy income limits up to 100% of the federal poverty guidelines;[116] and to expand the number of people served by the CAP-DA and CAP-MR/DD Medicaid programs. Both of these approaches would enable people to receive long-term care services while living at home or a community setting.[117] In addition, the state should explore ways to support family caregivers, thereby reducing the risk for needing formal, publicly-financed services.[118]

The Task Force recognized the state's strong interest in maximizing the use of federal Medicaid dollars to financing long-term care services, as the federal government pays approximately 62% of all Medicaid service costs. As such, the Task Force recommends that the state explore ways to use existing resources as the state's match in further Medicaid expansions.[119] Another idea, successfully used in other states, is to ensure that Medicare pays for covered long-term care services for Medicare-eligible individuals.[120]

In addition, the state should launch an outreach effort targeted at "baby-boomers," to explain different long-term care financing and payment options. The outreach effort should include information on what Medicare covers, what Medicaid covers, what individuals must pay on their own, and what private long-term care insurance can cover.

FOLLOW-UP TO THE TASK FORCE REPORT

The Task Force acknowledges that it was not able to fully explore the implications of long-term care policies for persons (of any age) with mental illness or developmental disabilities, and its analyses of the important problem of assuring adequate housing for older adults and people with disabilities were inadequate. These problems need further study if our state is to deal with the issues in long-term care comprehensively. In addition, the Task Force was frustrated by the fact that its work was taking place at a point just before revised census figures would be available for the state and its 100 counties. Hence

The state needs better data systems to conduct policy analysis for long-term care.

population estimates may be in error for the decade ahead in some cases. In addition, occupancy figures for certain kinds of long-term care facilities, such as some types of adult care homes, may not reflect the current occupancy situation in these facilities as accurately as would be hoped. Hence, projections of future need for these facilities may be subject to error. In all of these circumstance, data systems by which to conduct policy analysis in long-term care were found to be inadequate or non-existent. This is seen as a major challenge of the newly envisioned DHHS Office of Long-Term Care.

Due to the importance of the issues described in this report, it is the intention of the Board of Directors of the North Carolina Institute of Medicine to re-convene the Task Force one year from the date this report is published for the purpose of formulating an assessment of progress in relation to the report's major recommendations. At that time, certain recommendations may need reformulation on the basis of new and emerging data. Others may require extensions or deletions. A "report card" assessment of progress will help to guide further efforts in the long-term care arena and help the Institute, the General Assembly, and the NC Department of Health and Human Services evaluate the efforts of the Task Force as a basis for further initiatives.

[1] Maddox G. Program Director of the Duke Long-Term Care Resources Program in a speech to the North Carolina Study Commission on Aging, Cited in Campbell, R. Performance Audit: Long-Term Care Programs in North Carolina as administered by the Department of Health and Human Services, April 1998.
[2] Long-Term Care Policy Office. National Trends in Long-Term Care: How Does North Carolina Stack Up? NC Department of Health and Human Services. October 1, 1998.
[3] Long-Term Care Policy Office. National Trends in Long-Term Care: How Does North Carolina Stack Up? NC Department of Health and Human Services. October 1, 1998. The report also notes that 40% of older adults will spend some time in a nursing home.
[4] Bodenheimer T. Long-Term Care for Frail Elderly People—The On-Lok Model. New England Journal of Medicine. 1999 Oct21;341(17):1324-1328.
[5] Long-Term Care Policy Office. National Trends in Long-Term Care: How Does North Carolina Stack Up? NC Department of Health and Human Services. October 1, 1998, citing National Conference of State Legislatures. New Thinking on Financing and Regulating Long-Term Care. April 1998, p. 2.
[6] Feder J, Komisar HL, Niefeld M. Long-Term Care in the United States: An Overview. Health Affairs. 2000 May/June:19(3):40-56.
[7] Ibid.
[8] North Carolina Office of State Planning and Millennium Healthcare Solutions
[9] Ibid, citing Komisar HL, Niefeld M. Long-Term Care Needs, Care Arrangements, and Unmet Needs among Community Adults. Findings from the National Health Interview Survey on Disability. Working Paper No. IWP-00-102. Washington: Georgetown University, Institute for Health Care Research and Policy, 2000.
[10] State Auditors Office. Long-Term Care Programs in North Carolina as Administered by the Department of Health and Human Services. Performance Audit. April 1998.
[11] Chapter 237, Sec. 11.7A of the 1999 Session Laws.
[12] Sec. 11.4a,b of Session Law 2000-67.
[13] Developmental disabilities is defined under N.C.G.S. §122C-3(12a) as "a severe, chronic disability of a person which:

(a) Is attributable to a mental or physical impairment or combination of mental or physical impairments;
(b) Is manifested before the person attains age 22, unless the disability is caused by a traumatic head injury and is manifested after age 22;
(c) Is likely to continue indefinitely;
(d) Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, capacity for independent living, learning, mobility, self-direction, and economic self-sufficiency; and
(e) Reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of a lifelong or extended duration and are individually planned and coordinated; or
(f) When applied to children from birth through four years of age, may be evidenced as developmental delay."

People with developmental disabilities may have different experiences and need for long-term care services than the older adults or other adults with disabilities. By definition, people with developmental disabilities require a long-term care system of support that may begin at birth. The focus of this report is on adults (age 18 or older) who need long-term care services, although the Task Force did consider the needs of individuals with mental illness or developmental disabilities. Because of the ongoing Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities and Substance Abuse Reform, the Task Force concentrated their efforts on older adults and other people with disabilities, and not on people with developmental disabilities or mental illness who may need long-term care services.

[14] *Olmstead* refers to the United States Supreme Court's opinion in the case of *Olmstead v. L.C.*, 119 S.Ct. 2176 decided in June, 1999. The case was brought on behalf of two Georgia women with mental retardation and mental illness. Both women were receiving treatment in state institutions, even though their doctors said that they could be served in community-based programs. The women sued, saying that the state's failure to place them in a community setting constituted discrimination under the Americans with Disabilities Act (ADA).

The Supreme Court concluded that inappropriate institutionalization of a person with a mental disability may be discrimination under the ADA. It held that the ADA requires placement of individuals with mental disabilities in community settings when:

- the state's treatment professionals have determined that community placement is appropriate;
- transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and
- placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities.

[15] NCGS 143B-181.6.

[16] Duke Long Term Care Resources Program, Occasional LTC Policy Paper Series. Paper No. 10 (July 1999).

[17] The Task Force recommends that the Department pull together a workgroup of local and state agency staff, long-term care providers, and other stakeholders to evaluate whether the level of service assessment should be required of all individuals seeking non-state funded out-of-home services in a long-term care facility or licensed in-home or community-based service. This evaluation should occur after the state has at least one year of experience using the level of service assessment instrument for state-publicly-funded long-term care services.

[18] The costs would increase annually as more people become aware of its availability and effectiveness in helping them remain at home instead of moving to a nursing home or adult care home. When the program is fully implemented with no additional start-up cost needed (i.e., 6th year and after), annual public costs will be estimated at $16,200,000.

[19] Sec. 11.7A(a) of HB 168, 1999 Session.

[20] There are six activities of daily living that relate to daily personal tasks such as bathing, dressing, toileting, transferring from bed to chair, personal grooming, and eating. These are discussed in more detail in Chapter 4.

[21] US Census Bureau. Poverty Status by State in 1999. People 65 or Older. Annual Demographic Survey, March Supplement. 2000.

[22] NC Division of Community Assistance. Consolidated Housing Plan: 2000-2005. NC Department of Commerce. 2000 at p. 93.

[23] Goins R. Turner and Leak SC. Distribution of Home and Community-Based Long Term Care Services for the Elderly in North Carolina. Occasional LTC Policy Paper Series. Duke Long Term Care Resources 1999 Nov;Program Paper No. 11.

[24] The NC Department of Health and Human Services, Division of Facility Services collects information on use of nursing homes among individuals with private sources of funding. Utilization of nursing home beds among both private- and public-pay residents is used to determine the need for additional nursing home beds that is part of the state's Certificate of Need process. In addition, adult care homes report some information about private-pay residents in their cost-reports to the Department. This is limited to adult care homes that take some State/County Special Assistance funding and does not include facilities that serve solely private-pay residents.

[25] Medicaid CAP/DA and Personal Care Services were converted into ratios based on the number of users per 1,000 Medicaid-eligible aged or disabled individuals. Home and community care block grant services were converted into ratios based on the number of users per 1,000 older adults (60+). Nursing home and adult care homes were converted into ratios based on the number of beds per 1,000 older adults (65 or older).

[26] NC Division of Facility Services. Comparing State Efforts to Address the Recruitment and Retention of Nurse Aide and Other Paraprofessional Aide Workers. Sept. 1999. Note: the 112 agencies that provided in-home aides services provided the same type of services that would meet the criteria for Medicaid reimbursement (e.g., Level II or Level III in-home aide services).

[27] Generally the rate of ADL/IADL impairment is declining among older adults, with the exception of women aged 85 or older, where the rate of impairment appears to be rising.

[28] During the deliberations of the Task Force, concern was raised that the occupancy rates for Adult Care Homes was understated, and thus would lead to inaccurate projections of the number of people in adult care homes now and in the future. The data used in these projections come directly from the adult care homes (self-reports) to the Division of Facility Services. These data include all licensed beds, not just those that are regularly in use. Occupancy rates were calculated as a percentage of occupied beds divided by total licensed beds as of December 31, 1999. The Division of Facility Services is in the process of trying to validate these numbers; and should have more accurate numbers for 2000.

The Controller's Office within the NC Department of Health and Human Services maintains another database of adult care homes. This data system shows occupancy rates for homes eligible for State-County Special Assistance (SA)—not all homes—based on the percentage of SA patient days divided by the maximum possible patient days for all of 1999. The Controller's data shows higher occupancy rates, but a lower overall number of beds (presumably, because it only collects data on homes eligible for SA). Using the Controller's data to calculate the number of people in adult care homes actually yields a lower number than using the Division of Facility Services' numbers.

Because there was no easy way to clear up this potential discrepancy, the Task Force used the original DFS data that include all adult care homes, not just those eligible to receive SA. However, the Task Force recognizes the limitation in this approach, and recommends that additional refinements be made as better data become available.

[29] This definition is restricted to older adults with ADL impairments lasting three months or more, and matches the "SMI-1" definition of unmet need presented in Jackson (1991).

[30] As reported in *Chartbook on Disability in the United States, 1996*.

[31] Where have All the Nurses Aides Gone. Presentation by Thomas R. Konrad to the NC IOM Long Term Care Task Force, May 31, 2000. North Carolina Institute on Aging. Note: 180,000 people who have been certified as nurse aides include nursing students who are certified as nurse aides during their training. The actual number of individuals, who are being trained as nurse aides, rather than nurses, is unknown. It is likely that some of the people who are no longer certified as nurse aides are those who were being trained as nurses—and never part of the nurse aide workforce.

[32] NC Division of Facility Services. Comparing State Efforts to Address the Recruitment and Retention of Nurse Aide and Other Paraprofessional Aide Workers. September 1999.

[33] Press release by the North Carolina Employment Securities Commission, November 17, 2000. [http://www.esc.state.nc.us/]

[34] Where have All the Nurses Aides Gone. Presentation by Thomas R. Konrad to the NC IOM Long Term Care Task Force, May 31, 2000. North Carolina Institute on Aging.

[35] NC Division of Facility Services. Comparing State Efforts to Address the Recruitment and Retention of Nurse Aide and Other Paraprofessional Aide Workers. September 1999.

[36] Missouri information from Mary Shantz, Executive Director, Missouri Council for In-Home Services, April 28, 2000.

[37] NC Division of Facility Services. Results of a Follow-Up Survey to States on Wage Supplements for Medicaid and Other Public Funding to Address Aide Recruitment and Retention in Long-Term Care Settings. November 4, 2000.

[38] North Carolina Center for Nursing. A Profile of Newly Licensed Registered Nurses in North Carolina: 1997. June 1998.

[39] Cecil G. Sheps Center for Health Services Research. North Carolina Health Professions: October 1999. University of North Carolina, Chapel Hill. In 1999, the licensure board changed the practice settings categories—eliminating Nursing Home and adding Long-Term Care and Home Care/Hospice as options. In 1999, 4,955 registered nurses listed their primary specialty as geriatrics; 4,704 RNs reported their primary practice location as long-term care and an additional 5,205 reported their primary practice location as home care/hospice.

[40] North Carolina Center for Nursing. A Profile of Newly Licensed Registered Nurses in North Carolina: 1997. June 1998.

[41] Cecil G. Sheps Center for Health Services Research. North Carolina Health Professions: October 1999. University of North Carolina, Chapel Hill. In 1999, the licensure board changed the practice settings categories—eliminating Nursing Home and adding Long-Term Care and Home Care/Hospice as options.

[42] Only two geriatricians listed their primary practice location as a nursing home or extended care facility.

[43] Cecil G. Sheps Center for Health Services Research. North Carolina Health Professions: October 1998. University of North Carolina, Chapel Hill.

[44] US Senate Special Committee on Aging Sponsors Forum on the National Shortage of Health Professionals Trained in Geriatrics. http://www.americangeriatrics.org/policy/ger_need.shtml. May 20, 1998, Washington, DC.

[45] US Census Bureau Web Page: http://www.census.gov/population/estimates/nation/intfile2-1.txt.

[46] Information from Lynn Hardy, North Carolina Association for Home and Hospice Care, June 8, 2000.

[47] Cecil G. Sheps Center for Health Services Research. North Carolina Health Professions: October 1998. University of North Carolina, Chapel Hill.
[48] Maslow, Abraham H. 1971. The Farthest Reaches of Human Nature. Viking: New York, NY. Maslow, Abraham H. 1962. Toward a Psychology of Being. Van Nostrand: Princeton, NJ.
[49] Kane RA, Kane RL, Ladd RC. 1998:190-195. The Heart of Long-Term Care. Oxford:New York.
[50] Kane RA, Kane RL, Ladd RC. 1998:189. The Heart of Long-Term Care. Oxford:New York.
[51] Kane, RA, Kane RL, Ladd RC. 1998:193. The Heart of Long-Term Care. Oxford:New York.
[52] DFS has 76 full-time equivalent (FTE) personnel assigned to the task of surveying nursing homes in North Carolina. These personnel receive two weeks of training by federal HCFA officials and must pass the Surveyor Minimum Qualifications Test before conducting surveys independently. Additional components in licensure and certification training are also federally required.
[53] Facility Quality Indicator Profile. Information provided by: Cynthia DePorter, Feb. 18, 2000.
[54] Information is for State Fiscal Year 1999, from Lynda McDaniel at the NC Department of Facility Services. June 15, 2000.
[55] The Division of Facility Services licenses and inspects mental health, developmental disability and substance abuse facilities licensed under N.C.G.S. §122C. Some of these facilities provide residential or community-based long-term care services to people with mental illness or developmental disabilities, including: psychosocial rehabilitation (69 facilities), specialized community residential care (30 facilities), adult developmental vocational programs (147 facilities), community respite services (122 facilities), day activity (40 facilities), MH supervised living (86 facilities), DD/BD supervised living for children or adults (505 facilities), DD supervised living for adults (517 facilities), MD supervised living for adults (96 facilities). There are additional long-term care facilities that focus on the needs of children and adolescents. Personal communication with Lynda McDaniel, Division of Facility Services. June 27, 2000.
[56] County Adult Care Home Specialists are, as of 2000, generally classified as Social Worker III personnel under the state personnel system, though not all counties have implemented this change. A history of high turnover rates among county-level inspection personnel motivated this change in the position classifications for those performing these important tasks. Statewide there are 153 Adult Care Home Specialists who have the responsibility of inspecting 1,568 adult care homes. Many of these specialists have other responsibilities in addition to their inspection work. On average, each Adult Care Home Specialist works only 0.59 percent time on inspections. Information provided by Sue Madson, Division of Social Services, June 21, 2000.
[57] County DSS inspectors receive standardized training from the Division of Facility Services. The Division of Facility Services offers basic training for Adult Care Home Specialists twice a year. There is also extensive training available for specific areas such as how to write negative action proposals or how to monitor medication administration. Specific criteria and measures of quality are required to be used across the state by county inspectors of adult care homes.
[58] There are seven state inspectors on the DFS staff. These inspectors receive one week of basic orientation, one week of training on how to conduct investigations, one week of HCFA training, and four weeks of field training with another surveyor. Information from Cynthia DePorter, Division of Facility Services, June 21, 2000.
[59] Four DFS inspectors monitor the care provided in home health agencies; three inspectors monitor the care provided in home care agencies (i.e., agencies that are not federally-certified for the care of Medicare clients).
[60] Feder J, Komisar HL, Niefeld M. Long-Term Care in the United States: An Overview. Health Affairs. 2000 May/June;19(3):40-56.
[61] Initially community volunteers must complete a minimum of fifteen hours of training, with an additional ten hours of in-service training each year in their role as grassroots advocates. Information from Sharon Wilder, Division of Aging, June 21, 2000. Topics covered by the regional Ombudsmen for the training of the community advisory committee volunteers include: roles and responsibilities as defined by state statutes; residents' bill of rights; licensure processes for the different types of facilities; Adult Protective Services laws and reporting requirements; complaint resolution; and confidentiality requirements.
[62] The Long-term Care Ombudsman Program in North Carolina: Report on the Consumer Satisfaction Survey of 1997. The Center for Aging Research and Educational Services (CARES), Jordan Institute for Families, School of Social Work, The University of North Carolina at Chapel Hill. September 1998. A random sample was drawn to answer the survey questions from four constituencies: 120 members of the public who filed formal complaints through the program; 108 people who called for information, referral, and technical assistance; 243 representatives of long-term care facilities; and 148 members of community advisory committees. There was also a job satisfaction survey completed by 21 regional long-term care ombudsmen.

[63] North Carolina Constitution, Art. IX, Sec. 7 "All moneys, stocks, bonds, and other property belonging to a county school fund, and the clear proceeds of all penalties and forfeitures and of all fines collected in the several counties for any breach of the penal laws of the State, shall belong to and remain in the several counties, and shall be faithfully appropriated and used exclusively for maintaining free public schools." The term "penal laws" has been defined to mean laws that impose a monetary payment for their violation; the payment is punitive rather than remedial in nature and is intended to penalize the wrongdoer rather than compensate a particular party. See, McMillan v. Robeson County, 262 N.C. 413, 137 S.E.2d 105 (1964).

[64] The $1.7 billion excludes long-term care services operated through the Division of Mental Health, Developmental Disabilities and Substance Abuse Services, because their accounting cannot specifically identify long-term care expenditures

[65] NC Division of Medical Assistance. Medicaid Tables for SFY 1999. Table 1: Federal Matching Rates; Table 13: Expenditures for the Elderly; Table 14: Expenditures for the Disabled and Blind.

[66] The disability expenditures include both adults and children with disabilities. However, with the exception of ICF-MR, most long-term care services are provided to adults 18 or older.

[67] About 92% of CAP-MR/DD expenditures are for children under the age of 18.

[68] Home health expenditures were included in this table, but not all home health services are for long-term care. Many home health services are provided as rehabilitative services after an acute illness or episode.

[69] Information from Hank Bowers, Division of Social Services, January 4, 2001.

[70] Information provided by the Division of Aging, December 20, 2000. These numbers reflect duplication between services.

[71] Information from Donna Holt and John Dalrymple, Division of Vocational Rehabilitation, December 20, 2000.

[72] Information from John Griswold, Division of Public Health, January 5, 2001.

[73] Health Care Financing Administration. Medicare Enrollment as of July 1, 1998.

[74] State Summary of Nursing Facilities, 2000. American Health Care Association, Research and Information Services. Web Page: http://www.ahca.org. In 1998, there were 48,539 Medicare skilled nursing facility stays at an average payment of $234.33/day. The average stay per Medicare beneficiary was 29 covered days with an average co-payment per Medicare beneficiary of $1,595 per care episode.

[75] 1998 pay claims data from HCFA statistics, compiled by Palmetto Government Benefits Administrator (PGBA). As of June 2000, the 1999 figures had not been released for the period July1, 1999 to December 31, 1999. The 1998 North Carolina home health data include 4,090,749 visits to 101,043 people. The average reimbursement per person was $2,786 and the average number of visits per person was 40. Nationally the average reimbursement per person was $3,384 and the average number of visits per person was 50, so North Carolinians on average receive fewer home health visits and lower average reimbursement.

[76] N.C.G.S. §143B-181.1

[77] Division of Facility Services. Long-Term Care Expenditures for Older Adults Reported for SFY 98-99. April 10, 2000, based on information provided by the Division on Aging.

[78] Division of Aging. SFY 1998-99 Long-Term Care Expenditures: Persons 60 or Older. Information from Bill Lamb, Division of Aging June 5, 2000.

[79] Local area programs negotiate the budget at the county level. There are no set requirements across counties, and county contributions vary as a function of wealth of the county. Communication with Bonnie Morell, NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services, June 9, 2000.

[80] This table lists the lowest Medicaid nursing home and ICF-MR reimbursement rates. To determine eligibility for nursing facility or ICF-MR, the Division of Medical Assistance (DMA) first looks at a person's countable income compared to the lowest reimbursement rate in the state. If the person's countable income exceeds the lowest reimbursement rates, then DMA looks at the specific facility's rate for the level of care to determine if the person's countable income is less than the specific facility's rate. Individuals are allowed to take certain deductions from their gross income to determine their countable income. For example, a person who has applied for Medicaid to pay for nursing home care can deduct up to $1,383 to help support a spouse living at home. Additional deductions are allowed to support minor or dependent children, to meet excess shelter costs for the spouse or children living at home, or to pay for personal needs while in the nursing home.

[81] Medicaid eligibility for people living at home is set at 100% of the federal poverty guidelines. The Medicaid income eligibility guidelines are adjusted annually to reflect changes in the federal poverty guidelines.

[82] In SFY 2003, the estimated number of people served would be 36,781, with an average monthly cost of $341.30 for home and community care costs. Information from the NC Department of Health and Human Services, Division of Medical Assistance, Office of Financial Operations.

[83] The state would also need approval from the Health Care Financing Administration to expand the number of people served through CAP, but HCFA generally approves requests to expand state CAP allocations.

[84] Division of Medical Assistance. Letter to CAP/DA Supervisors and Case Managers. April 17, 2000.
[85] Resources are also considered in determining eligibility for both Medicaid and State-County Special Assistance. Each program has slightly different rules about which resources are counted or excluded; however the amount of the resource limits for each program is similar: $2,000 for an individual and $3,000 for a couple. Communication with Matt Oathout, Division of Medical Assistance, June 13, 2000.
[86] Currently NC 143B 181.1(a) #10 requires that the Division of Aging "establish a fee schedule to cover the cost of providing in-home and community-based services funded by the Division. The fees may vary on the basis of the type of service provided and the ability of the recipient to pay for the service. The fees may be imposed on the recipient of a service unless prohibited by federal law. The local agency shall retain the fee and use it to extend the availability of in-home and community-based services provided by the Division in support of functionally impaired older adults and family caregivers of functionally impaired older adults."
[87] Presentation by Mary Reca Todd to the NC IOM Long Term Care Task Force. NC Housing Finance Agency. April 25, 2000.
[88] All the counselors receive training from the NC Housing Finance Agency, and may not receive a commission from the proceeds of a loan. The borrowers may not be charged for the counseling.
[89] Presentation by Carla Obiol to the NC IOM Long Term Care Task Force. NC Department of Insurance. April 25, 2000.
[90] Division of Facility Services. Increasing Personal Responsibility for Long-Term Care Through Private Long-Term Care Insurance: An Update to the 1996 Report. August 2000.
[91] National Association of Insurance Commissioners. 1998 Long-Term Care Insurance Experiences Reports—Form C. December 20, 1999.
[92] There are six activities of daily living: feeding, bathing, dressing, grooming, transfers (e.g., moving from bed to chair or getting out of a chair), and mobility (ability to walk). Some long-term care policies exclude the need for bathing assistance as one of the qualifiers for long-term care services. Since most people need assistance with bathing before other activities of daily living, these policies effectively require that a person show a need for help with three of the six activities of daily living before qualifying for benefits under the policy.
[93] LTC premiums can be based on attained age (which increases as the person gets older), or on issue age (which is a constant premium based on the age of the purchaser). State law prohibits long-term care insurers from selling policies based on attained age once the person reaches age 65.
[94] SHIIP Long Term Care Insurance Policy Survey, Department of Insurance, 1999. Information provided by Carla Obiol.
[95] Presentation by Tom Jacks to the NC IOM Task Force on Long-Term Care. Deputy Commissioner. NC Department of Insurance. May 31, 2000.
[96] Presentation by Susan Harmuth. NC Division of Facility Services. May 31, 2000.
[97] Presentation by Barbara Brooks. NC Division of Medical Assistance. March 17, 2000.
[98] NC Department of Health and Human Services. Study and Comparison of Eligibility Requirements: Report to House and Senate Appropriations Subcommittee on Human Resources and Study Commission on Aging. March 1998.
[99] Presentation by Andy Wilson. NC Division of Medical Assistance. April 25, 2000.
[100] 10 NCAC 35F.
[101] See Recommendation #2 on page 28.
[102] See Recommendation #16 on page 58.
[103] See Recommendations #44-45 on pages 97-98.
[104] See Recommendations #4-7 on pages 40-42.
[105] See Recommendation #24 on page 73.
[106] See Recommendation #26 on page 74.
[107] See Recommendation #27 on page 75.
[108] See Recommendation #25 on page 74.
[109] See Recommendation #17 on page 64.
[110] See Recommendation #18 on page 64.
[111] See Recommendation #19 on page 64.
[112] See Recommendation #20 on page 65.
[113] See Recommendation #22 on page 65.
[114] See Recommendation #21 on page 65.
[115] See Recommendation #23 on page 65.
[116] See Recommendation #28 on page 84.
[117] See Recommendation #29 on page 84-85.
[118] See Recommendation #43 on page 96.
[119] See Recommendation #33 on page 87.
[120] See Recommendation #32 on page 87.

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APPENDIX A

Demand For Long-Term Care In North Carolina:

Projections for 2000, 2005 and 2010

FINAL REPORT

Prepared for the North Carolina Institute of Medicine

By

Millennium Healthcare Solutions, Inc.

Edison, New Jersey

December 8, 2000

Preface

Millennium Healthcare Solutions (Millennium) has prepared this report for the North Carolina Institute of Medicine, in support of the North Carolina Long-Term Care Task Force. Millennium has assisted a large number of state agencies and local programs in the area of planning, policy development and new program design for publicly-funded long-term care, and has been involved with several health and long-term care initiatives in North Carolina. Drawing from this experience, we appreciate the importance of developing accurate projections of demand for long-term care. We have carefully reviewed the data sources and methodologies used to develop the projections presented in this report, and believe that they represent a well-grounded approach to forecasting the number of North Carolinians who will need long-term care in coming years.

Dan Lehman, a Senior Associate at Millennium, was the sole author of this report. Millennium wishes to acknowledge to contributions made by members of the North Carolina Long-Term Care Task Force and its Advisory Committee in providing insights and guidance in developing and refining the methodologies and data sources used in its preparation. Millennium would like to acknowledge the assistance of several members of the North Carolina Department of Health and Human Services, including Cindy DePorter, Susan Harmuth, Beth Kidder, Sandra McLamb, Lea Slaton, Dennis Streets and Judy Walton; Sandy Crawford Leak of the Duke University Center for the Study of Aging, Long-Term Care Resources Program; and Dr. Elise Bolda of the University of Southern Maine, Edmund S. Muskie School of Public Service. Finally, Millennium would like to thank the North Carolina Institute of Medicine, in particular Dr. Gordon DeFriese and Dr. Pam Silberman, for this opportunity to support the efforts of the North Carolina Long-Term Care Task Force in developing a long-term care system that provides a continuum of care for elderly and disabled individuals and their families.

Millennium Healthcare Solutions
December 8, 2000

Executive Summary

This report has been prepared by Millennium Healthcare Solutions, Inc. of Edison New Jersey under contract with the North Carolina Institute of Medicine. It provides detailed projections of the need for long-term care in North Carolina for the years 2000, 2005 and 2010 for use by the North Carolina Long-Term Care Task Force. For the population aged 18 and older, these projections address:

- The number of persons needing long-term care in North Carolina, both community-dwelling and institutional;
- The severity of their functional impairments;
- Their income levels;
- Their sources of care and the prevalence of unmet needs; and
- The number of persons with disabling mental retardation and/or developmental disability.

Projections for the State of North Carolina as a whole, for individual Area Agency on Aging (AAAs) and Area Mental Health, Developmental Disabilities and Substance Abuse program regions, and for large and mid-size individual counties.

The projections rely on population trends and projections for North Carolina, current utilization data for selected long-term care services, and findings from national studies on functional impairment and related topics. The projection methodology employed accounts for the unique demographic characteristics for North Carolina as a whole and individual service regions and counties. The projections are limited to persons aged 18 years and older, and rely on a series of assumptions which are explained in detail in the main sections of this report.

Throughout this report, the need for long-term care is defined in terms of limitations in Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs include such daily personal care tasks as bathing, mobility inside the home, transferring from a bed to a chair, dressing, toileting and eating. IADLs include activities such as using the telephone, taking medications, managing personal finances, using transportation outside the home, preparing meals, and performing general housework. ADLs and IADLs constitute an accepted set of measures for functional impairment that focus on limitations in performing everyday tasks that require assistance from others, rather than the underlying causes for the impairments themselves.

Based on the analysis conducted for this report, it is projected that between the years 2000 and 2010:

- **The total number of persons with long-term care needs will increase from 351,600 to 418,400.** This includes community-dwelling (non-institutional) persons with 1 or more ADL or IADL limitation and all residents of long-term care facilities.
- **The number of community-dwelling persons with long-term care needs will increase from 308,000 to 366,700.** Of this group, the number with a high level of impairment will increase from 79,800 to 98,400. “Community dwelling” includes residents of adult care homes; “high level of impairment” is defined as needing assistance with 3 or more ADLs.
- **The number of residents of institutional long-term care facilities will increase from 42,700 to 51,700.** This includes residents of nursing facilities and large (40+ beds) intermediate care facilities for the mentally retarded and developmentally disabled.
- **The number of community dwelling persons with high levels of impairment and incomes below 100% of poverty will grow from 27,400 to 34,000.** The number of community-dwelling persons with moderate impairment (1 to 2 ADLs) will grow from 26,000 to 30,700, while the number of persons in long-term care institutions who rely exclusively on Medicaid will grow from 20,800 to 25,200.

- **The number of elderly persons (aged 65 and older) with a high level of impairment who have unmet ADL needs will grow from 5,200 to 6,500.** The number of elderly persons with moderate impairment who have unmet ADL needs will grow from 5,600 to 6,600. Here, unmet need is defined as requiring human assistance to perform an ADL task but not receiving the assistance needed, for ADL limitations lasting 3 months or more.
- **The number of community-dwelling persons aged 18 to 64 with disabling mental retardation and/or developmental disability (MR/DD) will grow from 34,300 to 38,600.** Of these, the number with any long-term care need (defined as needing assistance with at least 1 ADL or IADL) will grow from 21,700 to 24,400. "Community-dwelling" includes all persons not residing in large (40+ bed) intermediate care facilities (ICFs), including those living in smaller ICFs and other group home settings.

These projections assume no changes in long-term care policy related to the settings in which people receive care (in their own homes, in adult care or other group homes, or in large long-term care institutions). Rather, they reflect the growth in demand for long-term care that would be expected to result based on the number of persons currently residing in long-term care institutions and the estimated number of community-dwelling persons with long-term care needs, given changes in the size and demographic structure of the overall population of North Carolina and nationally-observed trends in impairment and institutionalization among the elderly.

As for any analysis that relies heavily on integrating data and findings from numerous sources that cover different populations, timeframes and subject matter, it was necessary to make certain assumptions in developing the projection methodology used for this report. In addition, due to data and methodological limitations, some projections are only presented for certain populations, such as persons with at least 1 ADL limitation, persons aged 65 and older, etc. These limitations form the basis for further analysis and refinement of the methodologies employed.

As a whole, this report represents a significant step forward in understanding the changing nature of the demand for long-term care in North Carolina on the state, regional and county levels. This understanding is crucial for developing well-considered public policy, implementing new programs and service models and evaluating their impact over time. Lastly, the projections presented in this report should be reviewed on an ongoing basis as part of a continuing planning process for long-term care.

I. Introduction

The North Carolina Institute of Medicine is coordinating a study mandated by the state legislature seeking to develop forward-looking policies to guide publicly funded long-term care programs in North Carolina. As part of the analysis phase of the project, a careful look is being taken at the trends related to the demand for long-term care throughout the state and the implications such trends may have on the demand for services and supports funded through public programs. Long-term care services consume a large share of the North Carolina budget, with much of the cost borne by the Medicaid program. Because of the size of the long-term care program, estimates of future demand are important prerequisites to any policy initiative related to long-term care.

The Institute of Medicine contracted with Millennium Healthcare Solutions (MHS) to provide assistance in development of profiles of the future demand for long-term care services. This report presents final projections of the prevalence of functional impairment for residents of North Carolina for the years 2000, 2005 and 2010. These projections were developed for the state as a whole, for distinct service regions and for individual counties. They were developed through the integration of various data sources, and the methodologies used to construct them will be discussed in detail, as will their limitations.

Projecting the number of residents requiring long-term care is an essential step in developing policies, designing programs, and planning and budgeting for state-funded services for people with chronic care needs. This final report updates the projections presented in earlier versions and incorporates other key factors affecting demand for long-term care services, including income levels, use of formal (paid) and informal (unpaid) supports and prevalence of unmet needs among people with chronic impairments. This final report also presents projections for mentally retarded/developmentally disabled (MR/DD) persons.

II. Methodology Used To Estimate Number of People Needing Long-Term Care

Demand for long-term care can be expressed in numerous ways. Different population characteristics and circumstances act in combination to affect demand for long-term care services. In recent years, measures of need for publicly-supported long-term care are typically expressed in terms of functional impairments in Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), and this report will focus on these measures as well.

ADL impairments relate to daily personal tasks as bathing, dressing, toileting, transferring from bed to chair, personal grooming and eating. IADL impairments relate tasks as preparing meals, using the telephone, managing finances, doing light housework, transportation outside the home, etc. ADL and IADL impairments are intended to capture the functional impact of disease, cognitive deficits and/or physical disabilities on everyday life. Both ADL and IADL measures help identify persons who need assistance with long-term care services, as well as gauge the severity of need and determine what type of services may be needed.

The methodology for this report draws on ADL and IADL impairment rates derived from national longitudinal surveys that are adjusted based on demographic estimates for the North Carolina population age 18 and over on a county-by-county basis. Once the number of persons needing long-term care were estimated for each county, additional factors that may affect the nature of the demand for long-term care services were considered, such as income levels and availability of informal (unpaid) support. Lastly, a separate set of projections were prepared for North Carolinians with MR/DD impairments.

Projections of demand for long-term care were first developed for the year 2000. Additional projections for the years 2005 and 2010 were then prepared, using a similar base methodology as was developed for the year 2000 projections and incorporating certain assumptions regarding trends for population dynamics and impairment levels in future years.

Each step in the methodology is described below.

Step 1: Establish the total population for each county by age-sex cohort

Using data provided by the North Carolina Office of State Planning, population estimates were developed for specific age cohorts for each county for the year 2000. The age cohorts used for the projections were 18-to-44, 45-to-64, 65-to-74, 75-to-84 and 85-and-older. Given observed differences in impairment rates among men and women of various ages, separate male and female population estimates were developed for each age cohort.

Step 2: Estimate white/non-white population by age-sex cohort for each county

Once the population for each age-sex cohort was estimated for each county, county-specific data from the U.S. Census on changes in racial composition over the period 1990-1998 was used to project the respective white and non-white populations for each age-sex cohort for each county. As with males and females, there are observable differences in impairment rates between whites and non-whites, which are especially relevant in a racially-diverse state such as North Carolina.

Step 3: Estimate the number of residents in correctional institutions

Using data from the North Carolina Department of Corrections and the Federal Bureau of Prison Statistics, the number of residents for each age-sex-race cohort who are incarcerated in prison facilities within each county was estimated.

Step 4: Estimate the number of residents in long-term care institutions

Using data from several sources, the number of county residents in long-term care institutions, such as nursing facilities (NFs) and intermediate care facilities for the mentally retarded (ICFs) was estimated for each age-sex-race cohort.[1]

Step 5: Estimate the number of community-dwelling residents with long-term care need

For each age-sex-race cohort in each county, the estimated number of correctional facilities and long-term care institutions residents was subtracted from the total cohort population, yielding the number of community-dwelling residents for each cohort in each county. Prevalence rates for long-term care need among community-dwelling persons derived from national longitudinal surveys for each age-sex-race cohort were then applied to the county-specific cohort population estimates to estimate number of non-institutional county residents needing long-term care.

Three different levels of need were estimated: assistance with IADLs only, assistance with 1 or 2 ADLs, and assistance with 3 or more ADLs. In the case of persons aged 65 and older, impairment prevalence rates were adjusted to reflect changing levels of impairment among community-dwelling elderly.[2]

[1] Patients in federal Veterans Administration (VA) nursing facilities were classified as long-term care institutional residents, and were assumed to be male. Residents in adult care homes, family care homes, homes for the developmentally disabled and ICFs with fewer than 40 beds were not classified as institutional residents, but rather as living in “other group quarters”, in keeping with U.S. Census population definitions.

[2] Findings from the National Long-Term Care Survey (NLTCS) show generally declining institutionalization and impairment rates among the elderly. However, there are differences in this trend between the sexes and across different levels of impairment, with prevalence and/or severity of long-term care needs appearing to be increasing among certain groups.

Step 6: Estimate the number of low-income persons with long-term care needs

Separate estimates were prepared for community-dwelling persons and long-term care facilities residents. For community-dwelling residents, two classifications were used: those with incomes below 100% of the federal poverty level, and those with incomes between 100% and 200% of poverty. Data from the 1990 U.S. Census on poverty among men and women by age category (18-64 and 65+) for each county was adjusted using national U.S. Census data on differences in poverty between whites and non-whites and trends in poverty between 1990 and 1998 to estimate county-specific age-sex-race poverty rates for each county for the year 2000. These cohort/county-specific poverty estimates were then adjusted to account higher rates of poverty among persons with long-term care needs and to estimate the number of "near-poor" (incomes between 100% and 200% of poverty) persons needing long-term care. This process was followed for community-dwelling persons with both moderate-level (1-2 ADLs) and high-level (3+ ADLs) functional impairment.

For persons in residential care facilities, detailed data from two separate studies of adult care homes[3] and North Carolina Department of Health and Human Services statistics on nursing facilities residents were used to estimate the number of residents who receive state-supported care (e.g., Medicaid, state-only assistance, etc.) These estimates were used as a proxy for income levels for persons in residential care settings.

Step 7: Estimate number of community-dwelling elderly receiving paid and unpaid care and the number with unmet ADL needs

Using data from a recent study of trends in reliance on formal (paid) and informal (unpaid) care among non-institutional elderly (65+), estimates were developed for each county of the number of seniors needing long-term care receiving (a) formal care only, (b) informal care only, (c) both formal and informal care, and (d) neither formal nor informal care. In addition, the number of seniors with unmet needs for assistance with ADL tasks was projected as well. These estimates were made for community-dwelling seniors at both moderate (1-2 ADL impairments) and high (3+ ADL impairments) levels of need.

Step 8: Estimate the number of persons with functional impairment due to MR/DD

Using national findings on the prevalence of MR/DD and related functional impairment (here defined as 1 or more IADL or ADL impairments), and adjusting for male/female and white/non-white differences, the number of MR/DD individuals whose condition is considered "disabling" and the subset of individuals who are functionally impaired was estimated for each county.

The steps listed above outline the key facets of the methodology used to estimate the population aged 18 and older with long-term care needs in each county for the year 2000. To estimate the corresponding projected population for both 2005 and 2010, a similar process was followed, with the following adjustments:

- Total population and age-sex break-downs for 2005 and 2010 were used for each county, based on projections prepared by the North Carolina Office of State Planning.

- The same base rate for institutionalization for each age-sex-race cohort for long-term care institutional residents for each cohort were used for 2005 and 2010 as for 2000. For the elderly, the same age cohort adjustment factor to account for declining rates of institutionalization among the elderly was used as well, based on trends observed on national longitudinal studies.

[3] Background data for dissertation by Dr. Elise Bolda and findings from 1995 report by Research Triangle Institute (RTI) on adult care homes.

- The same trends in racial composition (white/non-white) for specific age-sex cohorts in each county estimated during the period 1990 to 1998 were projected for 2005 and 2010.

- The same base rates of functional impairment among the community-dwelling population aged 18 and older and the same adjustment factor to account for declining functional impairment rates among the elderly were used for 2005 and 2010 as were used for 2000.

III. Data Sources Used In Estimating The Prevalence of Functional Impairment

The methodology used to develop the projections presented in this report drew on a wide range of data sources and reports were used, including the following:

1. State-developed projections of county populations broken down by age and sex for the years 2000, 2005 and 2010

These projections provide the base population base for each of the time periods included in the analysis. The availability of specific age-sex cohort estimates is especially important, given differences in impairment levels and institutionalization rates for males and females and for different age groups. These projections were provided by the North Carolina Office of State Planning.

2. U.S. Census data and projections of age-sex-race cohorts for individual counties for the years 1990 and 1998

These data sets were used to estimate the change in racial composition for specific age-sex cohorts over time on a county-by-county basis. Since functional impairment levels vary by race (white versus non-white), trends in racial composition of age-sex cohorts on the county level were incorporated as a key part of the projection methodology.

3. Data from North Carolina Department of Corrections and federal Bureau of Prison Statistics on prison populations

These sources provide the basis for estimates of numbers of prisoners in state and federal correctional facilities for each age-sex-race cohort for each county. Data from these sources were current as of 1999-2000, so no adjustments were made to these estimates.

4. Data on residential long-term care populations

Several sources were used to estimate the size and composition of the population receiving long-term care in a residential setting in each county. These include a 1995 report on adult care homes in North Carolina by Research Triangle Institute; a 1990 census database on adult care home residents developed by Dr. Elise Bolda; a 1999 quality assurance report on North Carolina nursing facility residents prepared by the University of Wisconsin Center for Health Systems Research Analysis; a special report on characteristics of ICF-MR/DD residents prepared by the North Carolina Department of Health and Human Services; the 1985 National Nursing Home Survey and the 1996 Chartbook on Disabilities.

5. Estimates of the prevalence of institutionalization and functional impairment among the elderly from the National Long-Term Care Survey (NLTCS 1982, 1989, 1994)

The NLTCS has been provides data on functional impairment levels in terms of ADLs and IADLs, broken down by age-sex and age-race cohorts for elderly living in institutional and community settings. Detailed estimates from the 1989 NLTCS were used to establish base rates of functional impairment at the IADL-only, 1-2 ADLs and 3+ ADLs among community-dwelling elderly by age-sex-race cohort. Analysis of trends in institutionalization and functional impairment over the period 1982-1994 yielded adjustment factors that were used to forecast prevalence rates for 2000, 2005 and 2010.[4]

6. Data from the 1994 Survey of Income and Program Participation on functional impairment among working-age adults

Data from the 1994 SIPP provides the basis for estimating the prevalence of functional limitation among persons aged 18 to 64, including IADL-only, 1-2 ADLs and 3+ ADLs.

7. Data from the 1994 U.S. Census on total U.S. age-sex-race composition

In order to estimate the impact of the interaction between sex and race (white/non-white) on functional impairment from NLTCS and SIPP, data from the 1994 U.S. Census were used to determine age-sex-race composition of the entire U.S. non-institutional population aged 18 and older.

8. Report by Office of Disability, Aging and Long-Term Care Policy, U.S. Department of Health and Human Services on disability among working-age adults (aged 18 to 64)

This report provided information on sex-distribution of adults with disabilities and on prevalence of mental retardation and developmental disabilities among persons under age 65, based on data from the 1990 Survey of Income and Program Participation (SIPP).

9. Data from the 1990 and 1998 U.S. Census and 1992 SIPP on poverty rates

These two sources were used to estimate county-specific poverty rates for each age-sex-race cohort for the year 2000, and then estimate corresponding rates of poverty among community-dwelling persons with long-term care needs. The same trends in poverty estimated for 2000 were forecast for 2005 and 2010.

10. Findings from Liu et al. (2000) from 1994 NLTCS on formal and informal care

This report was used to project use of formal and informal care among community-dwelling seniors with moderate (1-2 ADLs) and high (3+ ADLs) long-term care needs.

11. Findings from Jackson (1991) on unmet need among community-dwelling elderly

This report was used to develop estimates prevalence of unmet ADL needs among community-dwelling seniors, based on data from the 1984 NLTCS.

[4] These adjustment factors were estimated separately for males and females and for different levels of impairment. In addition, the trend observed for each group was forecast to continue at 50% of the rate observed over the period 1982-1994, thus generating a somewhat conservative estimate of the degree of change in future impairment levels.

IV. Results: Projected Population Needing Long-Term Care for 2000, 2005 and 2010

Table 1 presents projected growth for the population aged 18 and older for North Carolina as a whole over the period 2000 to 2010. Separate population projections are shown for distinct age-sex-race subgroups, as well as the projected percentage increase for each subgroup. As can be seen, the total population in North Carolina aged 18 and older is projected to grow 14% between 2000 and 2010, from 5.86 million to 6.69 million. Growth rates across different age-sex-race subgroups are projected to range from less than 12% for non-white males aged 18-64 to approximately 28% for white males 65 and older. Of particular interest is the projected 22% increase in persons aged 65 and older, from less than 1 million persons in 2000 to nearly 1.22 million persons in 2010. This large growth among the elderly has a strong effect on the projections of persons needing long-term care that will be presented below.

TABLE 1 - Total Persons Aged 18+ By Age, Sex and Race

Age-Sex-Race Cohort	2000	2005	2010	*% Change 2000-2010*
Ages 18-64	**4,865,700**	**5,199,700**	**5,467,400**	***12.4%***
Female, White	1,678,900	1,795,100	1,888,900	*12.5%*
Female, Non-White	786,300	838,400	882,400	*12.2%*
Male, White	1,662,200	1,779,400	1,870,700	*12.5%*
Male, Non-White	738,300	786,800	825,400	*11.8%*
Ages 65+	**999,200**	**1,082,100**	**1,219,300**	***22.0%***
Female, White	439,000	471,100	522,500	*19.0%*
Female, Non-White	163,500	173,700	191,200	*16.9%*
Male, White	298,000	329,300	381,300	*28.0%*
Male, Non-White	98,700	108,000	124,300	*25.9%*
Ages 18+	**5,864,900**	**6,281,800**	**6,686,700**	***14.0%***
Female, White	2,117,900	2,266,200	2,411,400	*13.9%*
Female, Non-White	949,800	1,012,100	1,073,600	*13.0%*
Male, White	1,960,200	2,108,700	2,252,000	*14.9%*
Male, Non-White	837,000	894,800	949,700	*13.5%*

Table 2 presents the projected persons aged 18 and older needing long-term care for the years 2000, 2005 and 2010 state of North Carolina as a whole, by level of functional impairment and setting of care:

TABLE 2 - Persons Aged 18+ With Long-Term Care Needs				
Level of Impairment and Care Setting	**2000**	**2005**	**2010**	***% Change 2000-2010***
Community-Dwelling	**308,800**	**337,500**	**366,700**	***18.8%***
(includes adult care home residents)				
IADL Impairments Only	123,600	134,400	143,500	*16%*
1-2 ADL Impairments	105,400	114,800	124,800	*18%*
3+ ADL Impairments	79,800	88,400	98,400	*23%*
Institutional Residents	**42,700**	**45,500**	**51,700**	***21.1%***
(includes all nursing and intermediate care institutions)				
Total Long-Term Care	**351,600**	**383,100**	**418,400**	***19.0%***

Detailed regional and county projections of residents with long-term care needs for the years 2000, 2005 and 2010 are attached as Appendix A.1 to this report.

The estimates of the population 18 and over by both institutional and non-institutional settings do not imply or reflect policy. For policy analysis purposes, we assume the demand for long-term care is simply the aggregate of our institutional and non-institutional profiles of persons with long-term care needs. Policy options can then be introduced that express strategies for preferred utilization rates for nursing home care, residential care and home/community based services.

Given their prominent role in North Carolina's current service environment for long-term care, a separate set of projections was developed for adult care homes. Adult care homes are classified as "group quarters" rather than as "institutions", and thus the estimated number of adult care home residents with long-term care needs (e.g., at least 1 ADL or IADL impairment) is included in the table above in the "community dwelling" category. **Table 3** presents projections of the total number of adult care home residents (including homes for the aged, family care homes, homes for the developmentally disabled and non-institutional intermediate care facilities for the mentally retarded) for the years 2000, 2005 and 2010, regardless of level of impairment among the resident population.

TABLE 3: Persons Aged 18+ Residing In Adult Care Homes				
Adult Care Home Category	**2000**	**2005**	**2010**	***% Change 2000-2010***
Homes For The Aged	23,800	26,500	29,600	*24%*
Family Care and Developmentally Disabled Homes	3,900	4,100	4,400	*15%*
Intermediate Care Facilities For The Mentally Retarded *(less than 40 beds)*	1,900	2,000	2,100	*11%*
Total Adult Care Home Population	**29,600**	**32,700**	**36,100**	***22.0%***

NOTE: Since many adult care home residents do not have IADL or ADL impairments, not all persons projected as adult care home residents in Table 3 are included in Table 2 above.

Unlike the projections developed for numbers of community-dwelling persons and institutional residents with long-term care needs, the projections for number of adult care home residents shown in Table 3 do not account for declining rates of impairment among the elderly. They assume the same rates of utilization of adult care homes by age-sex-race cohort for the years 2005 and 2010 as estimated for 2000. They do not account for any planned policy or regulator changes governing adult care homes, such as the current state-only assistance demonstration for potential adult care home residents. For these reasons, they should be considered as and estimated "upper bound" of likely demand, based on current occupancy rates and prior studies of resident characteristics.

V. Income and Sources of Care Among Persons with Long-Term Care Needs

Income patterns and the availability of informal support (i.e., unpaid care) both play important roles in determining the demand for formal care services and in planning and budgeting for publicly-funded long-term care services. As noted above, these projections assume that the same trends in income and use of formal and informal care projected for 2000 would continue through 2005 and 2010.

Table 4 shows projected income levels among community-dwelling persons and payment sources among institutional residents for persons aged 18 and older with long-term care needs for 2000, 2005 and 2010.

TABLE 4 - Persons Aged 18+ With Long-Term Care Needs By Income Grouping/Payment Source

Income Grouping/Payment Source	2000	2005	2010	*% Change 2000-2010*
Community-Dwelling, 1-2 ADL Impairments				
Total Community-Dwelling, 1-2 ADLs *(100%)*	105,400	114,800	124,800	18.4%
Income Less Than Poverty *(25%)*	26,000	28,200	30,700	18%
Income 100% to 200% of Poverty *(33%)*	34,800	37,700	41,100	18%
Income More Than 200% of Poverty *(42%)*	44,600	48,900	53,000	19%
Community-Dwelling, 3+ ADL Impairments				
Total Community-Dwelling, 3+ ADLs *(100%)*	79,800	88,400	98,400	23.2%
Income Less Than Poverty *(34%)*	27,400	30,400	34,000	24%
Income 100% to 200% of Poverty *(41%)*	32,400	35,900	40,300	24%
Income More Than 200% of Poverty *(25%)*	20,000	22,100	24,100	20%
Institutional Residents By Payment Source				
Total Institutional Residents*(100%)*	42,700	45,500	51,700	21.1%
Medicaid Per Diem *(49%)*	20,800	22,200	25,200	21%
Medicaid w/ Liability/Medicare Copay *(20%)*	8,500	9,100	10,300	21%
Other *(31%)*	13,400	14,200	16,200	21%

These projections are presented in detail for individual regions and counties in Appendix A.2 of this report.

Table 5 presents projections of utilization of formal and informal support among community-dwelling persons aged 65 and older, based on level of functional impairment, where "formal support" is defined as receiving paid assistance and "informal support" as receiving unpaid assistance." Table 5 above also includes projections persons aged 65 and older who have unmet ADL needs, defined as requiring human assistance to perform an ADL task but not receiving the assistance that is required.[5]

TABLE 5 - Community-Dwelling Persons Aged 65+ With Long-Term Care Needs By Source of Care			
Level of Impairment/Source of Care	**2000**	**2005**	**2010**
Community-Dwelling, 65+, 1-2 ADL Impairments			
Total *(100%)*	66,500	71,800	78,900
Formal (Paid) Support Only *(8%)*	5,500	6,000	6,600
Informal (Unpaid) Support Only *(57%)*	37,600	40,600	44,600
Both Formal And Informal *(23%)*	15,500	16,700	18,300
Neither Formal Nor Informal *(12%)*	7,900	8,500	9,400
Persons With Any Unmet ADL Needs (8.4%)	*5,600*	*6,000*	*6,600*
Community-Dwelling, 65+, 3+ ADL Impairments			
Total *(100%)*	64,900	72,000	80,800
Formal (Paid) Support Only *(4%)*	2,400	2,700	3,000
Informal (Unpaid) Support Only *(49%)*	31,700	35,100	39,400
Both Formal And Informal *(46%)*	29,800	33,100	37,100
Neither Formal Nor Informal *(1%)*	1,000	1,100	1,300
Persons With Any Unmet ADL Needs (8.0%)	*5,200*	*5,800*	*6,500*

For detailed regional and county projections, please refer to Appendices A.3 and A.4 to this report.

VI. Mental Retardation and Developmental Disabilities Among Working-Age Adults

Very few persons with mental retardation and developmental disability (MR/DD) are elderly, with just .1% of those 70 and older are classified MR/DD.[6] Therefore, the projections in this report for the MR/DD population will focus on those under age 65. From the 1990 SIPP, an estimated .7% of the working-age noninstitutionalized adults have some form of MR/DD, and of these, 63.2% have long-term care needs (defined as needing assistance with at least 1 ADL or IADL). In addition, the overall prevalence rate of MR/DD appears to be higher among males (.8%) than among females (.6%), and among non-whites (1.1%) than among whites (.6%).

[5] This definition is restricted to elderly persons with ADL impairments lasting three months or more, and matches the "SMI-1" definition of unmet need presented in Jackson (1991).
[6] As reported in *Chartbook on Disability in the United States, 1996*.

Using these findings from the 1990 SIPP, the number of noninstitutionalized persons in each county aged 18 to 64 with some form of MR/DD and the number with MR/DD requiring long-term care was projected for 2000, 2005 and 2010, adjusting for differences in sex/race population make-up. **Table 6** presents corresponding statewide projections of working-age adults with any MR/DD and those with MR/DD that requires at least some ADL or IADL assistance.

TABLE 6 – Prevalence of MR/DD Among Persons 18-64			
Measure of Impairment	**2000**	**2005**	**2010**
Persons Aged 18-64 with Disabling MR/DD Condition	34,300	36,600	38,600
Those With Disabling MR/DD Needing Assistance With At Least 1 ADL Or IADL	21,700	23,200	24,400
Total Persons Aged 18-64 Needing Assistance With 1+ ADLs or IADLs	*145,000*	*159,900*	*171,300*

These estimates are presented on a county-by-county basis in Appendix A.5 to this report.

VII. Limitations Of the Projection Methodology And Further Areas For Analysis

As can be seen from the discussions in Sections II and III of the data sources and methodologies used in preparing the above projections, there are several significant components that rely on various assumptions and estimation methodologies which contribute to the end-results.

- County-by-county trends in racial composition (white/non-white) estimated for the period 1990 to 1998 based on U.S. Census data remain constant through 2000, 2005 and 2010.

- The age-sex-race composition of residents long-term care facilities (both institutions and other care homes) remain constant over time. The projections assume that the prevalence rate of nursing facility utilization among the elderly will decline at 50% of the trend observed during the period 1982-1994 on the NLTCS, while intermediate care facility and adult care home utilization will continue at the same rate as estimated for 2000. Also, residents of nursing home facilities in a particular county are assumed to have the same race composition for a given age-sex county as estimated for adult care homes residents in that county.

- Changes in relative rates of functional impairment by sex and impairment level among the elderly continue at 50% of the level observed during the period 1982-1994, and are consistent across racial subgroups (white/non-white). The relative racial differences (white/non-white) in functional impairment rates are assumed to be the same among males and females within a given age cohort, for both elderly and non-elderly community-dwelling persons.

- With respect to income, sources of care and prevalence of unmet ADL needs, the same trends estimated for 2000 are expected to continue through 2005 and 2010. Also, the projections assume that rates of state-support are the same for persons in ICF and developmentally-disabled group home settings.

In preparing this final report, these assumptions have all been carefully reviewed. In some instances, methodological assumptions were made due to incomplete data on historical trends or current population characteristics. Other assumptions are forward-looking, forecasting future demand for long-term care based on historical trends and current conditions. Finally, this report does not present certain projections

due to a lack of available data and/or challenges to developing a robust estimating methodology, including:

- Level of impairment among long-term care institutional residents, in terms of ADL limitations, for both nursing facilities and intermediate care facility for the mentally retarded
- Level of ADL and IADL impairment among adult care home residents
- Income levels among persons aged 18 and older with IADL limitations only
- Source of care and prevalence of unmet needs among persons aged 65 and older with IADL limitations only
- Source of care and prevalence of unmet needs among persons aged 18 to 64 with any level of long-term care needs (IADLs only, 1-2 ADLs, 3+ ADLs)
- Detailed level of impairment (IADLs only, 1-2 ADLs, 3+ ADLs) among community-dwelling mentally retarded and developmentally disabled persons with long-term care needs (defined as 1 or more IADL or ADL limitations)

These and other issues not addressed in this report would constitute important extensions for future analysis and projections related to long-term care planning, policy development, budgeting and new program initiatives in North Carolina.

VIII. References and Data Sources

State of North Carolina, Office of State Planning website on county population projections for the years 2000, 2005 and 2010.

1990, 1992 and 1994 Survey of Income and Program Participation (SIPP) data on severe functional impairment among working-age adults.

U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy website: Conditions and Impairments Among the Working-Age Population with Disabilities. (Includes findings from 1990 SIPP).

Manton, Kenneth G.; Corder, Larry; and Stallard, Eric. "Chronic Disability Trends in Elderly United States Populations: 1982-198.," Proceedings of the National Academy of Sciences, vol. 94: March, 1997.

Liu, Korbin, Manton, Kenneth G. and Aragon, Cynthia. "Changes in Home Care Use by Older People With Disabilities: 1982-1994." AARP Public Policy Institute: January 2000.

Jackson, Mary E. "Prevalence And Correlates Of Unmet Need Among The Elderly With ADL Disabilities." U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy: February, 1991.

U.S. Census Bureau website (various reports on projected changes in county age-sex-race composition between 1990 and 1998; poverty, 1990 and 1998; population living in group quarters by county, 1990; total U.S. elderly population age-sex-race composition, 1990).

1989 National Long-Term Care Survey summary data on institutionalization and impairment among the elderly, compiled by the National Aging Information Center, 1996.

1985 National Nursing Home Survey.

National Institute on Disability and Rehabilitation Research. Chartbook on Disability in the United States: 1996. (Includes findings from 1992 SIPP and 1992 NHIS).

Hawes, Catherine, et al. "Study of North Carolina Domiciliary Care Home Residents." Research Triangle Institute: February, 1995.

Older Americans 2000: Key Indicators Of Well-Being. Federal Inter-Agency Forum On Aging-Related Statistics: 2000.

APPENDIX A.1

PROJECTED PERSONS AGED 18 AND OLDER NEEDING LONG-TERM CARE BY AREA AGENCY ON AGING (AAA) REGIONS AND SELECTED COUNTIES

	2000						2005						2010					
	Community-Dwelling						Community-Dwelling						Community-Dwelling					
	IADLs Only	1-2 ADLs	3+ ADLs	All Levels	LTC Inst.	All LTC	IADLs Only	1-2 ADLs	3+ ADLs	All Levels	LTC Inst.	All LTC	IADLs Only	1-2 ADLs	3+ ADLs	All Levels	LTC Inst.	All LTC
All Regions	**123,609**	**105,404**	**79,829**	**308,842**	**42,744**	**351,586**	**134,407**	**114,785**	**88,351**	**337,543**	**45,542**	**383,084**	**143,518**	**124,799**	**98,396**	**366,713**	**51,707**	**418,421**
Southwestern																		
Region	**2,768**	**2,907**	**2,287**	**7,961**	**1,035**	**8,996**	**2,947**	**3,170**	**2,557**	**8,673**	**1,091**	**9,764**	**3,054**	**3,436**	**2,857**	**9,347**	**1,319**	**10,666**
Haywood	885	963	754	2,601	401	3,002	932	1,045	841	2,818	419	3,237	963	1,133	945	3,042	498	3,540
Land-of-Sky																		
Region	**5,343**	**5,492**	**4,309**	**15,144**	**3,163**	**18,307**	**5,737**	**5,939**	**4,764**	**16,441**	**3,353**	**19,794**	**5,995**	**6,404**	**5,274**	**17,673**	**3,775**	**21,448**
Buncombe	3,134	3,047	2,356	8,536	1,941	10,477	3,347	3,255	2,564	9,166	2,046	11,212	3,499	3,471	2,801	9,771	2,240	12,011
Henderson	1,430	1,622	1,313	4,365	787	5,151	1,563	1,785	1,475	4,823	852	5,675	1,645	1,965	1,674	5,283	997	6,281
Isothermal																		
Region	**3,500**	**3,339**	**2,595**	**9,433**	**1,205**	**10,638**	**3,660**	**3,527**	**2,801**	**9,988**	**1,254**	**11,242**	**3,779**	**3,737**	**3,044**	**10,560**	**1,357**	**11,917**
Cleveland	1,543	1,401	1,087	4,031	487	4,518	1,611	1,486	1,181	4,279	502	4,781	1,663	1,578	1,290	4,531	574	5,105
McDowell	690	648	484	1,822	165	1,987	729	691	526	1,946	174	2,120	761	744	584	2,089	154	2,243
Rutherford	953	925	722	2,601	283	2,884	984	958	761	2,704	291	2,995	1,005	992	804	2,802	309	3,111
Region D																		
Region	**2,901**	**2,773**	**2,072**	**7,746**	**1,083**	**8,830**	**3,042**	**2,968**	**2,269**	**8,280**	**1,117**	**9,397**	**3,124**	**3,165**	**2,486**	**8,775**	**1,275**	**10,050**
Watauga	618	520	368	1,506	95	1,600	663	572	416	1,650	100	1,750	696	624	467	1,787	121	1,908
Wilkes	986	902	664	2,552	389	2,940	1,032	969	731	2,732	402	3,134	1,060	1,029	798	2,887	465	3,352
Western Piedmont																		
Region	**4,911**	**4,338**	**3,160**	**12,409**	**2,308**	**14,717**	**5,215**	**4,674**	**3,482**	**13,371**	**2,420**	**15,791**	**5,486**	**5,085**	**3,905**	**14,475**	**2,700**	**17,175**
Burke	1,298	1,193	886	3,376	823	4,199	1,360	1,273	967	3,601	861	4,461	1,435	1,388	1,086	3,908	927	4,835
Caldwell	1,129	1,010	736	2,875	382	3,257	1,184	1,077	802	3,063	393	3,457	1,224	1,160	892	3,276	461	3,737
Catawba	2,010	1,729	1,250	4,989	936	5,925	2,157	1,875	1,386	5,417	987	6,404	2,279	2,036	1,552	5,868	1,095	6,963
Centralina																		
Region	**22,301**	**18,260**	**13,442**	**54,002**	**7,516**	**61,518**	**24,575**	**20,005**	**14,919**	**59,499**	**8,111**	**67,610**	**26,711**	**21,925**	**16,674**	**65,310**	**9,188**	**74,498**
Cabarrus	1,893	1,658	1,230	4,781	661	5,442	2,089	1,809	1,360	5,258	725	5,983	2,267	1,983	1,519	5,768	787	6,556
Gaston	2,715	2,343	1,723	6,781	1,082	7,863	2,822	2,430	1,809	7,062	1,107	8,169	2,891	2,523	1,929	7,342	1,204	8,547
Iredell	1,840	1,625	1,230	4,694	528	5,222	2,023	1,803	1,392	5,218	575	5,793	2,186	1,982	1,563	5,731	664	6,395
Lincoln	892	757	542	2,191	313	2,504	983	846	622	2,450	340	2,790	1,060	932	699	2,691	406	3,097
Mecklenburg	9,946	7,459	5,347	22,752	3,158	25,910	11,214	8,349	6,049	25,612	3,475	29,087	12,491	9,357	6,913	28,762	4,054	32,816
Rowan	2,045	1,916	1,505	5,466	915	6,381	2,198	2,040	1,631	5,869	974	6,843	2,324	2,162	1,755	6,240	1,050	7,290
Stanly	851	790	598	2,239	427	2,666	889	822	635	2,346	442	2,789	921	852	665	2,437	469	2,906
Union	1,665	1,284	896	3,845	323	4,168	1,895	1,473	1,041	4,409	363	4,772	2,114	1,699	1,238	5,051	440	5,491

PROJECTED PERSONS AGED 18 AND OLDER NEEDING LONG-TERM CARE BY AREA AGENCY ON AGING (AAA) REGIONS AND SELECTED COUNTIES

	2000						2005						2010					
	Community-Dwelling						Community-Dwelling						Community-Dwelling					
	IADLs Only	1-2 ADLs	3+ ADLs	All Levels	LTC Inst.	All LTC	IADLs Only	1-2 ADLs	3+ ADLs	All Levels	LTC Inst.	All LTC	IADLs Only	1-2 ADLs	3+ ADLs	All Levels	LTC Inst.	All LTC
Piedmont Triad																		
Region	**14,703**	**12,837**	**9,763**	**37,303**	**4,868**	**42,171**	**15,793**	**13,836**	**10,711**	**40,340**	**5,166**	**45,506**	**16,623**	**14,837**	**11,778**	**43,239**	**5,869**	**49,108**
Alamance	2,019	1,922	1,483	5,423	588	6,011	2,161	2,059	1,622	5,842	643	6,485	2,273	2,200	1,779	6,252	701	6,953
Davidson	2,183	1,880	1,362	5,424	814	6,238	2,360	2,056	1,526	5,942	868	6,810	2,501	2,230	1,691	6,421	1,012	7,434
Guilford	6,700	5,638	4,349	16,686	2,355	19,041	7,215	6,086	4,763	18,064	2,479	20,543	7,612	6,543	5,268	19,424	2,833	22,257
Randolph	1,859	1,630	1,183	4,671	637	5,309	2,039	1,795	1,332	5,166	690	5,856	2,183	1,966	1,488	5,637	797	6,435
Rockingham	1,541	1,418	1,116	4,075	372	4,447	1,601	1,481	1,186	4,268	381	4,649	1,630	1,532	1,260	4,422	415	4,837
Northwest Piedmont																		
Region	**7,706**	**6,831**	**5,224**	**19,761**	**2,974**	**22,735**	**8,213**	**7,348**	**5,727**	**21,288**	**3,118**	**24,406**	**8,662**	**7,882**	**6,295**	**22,840**	**3,559**	**26,399**
Davie	515	476	357	1,348	239	1,587	559	531	411	1,500	256	1,756	586	576	458	1,620	309	1,929
Forsyth	4,878	4,200	3,262	12,340	1,908	14,248	5,179	4,474	3,533	13,185	1,979	15,165	5,463	4,766	3,856	14,084	2,235	16,320
Stokes	662	557	397	1,616	310	1,927	726	625	455	1,805	338	2,143	778	691	515	1,984	395	2,378
Surry	1,078	1,048	793	2,920	310	3,230	1,133	1,120	867	3,121	323	3,444	1,177	1,194	949	3,321	366	3,687
Yadkin	572	549	415	1,537	207	1,744	617	597	462	1,676	223	1,899	659	655	517	1,831	254	2,085
Triangle J																		
Region	**18,751**	**14,664**	**10,699**	**44,114**	**5,329**	**49,443**	**21,322**	**16,611**	**12,266**	**50,198**	**5,880**	**56,078**	**23,695**	**18,769**	**14,187**	**56,652**	**6,818**	**63,470**
Chatham	832	759	599	2,190	356	2,546	925	846	680	2,451	389	2,840	994	936	776	2,706	462	3,168
Durham	3,310	2,499	1,864	7,673	1,478	9,151	3,567	2,627	1,953	8,147	1,560	9,707	3,794	2,764	2,072	8,630	1,569	10,199
Johnston	1,748	1,481	1,097	4,326	438	4,764	1,974	1,668	1,254	4,897	492	5,388	2,184	1,876	1,441	5,501	570	6,071
Lee	843	758	594	2,195	214	2,409	930	842	671	2,443	233	2,676	998	933	770	2,702	280	2,982
Moore	1,355	1,504	1,266	4,125	427	4,552	1,508	1,684	1,456	4,647	467	5,114	1,600	1,868	1,675	5,142	578	5,721
Orange	1,695	1,261	886	3,842	543	4,385	1,897	1,411	1,002	4,310	595	4,904	2,077	1,587	1,162	4,825	705	5,530
Wake	8,968	6,401	4,394	19,762	1,874	21,636	10,520	7,533	5,250	23,303	2,145	25,448	12,048	8,807	6,292	27,146	2,654	29,800
Kerr-Tar																		
Region	**3,217**	**2,799**	**2,266**	**8,282**	**1,536**	**9,818**	**3,448**	**2,972**	**2,433**	**8,853**	**1,640**	**10,493**	**3,670**	**3,185**	**2,653**	**9,507**	**1,677**	**11,184**
Franklin	776	650	510	1,935	245	2,180	865	718	567	2,150	271	2,421	951	786	627	2,364	290	2,654
Granville	711	608	486	1,805	731	2,536	760	643	518	1,922	787	2,709	834	707	577	2,118	757	2,876
Person	599	543	435	1,577	132	1,709	634	573	468	1,675	139	1,814	663	609	508	1,780	152	1,932
Vance	734	613	489	1,835	282	2,117	768	634	509	1,912	292	2,204	790	655	538	1,982	306	2,288
Upper Coastal Plain																		
Region	**5,200**	**4,458**	**3,581**	**13,239**	**1,585**	**14,825**	**5,455**	**4,655**	**3,789**	**13,899**	**1,641**	**15,540**	**5,586**	**4,827**	**4,017**	**14,430**	**1,789**	**16,220**
Edgecombe	991	836	687	2,513	243	2,756	1,007	843	701	2,551	242	2,793	997	844	718	2,558	250	2,808
Halifax	1,018	908	769	2,695	283	2,978	1,046	928	799	2,773	287	3,060	1,047	928	813	2,788	296	3,084
Nash	1,529	1,270	961	3,760	518	4,279	1,678	1,387	1,064	4,129	560	4,688	1,795	1,503	1,179	4,477	633	5,110
Wilson	1,227	1,040	809	3,076	405	3,481	1,279	1,084	857	3,220	415	3,635	1,307	1,133	923	3,362	463	3,825

PROJECTED PERSONS AGED 18 AND OLDER NEEDING LONG-TERM CARE BY AREA AGENCY ON AGING (AAA) REGIONS AND SELECTED COUNTIES

	2000						2005						2010					
	Community-Dwelling						Community-Dwelling						Community-Dwelling					
	IADLs Only	1-2 ADLs	3+ ADLs	All Levels	LTC Inst.	All LTC	IADLs Only	1-2 ADLs	3+ ADLs	All Levels	LTC Inst.	All LTC	IADLs Only	1-2 ADLs	3+ ADLs	All Levels	LTC Inst.	All LTC
Mid-Carolina																		
Region	**6,719**	**5,085**	**3,699**	**15,502**	**1,759**	**17,261**	**7,308**	**5,618**	**4,186**	**17,112**	**1,878**	**18,990**	**7,789**	**6,135**	**4,706**	**18,629**	**2,283**	**20,912**
Cumberland	4,410	3,093	2,149	9,651	940	10,592	4,794	3,450	2,474	10,718	995	11,713	5,095	3,779	2,808	11,682	1,285	12,967
Harnett	1,335	1,121	850	3,306	507	3,813	1,483	1,241	951	3,675	555	4,230	1,623	1,376	1,077	4,077	636	4,712
Sampson	974	871	700	2,545	312	2,857	1,032	927	761	2,720	328	3,048	1,070	980	821	2,871	362	3,233
Lumber River																		
Region	**4,523**	**3,710**	**2,947**	**11,180**	**1,112**	**12,292**	**4,776**	**3,902**	**3,148**	**11,826**	**1,157**	**12,983**	**4,935**	**4,105**	**3,401**	**12,441**	**1,271**	**13,711**
Richmond	770	692	546	2,008	214	2,223	782	697	558	2,037	216	2,253	784	711	587	2,082	230	2,312
Robeson	2,064	1,620	1,290	4,974	420	5,394	2,188	1,716	1,389	5,293	439	5,732	2,262	1,794	1,482	5,538	473	6,011
Scotland	603	487	376	1,465	154	1,620	626	506	399	1,531	158	1,689	634	525	424	1,582	171	1,753
Cape Fear																		
Region	**5,377**	**4,748**	**3,642**	**13,767**	**1,530**	**15,297**	**6,019**	**5,383**	**4,217**	**15,619**	**1,685**	**17,304**	**6,534**	**6,061**	**4,908**	**17,504**	**2,112**	**19,616**
Brunswick	1,209	1,095	827	3,131	371	3,502	1,399	1,306	1,014	3,719	422	4,141	1,553	1,524	1,227	4,304	598	4,902
Columbus	913	816	646	2,376	290	2,666	954	860	695	2,508	300	2,809	967	905	756	2,627	339	2,966
New Hanover	2,554	2,215	1,677	6,446	693	7,139	2,859	2,495	1,928	7,282	761	8,043	3,117	2,798	2,231	8,146	923	9,069
Pender	701	622	492	1,814	176	1,990	808	722	580	2,110	201	2,311	898	834	695	2,427	252	2,679
Eastern Carolina																		
Region	**9,162**	**7,549**	**5,711**	**22,422**	**3,566**	**25,988**	**9,871**	**8,203**	**6,324**	**24,399**	**3,737**	**28,136**	**10,497**	**8,898**	**7,056**	**26,451**	**4,216**	**30,667**
Carteret	110	96	73	279	-	279	118	104	81	303	-	303	121	109	87	317	-	317
Craven	1,432	1,232	949	3,612	525	4,138	1,553	1,348	1,059	3,960	556	4,516	1,651	1,474	1,202	4,328	669	4,997
Duplin	791	703	566	2,060	259	2,319	837	743	607	2,187	273	2,460	868	781	651	2,300	293	2,593
Lenoir	1,075	961	775	2,811	917	3,728	1,084	980	811	2,874	929	3,803	1,106	1,023	873	3,003	955	3,957
Onslow	1,893	1,240	802	3,935	334	4,269	2,113	1,409	934	4,457	365	4,821	2,350	1,593	1,088	5,031	479	5,510
Wayne	1,850	1,481	1,105	4,436	807	5,242	1,979	1,601	1,220	4,800	847	5,647	2,089	1,722	1,347	5,158	919	6,077
Mid-East Commission																		
Region	**4,064**	**3,416**	**2,686**	**10,165**	**1,226**	**11,391**	**4,356**	**3,628**	**2,888**	**10,872**	**1,282**	**12,154**	**4,565**	**3,830**	**3,101**	**11,496**	**1,393**	**12,890**
Beaufort	781	717	578	2,076	274	2,350	814	748	611	2,172	282	2,454	820	775	651	2,245	302	2,547
Pitt	2,018	1,563	1,149	4,730	467	5,198	2,247	1,723	1,285	5,255	510	5,766	2,459	1,888	1,427	5,774	575	6,350
Albemarle Commission																		
Region	2,464	2,200	1,746	6,410	950	7,360	2,668	2,346	1,872	6,886	1,010	7,896	2,812	2,518	2,055	7,384	1,106	8,490
Pasquotank	612	551	452	1,615	243	1,858	665	586	484	1,736	260	1,995	705	630	533	1,869	283	2,152

NOTES: "IADLs Only" refers to persons with Instrumental Activities of Daily Living (using the telephone, preparing meals, doing housework, etc.) impairments only.
"1-2 ADLs" refers to persons with one or two Activities of Daily Living (bathing, mobility within home, dressing, etc.) impairments.
"3+ ADLs" refers to persons with three or more Activities of Daily Living (bathing, mobility within home, dressing, etc.) impairments.
"LTC Inst." (Long-Term Care Institutions) includes residents of both nursing facilities and intermediate care facilities for the mentally retarded.
"All LTC" includes all of the categories listed above.
County-specific projections are presented only for those counties with at least 25,000 residents aged 18 and older as of April 2000.

APPENDIX A.2

PROJECTED INCOME LEVELS AND PAYMENT SOURCES FOR PERSONS AGED 18 AND OLDER NEEDING LONG-TERM CARE BY AREA AGENCY ON AGING (AAA) REGIONS AND SELECTED COUNTIES

	2000						2005						2010					
	Community-Dwelling				LTC Institution		Community-Dwelling				LTC Institution		Community-Dwelling				LTC Institution	
	1-2 ADLs		3+ ADLs				1-2 ADLs		3+ ADLs				1-2 ADLs		3+ ADLs			
	Below Pov.	1x - 2x Pov.	Below Pov.	1x - 2x Pov.	MA Only	MA Liab, MCR Co.	Below Pov.	1x - 2x Pov.	Below Pov.	1x - 2x Pov.	MA Only	MA Liab, MCR Co.	Below Pov.	1x - 2x Pov.	Below Pov.	1x - 2x Pov.	MA Only	MA Liab, MCR Co.
All Regions	**25,998**	**34,782**	**27,446**	**32,418**	**20,859**	**8,549**	**28,204**	**37,675**	**30,431**	**35,939**	**22,224**	**9,108**	**30,675**	**41,063**	**34,005**	**40,276**	**25,233**	**10,341**
Southwestern																		
Region	**857**	**1,193**	**881**	**1,068**	**505**	**207**	**932**	**1,298**	**983**	**1,188**	**532**	**218**	**1,014**	**1,419**	**1,102**	**1,335**	**644**	**264**
Haywood	223	334	233	339	196	80	244	367	263	384	204	84	269	300	405	439	243	100
Land-of-Sky																		
Region	**1,155**	**1,513**	**1,214**	**1,505**	**1,544**	**633**	**1,261**	**1,630**	**1,360**	**1,666**	**1,636**	**671**	**1,374**	**1,758**	**1,525**	**1,846**	**1,842**	**755**
Buncombe	628	933	664	964	947	388	672	995	728	1,056	999	409	720	801	1,065	1,163	1,093	448
Henderson	243	360	254	368	384	157	269	398	288	418	416	170	299	330	444	480	487	199
Isothermal																		
Region	**843**	**1,262**	**934**	**1,265**	**588**	**241**	**888**	**1,327**	**1,010**	**1,376**	**612**	**251**	**938**	**1,403**	**1,096**	**1,517**	**662**	**271**
Cleveland	351	522	384	558	238	97	374	557	421	612	245	100	401	464	597	676	280	115
McDowell	155	232	184	234	81	33	162	243	197	261	85	35	169	211	252	301	75	31
Rutherford	263	396	286	354	138	57	272	408	303	372	142	58	282	322	423	395	151	62
Region D																		
Region	**936**	**1,120**	**972**	**855**	**529**	**217**	**1,011**	**1,212**	**1,075**	**942**	**545**	**223**	**1,094**	**1,317**	**1,191**	**1,043**	**622**	**255**
Watauga	141	195	131	183	46	19	157	218	150	210	49	20	174	171	242	240	59	24
Wilkes	299	352	316	256	190	78	325	383	353	284	196	80	352	390	416	312	227	93
Western Piedmont																		
Region	**884**	**1,321**	**925**	**1,305**	**1,126**	**462**	**959**	**1,431**	**1,028**	**1,448**	**1,181**	**484**	**1,061**	**1,588**	**1,173**	**1,652**	**1,317**	**540**
Burke	269	402	282	410	402	165	289	431	311	453	420	172	320	354	478	516	452	185
Caldwell	238	357	250	364	186	76	255	383	274	400	192	79	281	311	422	454	225	92
Catawba	269	399	279	405	457	187	293	434	313	454	481	197	322	355	478	516	534	219
Centralina																		
Region	**3,578**	**5,122**	**3,750**	**5,241**	**3,668**	**1,503**	**3,896**	**5,558**	**4,170**	**5,831**	**3,958**	**1,622**	**4,265**	**6,083**	**4,681**	**6,561**	**4,484**	**1,838**
Cabarrus	317	473	336	489	323	132	342	508	372	541	354	145	375	419	556	608	384	157
Gaston	494	730	519	752	528	216	512	753	548	792	540	221	533	589	784	852	588	241
Iredell	346	513	370	538	257	106	385	570	422	613	280	115	426	479	630	696	324	133
Lincoln	155	231	160	233	153	63	175	259	186	271	166	68	194	212	289	308	198	81
Mecklenburg	1,262	1,759	1,271	1,791	1,541	632	1,410	1,954	1,445	2,034	1,696	695	1,582	1,663	2,188	2,342	1,978	811
Rowan	385	571	418	607	446	183	407	601	455	660	475	195	430	492	635	714	513	210
Stanly	188	281	199	290	208	85	194	290	213	310	216	88	200	224	298	325	229	94
Union	261	386	275	398	158	65	301	443	321	465	177	73	353	389	522	564	215	88

PROJECTED INCOME LEVELS AND PAYMENT SOURCES FOR PERSONS AGED 18 AND OLDER NEEDING LONG-TERM CARE BY AREA AGENCY ON AGING (AAA) REGIONS AND SELECTED COUNTIES

	2000						2005						2010					
	Community-Dwelling				LTC Institution		Community-Dwelling				LTC Institution		Community-Dwelling				LTC Institution	
	1-2 ADLs		3+ ADLs				1-2 ADLs		3+ ADLs				1-2 ADLs		3+ ADLs			
	Below Pov.	1x - 2x Pov.	Below Pov.	1x - 2x Pov.	MA Only	MA Liab, MCR Co.	Below Pov.	1x - 2x Pov.	Below Pov.	1x - 2x Pov.	MA Only	MA Liab, MCR Co.	Below Pov.	1x - 2x Pov.	Below Pov.	1x - 2x Pov.	MA Only	MA Liab, MCR Co.
Piedmont Triad																		
Region	**2,602**	**3,806**	**2,757**	**3,963**	**2,376**	**974**	**2,806**	**4,093**	**3,045**	**4,373**	**2,521**	**1,033**	**3,021**	**4,409**	**3,375**	**4,852**	**2,864**	**1,174**
Alamance	366	548	393	572	287	118	393	586	434	633	314	129	421	480	628	700	342	140
Davidson	398	591	413	599	397	163	438	649	468	679	423	174	480	525	712	762	494	202
Guilford	1,064	1,517	1,120	1,597	1,149	471	1,151	1,636	1,235	1,762	1,210	496	1,244	1,380	1,770	1,972	1,383	567
Randolph	310	465	325	474	311	127	341	511	369	538	337	138	378	418	566	609	389	159
Rockingham	368	544	403	583	182	74	385	568	431	620	186	76	399	461	588	662	202	83
Northwest Piedmont																		
Region	**1,570**	**2,226**	**1,686**	**2,110**	**1,452**	**595**	**1,703**	**2,408**	**1,872**	**2,327**	**1,522**	**624**	**1,844**	**2,606**	**2,082**	**2,577**	**1,737**	**712**
Davie	125	190	135	170	117	48	141	215	158	198	125	51	156	179	238	221	151	62
Forsyth	808	1,165	867	1,244	931	382	864	1,241	945	1,356	966	396	921	1,039	1,324	1,491	1,091	447
Stokes	171	192	185	140	151	62	195	219	215	162	165	68	219	247	248	186	193	79
Surry	295	446	314	379	151	62	317	480	347	416	158	65	341	384	516	458	179	73
Yadkin	170	232	185	176	101	41	186	252	207	196	109	45	206	234	281	221	124	51
Triangle J																		
Region	**2,953**	**3,965**	**3,023**	**3,896**	**2,601**	**1,066**	**3,331**	**4,456**	**3,474**	**4,467**	**2,869**	**1,176**	**3,769**	**5,052**	**4,037**	**5,197**	**3,327**	**1,364**
Chatham	190	285	212	309	174	71	213	318	243	353	190	78	238	281	355	405	225	92
Durham	514	707	526	738	721	296	536	728	550	768	761	312	559	585	755	815	766	314
Johnston	510	546	547	398	214	88	572	612	629	452	240	98	646	727	695	523	278	114
Lee	191	276	203	291	104	43	213	307	230	330	114	47	238	267	344	383	137	56
Moore	290	433	318	462	208	85	326	485	369	537	228	93	365	429	545	626	282	116
Orange	235	306	210	285	265	109	266	344	240	325	290	119	301	281	392	382	344	141
Wake	1,021	1,412	1,007	1,414	914	375	1,206	1,663	1,213	1,701	1,047	429	1,422	1,467	1,966	2,064	1,295	531
Kerr-Tar																		
Region	**924**	**1,214**	**1,033**	**1,019**	**750**	**307**	**974**	**1,276**	**1,111**	**1,087**	**800**	**328**	**1,042**	**1,364**	**1,217**	**1,183**	**818**	**335**
Franklin	205	270	230	219	119	49	225	296	255	242	132	54	244	282	322	268	142	58
Granville	182	263	207	221	357	146	190	275	221	235	384	157	209	246	302	261	370	151
Person	153	226	171	215	65	26	161	237	185	230	68	28	171	203	253	251	74	30
Vance	201	282	214	234	138	56	207	289	224	242	143	58	214	237	298	255	149	61
Upper Coastal Plain																		
Region	**1,550**	**1,992**	**1,689**	**1,594**	**774**	**317**	**1,611**	**2,066**	**1,792**	**1,679**	**801**	**328**	**1,666**	**2,148**	**1,903**	**1,787**	**873**	**358**
Edgecombe	324	349	363	272	118	49	326	349	373	275	118	48	327	384	350	281	122	50
Halifax	352	434	385	351	138	57	360	442	402	362	140	57	360	411	441	368	145	59
Nash	373	542	399	437	253	104	406	587	444	481	273	112	440	494	638	536	309	127
Wilson	339	478	356	380	198	81	354	497	379	402	203	83	372	410	525	436	226	93

PROJECTED INCOME LEVELS AND PAYMENT SOURCES FOR PERSONS AGED 18 AND OLDER NEEDING LONG-TERM CARE BY AREA AGENCY ON AGING (AAA) REGIONS AND SELECTED COUNTIES

	2000						2005						2010					
	Community-Dwelling				LTC Institution		Community-Dwelling				LTC Institution		Community-Dwelling				LTC Institution	
	1-2 ADLs		3+ ADLs				1-2 ADLs		3+ ADLs				1-2 ADLs		3+ ADLs			
	Below Pov.	1x - 2x Pov.	Below Pov.	1x - 2x Pov.	MA Only	MA Liab, MCR Co.	Below Pov.	1x - 2x Pov.	Below Pov.	1x - 2x Pov.	MA Only	MA Liab, MCR Co.	Below Pov.	1x - 2x Pov.	Below Pov.	1x - 2x Pov.	MA Only	MA Liab, MCR Co.
Mid-Carolina																		
Region	**1,482**	**1,866**	**1,524**	**1,654**	**858**	**352**	**1,645**	**2,083**	**1,736**	**1,888**	**916**	**376**	**1,809**	**2,306**	**1,969**	**2,142**	**1,114**	**457**
Cumberland	760	1,038	748	1,027	459	188	862	1,184	876	1,197	486	199	958	1,012	1,323	1,374	627	257
Harnett	373	465	395	358	247	101	412	514	444	400	271	111	459	506	573	454	310	127
Sampson	348	363	381	269	152	62	371	386	416	291	160	66	393	451	410	314	177	72
Lumber River																		
Region	**1,420**	**1,548**	**1,539**	**1,177**	**542**	**222**	**1,492**	**1,619**	**1,653**	**1,249**	**565**	**231**	**1,575**	**1,714**	**1,799**	**1,350**	**620**	**254**
Richmond	222	315	239	254	105	43	222	315	245	259	105	43	227	259	323	272	112	46
Robeson	691	639	749	459	205	84	730	676	810	492	214	88	764	868	708	524	231	95
Scotland	154	214	163	173	75	31	160	222	175	183	77	32	167	187	233	196	83	34
Cape Fear																		
Region	**1,264**	**1,526**	**1,298**	**1,389**	**746**	**306**	**1,430**	**1,744**	**1,504**	**1,632**	**822**	**337**	**1,614**	**1,995**	**1,754**	**1,935**	**1,031**	**422**
Brunswick	273	391	272	388	181	74	330	474	339	484	206	84	391	416	565	598	292	120
Columbus	390	290	421	184	142	58	412	306	457	196	147	60	438	501	327	213	165	68
New Hanover	415	577	406	571	338	139	471	652	472	663	371	152	531	550	738	776	451	185
Pender	186	268	199	245	86	35	217	312	236	289	98	40	253	287	366	348	123	50
Eastern Carolina																		
Region	**2,136**	**2,799**	**2,269**	**2,428**	**1,740**	**713**	**2,315**	**3,039**	**2,518**	**2,701**	**1,824**	**747**	**2,517**	**3,316**	**2,826**	**3,037**	**2,057**	**843**
Carteret	155	222	152	217	542	222	176	252	177	253	565	231	197	205	283	293	191	78
Craven	293	423	308	441	256	105	323	465	348	499	271	111	356	401	515	577	326	134
Duplin	260	309	283	241	126	52	274	326	304	257	133	55	289	328	344	276	143	59
Lenoir	339	440	367	349	448	183	347	449	387	365	453	186	364	419	473	394	466	191
Onslow	265	364	259	350	163	67	306	421	307	413	178	73	350	364	483	487	234	96
Wayne	447	604	477	478	394	161	485	657	531	529	413	169	525	592	714	587	448	184
Mid-East Commission																		
Region	**1,233**	**1,482**	**1,298**	**1,167**	**598**	**245**	**1,309**	**1,568**	**1,403**	**1,248**	**626**	**256**	**1,387**	**1,657**	**1,512**	**1,343**	**680**	**279**
Beaufort	269	309	295	236	134	55	280	323	313	250	138	56	292	337	338	267	147	60
Pitt	550	662	549	492	228	93	606	727	616	550	249	102	663	685	797	611	281	115
Albemarle Commission																		
Region	**612**	**827**	**654**	**784**	**464**	**190**	**642**	**866**	**697**	**836**	**493**	**202**	**685**	**927**	**764**	**917**	**540**	**221**
Pasquotank	174	247	188	233	118	49	185	259	201	248	127	52	199	223	279	274	138	57

NOTES: "1-2 ADLs" refers to persons with one or two Activities of Daily Living (bathing, mobility within home, dressing, etc.) impairments.
"3+ ADLs" refers to persons with three or more Activities of Daily Living (bathing, mobility within home, dressing, etc.) impairments.
"LTC Institution" (Long-Term Care Institutions) includes residents of both nursing facilities and intermediate care facilities for the mentally retarded.
"Below Pov." refers to persons with incomes below the federal poverty line; "1x - 2x Pov." refers to persons with incomes between 100% and 200% of the federal poverty level.
"MA Only" refers to care that is paid solely by Medicaid; "MA Liab., MCR Co." refers to (a) Medicaid beneficiaries with self-pay responsibility or (b) Medicare beneficiaries with copay required.
County-specific projections are presented only for those counties with at least 25,000 residents aged 18 and older as of April 2000.

APPENDIX A.3

PROJECTED SOURCES OF CARE AND UNMET NEED AMONG COMMUNITY-DWELLING PERSONS AGED 65+ WITH 1-2 ADL IMPAIRMENTS BY AREA AGENCY ON AGING (AAA) REGIONS AND SELECTED COUNTIES

	2000					2005					2010				
	Formal Only	Informal Only	Both	Neither	Unmet Needs	Formal Only	Informal Only	Both	Neither	Unmet Needs	Formal Only	Informal Only	Both	Neither	Unmet Needs
All Regions	**5,549**	**37,567**	**15,451**	**7,898**	**5,583**	**6,001**	**40,624**	**16,709**	**8,541**	**6,037**	**6,582**	**44,561**	**18,328**	**9,368**	**6,623**
Southwestern															
Region	**179**	**1,210**	**498**	**254**	**180**	**196**	**1,330**	**547**	**280**	**198**	**217**	**1,472**	**605**	**309**	**219**
Haywood	60	408	168	86	61	66	448	184	94	63	73	496	204	104	74
Land-of-Sky															
Region	**333**	**2,254**	**927**	**474**	**335**	**359**	**2,432**	**1,000**	**511**	**361**	**393**	**2,658**	**1,093**	**559**	**395**
Buncombe	177	1,202	494	253	179	188	1,274	524	268	183	202	1,368	563	288	203
Henderson	105	709	292	149	105	115	778	320	164	111	129	872	359	183	130
Isothermal															
Region	**193**	**1,304**	**536**	**274**	**194**	**203**	**1,377**	**566**	**289**	**205**	**218**	**1,477**	**608**	**311**	**220**
Cleveland	78	529	218	111	79	83	564	232	119	84	90	608	250	128	90
McDowell	36	247	101	52	37	39	263	108	55	37	43	289	119	61	43
Rutherford	54	366	150	77	54	56	376	155	79	55	58	391	161	82	58
Region D															
Region	**158**	**1,070**	**440**	**225**	**159**	**171**	**1,156**	**475**	**243**	**172**	**186**	**1,259**	**518**	**265**	**187**
Watauga	26	178	73	37	27	30	200	82	42	28	33	225	92	47	33
Wilkes	50	337	139	71	50	54	367	151	77	51	59	398	164	84	59
Western Piedmont															
Region	**232**	**1,572**	**647**	**331**	**234**	**252**	**1,704**	**701**	**358**	**253**	**280**	**1,895**	**779**	**398**	**282**
Burke	66	448	184	94	67	71	482	198	101	68	79	536	220	113	80
Caldwell	55	369	152	78	55	59	397	163	84	55	65	439	181	92	65
Catawba	90	612	252	129	91	98	666	274	140	94	109	736	303	155	109
Centralina															
Region	**919**	**6,222**	**2,559**	**1,308**	**925**	**992**	**6,719**	**2,763**	**1,413**	**999**	**1,088**	**7,367**	**3,030**	**1,549**	**1,095**
Cabarrus	89	600	247	126	89	95	642	264	135	93	104	705	290	148	105
Gaston	123	835	343	176	124	127	858	353	180	123	132	895	368	188	133
Iredell	88	596	245	125	89	98	661	272	139	97	108	732	301	154	109
Lincoln	39	265	109	56	39	44	297	122	63	42	49	332	136	70	49
Mecklenburg	341	2,307	949	485	343	375	2,537	1,043	533	384	419	2,840	1,168	597	422
Rowan	109	741	305	156	110	115	775	319	163	116	121	816	336	172	121
Stanly	44	301	124	63	45	46	309	127	65	45	47	318	131	67	47
Union	60	407	167	85	60	69	467	192	98	67	82	556	228	117	83

PROJECTED SOURCES OF CARE AND UNMET NEED AMONG COMMUNITY-DWELLING PERSONS AGED 65+ WITH 1-2 ADL IMPAIRMENTS BY AREA AGENCY ON AGING (AAA) REGIONS AND SELECTED COUNTIES

	2000					2005					2010				
	Formal Only	Informal Only	Both	Neither	Unmet Needs	Formal Only	Informal Only	Both	Neither	Unmet Needs	Formal Only	Informal Only	Both	Neither	Unmet Needs
Piedmont Triad															
Region	**689**	**4,664**	**1,918**	**980**	**693**	**739**	**5,002**	**2,057**	**1,052**	**743**	**799**	**5,411**	**2,225**	**1,138**	**804**
Alamance	110	746	307	157	111	117	794	326	167	115	126	852	350	179	127
Davidson	99	668	275	140	99	108	733	301	154	104	119	807	332	170	120
Guilford	294	1,993	820	419	296	316	2,140	880	450	326	343	2,322	955	488	345
Randolph	87	587	241	123	87	95	643	265	135	91	105	714	294	150	106
Rockingham	80	542	223	114	80	83	564	232	119	84	86	585	241	123	87
Northwest Piedmont															
Region	**371**	**2,511**	**1,033**	**528**	**373**	**399**	**2,702**	**1,111**	**568**	**402**	**431**	**2,918**	**1,200**	**613**	**434**
Davie	27	180	74	38	27	30	204	84	43	29	33	226	93	47	34
Forsyth	224	1,514	623	318	225	237	1,606	660	338	244	253	1,711	704	360	254
Stokes	28	192	79	40	29	32	219	90	46	31	37	248	102	52	37
Surry	61	411	169	86	61	65	441	182	93	62	70	476	196	100	71
Yadkin	32	213	88	45	32	34	232	95	49	33	38	258	106	54	38
Triangle J															
Region	**704**	**4,763**	**1,959**	**1,001**	**708**	**787**	**5,325**	**2,190**	**1,120**	**791**	**898**	**6,082**	**2,502**	**1,279**	**904**
Chatham	43	289	119	61	43	47	320	132	67	48	53	359	148	76	53
Durham	116	786	323	165	117	117	793	326	167	125	120	813	334	171	121
Johnston	77	523	215	110	78	86	582	239	122	85	97	660	271	139	98
Lee	42	286	118	60	43	47	316	130	66	47	53	357	147	75	53
Moore	98	661	272	139	98	109	736	303	155	110	123	830	342	175	123
Orange	56	382	157	80	57	63	424	174	89	63	72	490	201	103	73
Wake	271	1,836	755	386	273	318	2,154	886	453	322	380	2,573	1,058	541	382
Kerr-Tar															
Region	**153**	**1,036**	**426**	**218**	**154**	**159**	**1,080**	**444**	**227**	**160**	**170**	**1,153**	**474**	**242**	**171**
Franklin	34	230	94	48	34	37	249	102	52	39	40	269	111	57	40
Granville	33	221	91	46	33	34	229	94	48	36	37	250	103	53	37
Person	30	206	85	43	31	32	215	88	45	33	34	230	94	48	34
Vance	32	219	90	46	33	33	221	91	47	35	34	227	94	48	34
Upper Coastal Plain															
Region	**241**	**1,632**	**671**	**343**	**243**	**248**	**1,680**	**691**	**353**	**250**	**258**	**1,745**	**718**	**367**	**259**
Edgecombe	45	303	125	64	45	44	300	123	63	49	44	301	124	63	45
Halifax	51	347	143	73	52	52	350	144	74	57	51	346	143	73	51
Nash	66	445	183	94	66	71	479	197	101	72	77	521	214	110	77
Wilson	55	374	154	79	56	57	387	159	81	59	60	409	168	86	61

PROJECTED SOURCES OF CARE AND UNMET NEED AMONG COMMUNITY-DWELLING PERSONS AGED 65+ WITH 1-2 ADL IMPAIRMENTS BY AREA AGENCY ON AGING (AAA) REGIONS AND SELECTED COUNTIES

	2000					2005					2010				
	Formal Only	Informal Only	Both	Neither	Unmet Needs	Formal Only	Informal Only	Both	Neither	Unmet Needs	Formal Only	Informal Only	Both	Neither	Unmet Needs
Mid-Carolina															
Region	**237**	**1,605**	**660**	**337**	**238**	**265**	**1,793**	**738**	**377**	**267**	**295**	**1,999**	**822**	**420**	**297**
Cumberland	130	880	362	185	131	150	1,013	417	213	155	169	1,146	471	241	170
Harnett	58	395	162	83	59	64	432	178	91	65	71	481	198	101	72
Sampson	49	329	135	69	49	51	349	143	73	54	55	371	153	78	55
Lumber River															
Region	**193**	**1,304**	**536**	**274**	**194**	**200**	**1,351**	**556**	**284**	**201**	**212**	**1,434**	**590**	**302**	**213**
Richmond	39	261	108	55	39	38	259	107	54	39	39	266	109	56	40
Robeson	81	548	225	115	81	85	573	236	121	94	89	601	247	126	89
Scotland	25	167	69	35	25	25	172	71	36	27	27	181	75	38	27
Cape Fear															
Region	**259**	**1,755**	**722**	**369**	**261**	**295**	**1,995**	**821**	**419**	**297**	**340**	**2,300**	**946**	**484**	**342**
Brunswick	61	414	170	87	61	74	503	207	106	72	89	605	249	127	90
Columbus	45	308	127	65	46	48	323	133	68	49	52	349	144	73	52
New Hanover	118	801	329	168	119	133	900	370	189	133	152	1,027	422	216	153
Pender	34	232	95	49	34	40	270	111	57	41	47	319	131	67	47
Eastern Carolina															
Region	**387**	**2,620**	**1,078**	**551**	**389**	**421**	**2,847**	**1,171**	**599**	**423**	**461**	**3,124**	**1,285**	**657**	**464**
Carteret	50	338	139	71	50	57	383	157	80	54	63	429	177	90	64
Craven	66	447	184	94	66	72	489	201	103	73	80	544	224	114	81
Duplin	39	264	109	56	39	41	276	114	58	43	43	291	120	61	43
Lenoir	54	365	150	77	54	55	372	153	78	58	58	393	162	83	58
Onslow	46	310	127	65	46	53	361	148	76	54	61	416	171	87	62
Wayne	74	499	205	105	74	80	542	223	114	82	87	590	242	124	88
Mid-East Commission															
Region	**180**	**1,218**	**501**	**256**	**181**	**187**	**1,269**	**522**	**267**	**189**	**197**	**1,337**	**550**	**281**	**199**
Beaufort	41	275	113	58	41	42	285	117	60	43	44	299	123	63	44
Pitt	75	505	208	106	75	81	545	224	115	84	88	593	244	125	88
Albemarle Commission															
Region	**122**	**828**	**340**	**174**	**123**	**127**	**862**	**355**	**181**	**128**	**138**	**931**	**383**	**196**	**138**
Pasquotank	31	210	86	44	31	32	217	89	46	34	35	234	96	49	35

NOTES: "1-2 ADLs" refers to persons with one or two Activities of Daily Living bathing, mobility within home, dressing, etc.) impairments.
"Formal Only" refers to receiving only paid care; "Informal Only" refers to receiving only unpaid care.
"Unmet Needs" refers to persons needing human assistance to perform certain ADL tasks but who lack the assistance required.
County-specific projections are presented only for those counties with at least 25,000 residents aged 18 and older as of April 2000.

APPENDIX A.4

PROJECTED SOURCES OF CARE AND UNMET NEED AMONG COMMUNITY-DWELLING PERSONS AGED 65+ WITH 3+ ADL IMPAIRMENTS BY AREA AGENCY ON AGING (AAA) REGIONS AND SELECTED COUNTIES

	2000					2005					2010				
	Formal Only	Informal Only	Both	Neither	Unmet Needs	Formal Only	Informal Only	Both	Neither	Unmet Needs	Formal Only	Informal Only	Both	Neither	Unmet Needs
All Regions	**2,398**	**31,693**	**29,847**	**1,015**	**5,196**	**2,656**	**35,112**	**33,066**	**1,124**	**5,757**	**2,984**	**39,445**	**37,146**	**1,263**	**6,467**
Southwestern															
Region	**74**	**973**	**916**	**31**	**160**	**83**	**1,095**	**1,031**	**35**	**180**	**94**	**1,239**	**1,167**	**40**	**203**
Haywood	24	323	304	10	53	27	363	342	12	60	31	414	390	13	68
Land-of-Sky															
Region	**138**	**1,822**	**1,716**	**58**	**299**	**153**	**2,019**	**1,902**	**65**	**331**	**171**	**2,256**	**2,125**	**72**	**370**
Buncombe	74	978	921	31	160	81	1,064	1,002	34	175	89	1,171	1,103	37	192
Henderson	43	572	539	18	94	49	644	606	21	106	56	738	695	24	121
Isothermal															
Region	**81**	**1,074**	**1,011**	**34**	**176**	**88**	**1,164**	**1,096**	**37**	**191**	**97**	**1,276**	**1,201**	**41**	**209**
Cleveland	34	444	418	14	73	37	485	457	16	80	41	536	505	17	88
McDowell	15	197	185	6	32	16	215	202	7	35	18	241	227	8	40
Rutherford	23	300	283	10	49	24	317	298	10	52	25	336	317	11	55
Region D															
Region	**64**	**847**	**798**	**27**	**139**	**71**	**935**	**881**	**30**	**153**	**79**	**1,038**	**978**	**33**	**170**
Watauga	11	142	133	5	23	12	162	153	5	27	14	186	175	6	30
Wilkes	20	267	251	9	44	22	297	280	10	49	25	329	309	11	54
Western Piedmont															
Region	**95**	**1,252**	**1,179**	**40**	**205**	**105**	**1,389**	**1,308**	**44**	**228**	**120**	**1,582**	**1,490**	**51**	**259**
Burke	27	358	337	11	59	30	393	370	13	65	34	448	422	14	73
Caldwell	22	293	276	9	48	24	321	303	10	53	28	364	342	12	60
Catawba	37	489	461	16	80	41	546	515	17	90	47	620	584	20	102
Centralina															
Region	**394**	**5,207**	**4,904**	**167**	**854**	**436**	**5,766**	**5,430**	**185**	**945**	**490**	**6,478**	**6,101**	**207**	**1,062**
Cabarrus	37	489	460	16	80	41	538	507	17	88	46	604	569	19	99
Gaston	51	680	640	22	111	54	713	671	23	117	58	766	721	25	126
Iredell	37	494	465	16	81	42	561	528	18	92	48	634	598	20	104
Lincoln	16	210	198	7	34	18	244	230	8	40	21	277	261	9	45
Mecklenburg	150	1,979	1,864	63	325	169	2,232	2,102	71	366	194	2,566	2,416	82	421
Rowan	47	621	585	20	102	51	671	632	21	110	55	722	680	23	118
Stanly	18	244	230	8	40	20	259	244	8	42	20	271	255	9	44
Union	25	332	313	11	54	29	387	365	12	64	36	470	443	15	77

PROJECTED SOURCES OF CARE AND UNMET NEED AMONG COMMUNITY-DWELLING PERSONS AGED 65+ WITH 3+ ADL IMPAIRMENTS BY AREA AGENCY ON AGING (AAA) REGIONS AND SELECTED COUNTIES

	2000					2005					2010				
	Formal Only	Informal Only	Both	Neither	Unmet Needs	Formal Only	Informal Only	Both	Neither	Unmet Needs	Formal Only	Informal Only	Both	Neither	Unmet Needs
Piedmont Triad															
Region	**296**	**3,909**	**3,681**	**125**	**641**	**325**	**4,297**	**4,047**	**138**	**704**	**361**	**4,766**	**4,488**	**153**	**781**
Alamance	46	611	576	20	100	51	669	630	21	110	56	739	696	24	121
Davidson	40	534	503	17	88	46	603	568	19	99	51	675	636	22	111
Guilford	131	1,728	1,627	55	283	143	1,896	1,785	61	311	160	2,117	1,993	68	347
Randolph	35	467	440	15	77	40	527	497	17	86	45	595	560	19	98
Rockingham	35	459	432	15	75	37	488	460	16	80	40	522	492	17	86
Northwest Piedmont															
Region	**159**	**2,104**	**1,981**	**67**	**345**	**175**	**2,316**	**2,181**	**74**	**380**	**194**	**2,565**	**2,415**	**82**	**420**
Davie	11	145	136	5	24	13	169	159	5	28	14	190	179	6	31
Forsyth	99	1,308	1,232	42	214	107	1,419	1,337	45	233	118	1,557	1,467	50	255
Stokes	12	153	144	5	25	13	178	167	6	29	15	204	192	7	33
Surry	25	327	308	10	54	27	360	339	12	59	30	397	374	13	65
Yadkin	13	171	161	5	28	14	190	179	6	31	16	215	203	7	35
Triangle J															
Region	**307**	**4,058**	**3,822**	**130**	**665**	**351**	**4,645**	**4,374**	**149**	**762**	**411**	**5,430**	**5,113**	**174**	**890**
Chatham	19	246	232	8	40	21	280	263	9	46	24	323	304	10	53
Durham	53	703	662	22	115	55	725	683	23	119	58	764	719	24	125
Johnston	33	431	406	14	71	37	493	464	16	81	43	571	538	18	94
Lee	18	243	229	8	40	21	275	259	9	45	24	320	301	10	52
Moore	42	555	523	18	91	48	639	602	20	105	56	743	699	24	122
Orange	24	323	304	10	53	28	366	344	12	60	33	433	407	14	71
Wake	118	1,557	1,466	50	255	141	1,868	1,759	60	306	172	2,277	2,144	73	373
Kerr-Tar															
Region	**70**	**926**	**872**	**30**	**152**	**75**	**989**	**931**	**32**	**162**	**82**	**1,081**	**1,018**	**35**	**177**
Franklin	15	203	191	7	33	17	225	212	7	37	19	248	234	8	41
Granville	15	196	185	6	32	16	209	196	7	34	18	232	218	7	38
Person	14	179	169	6	29	15	192	181	6	32	16	210	198	7	34
Vance	15	196	185	6	32	15	203	192	7	33	16	215	203	7	35
Upper Coastal Plain															
Region	**110**	**1,455**	**1,370**	**47**	**238**	**116**	**1,535**	**1,446**	**49**	**252**	**124**	**1,636**	**1,541**	**52**	**268**
Edgecombe	21	279	263	9	46	21	284	268	9	47	22	292	275	9	48
Halifax	24	321	302	10	53	25	332	313	11	54	26	338	318	11	55
Nash	29	379	357	12	62	32	418	394	13	69	35	467	440	15	77
Wilson	25	324	305	10	53	26	344	324	11	56	28	374	352	12	61

PROJECTED SOURCES OF CARE AND UNMET NEED AMONG COMMUNITY-DWELLING PERSONS AGED 65+ WITH 3+ ADL IMPAIRMENTS BY AREA AGENCY ON AGING (AAA) REGIONS AND SELECTED COUNTIES

	2000					2005					2010				
	Formal Only	Informal Only	Both	Neither	Unmet Needs	Formal Only	Informal Only	Both	Neither	Unmet Needs	Formal Only	Informal Only	Both	Neither	Unmet Needs
Mid-Carolina															
Region	**105**	**1,386**	**1,305**	**44**	**227**	**120**	**1,587**	**1,494**	**51**	**260**	**137**	**1,812**	**1,706**	**58**	**297**
Cumberland	58	762	718	24	125	68	898	846	29	147	79	1,044	983	33	171
Harnett	25	336	316	11	55	28	375	353	12	62	32	428	403	14	70
Sampson	22	288	271	9	47	24	314	295	10	51	26	340	320	11	56
Lumber River															
Region	**89**	**1,176**	**1,108**	**38**	**193**	**95**	**1,254**	**1,181**	**40**	**206**	**103**	**1,367**	**1,288**	**44**	**224**
Richmond	17	224	211	7	37	17	228	215	7	37	18	241	227	8	40
Robeson	38	508	479	16	83	41	547	515	18	90	44	587	552	19	96
Scotland	11	148	139	5	24	12	157	148	5	26	13	169	159	5	28
Cape Fear															
Region	**111**	**1,470**	**1,385**	**47**	**241**	**130**	**1,712**	**1,612**	**55**	**281**	**153**	**2,024**	**1,906**	**65**	**332**
Brunswick	25	336	316	11	55	32	417	393	13	68	39	514	484	16	84
Columbus	20	265	249	8	43	22	285	269	9	47	24	315	297	10	52
New Hanover	51	670	631	21	110	58	772	727	25	127	69	906	853	29	148
Pender	15	201	189	6	33	18	237	224	8	39	22	289	272	9	47
Eastern Carolina															
Region	**170**	**2,244**	**2,113**	**72**	**368**	**189**	**2,496**	**2,350**	**80**	**409**	**213**	**2,815**	**2,651**	**90**	**461**
Carteret	20	270	255	9	44	24	313	295	10	51	27	361	340	12	59
Craven	29	380	358	12	62	32	427	402	14	70	37	491	463	16	81
Duplin	18	232	219	7	38	19	249	234	8	41	20	268	253	9	44
Lenoir	24	320	301	10	52	25	335	316	11	55	28	365	344	12	60
Onslow	20	262	247	8	43	24	312	294	10	51	28	371	349	12	61
Wayne	32	428	403	14	70	36	476	448	15	78	40	531	500	17	87
Mid-East Commission															
Region	**81**	**1,076**	**1,013**	**34**	**176**	**87**	**1,151**	**1,084**	**37**	**189**	**94**	**1,240**	**1,168**	**40**	**203**
Beaufort	18	239	225	8	39	19	252	238	8	41	21	272	256	9	45
Pitt	33	436	411	14	71	37	486	458	16	80	41	540	508	17	88
Albemarle Commission															
Region	**54**	**715**	**673**	**23**	**117**	**58**	**760**	**716**	**24**	**125**	**64**	**840**	**791**	**27**	**138**
Pasquotank	14	187	176	6	31	15	198	187	6	33	17	220	207	7	36

NOTES: "3+ ADLs" refers to persons with three or more Activities of Daily Living bathing, mobility within home, dressing, etc.) impairments.
"Formal Only" refers to receiving only paid care; "Informal Only" refers to receiving only unpaid care.
"Unmet Needs" refers to persons needing human assistance to perform certain ADL tasks but who lack the assistance required.
County-specific projections are presented only for those counties with at least 25,000 residents aged 18 and older as of April 2000.

APPENDIX A.5
Projected Persons 18-64 with Mental Retardation/Developmental Disability
by Area Mental Health, Developmental Disabilities and Substance Abuse Program

	2000		2005		2010	
	Disabling MR/DD	1+ ADL/ IADL	Disabling MR/DD	1+ ADL/ IADL	Disabling MR/DD	1+ ADL/ IADL
All Regions	**34,287**	**21,670**	**36,647**	**23,161**	**38,556**	**24,367**
Alamance-Caswell	**632**	**399**	**667**	**421**	**687**	**434**
Alamance	540	341	572	361	594	375
Albemarle	**491**	**310**	**540**	**341**	**572**	**362**
Pasquotank	142	90	154	98	163	103
Blue Ridge	**1,059**	**669**	**1,110**	**702**	**1,138**	**720**
Buncombe	842	532	888	561	917	580
Catawba	**602**	**381**	**631**	**399**	**654**	**413**
CenterPoint	**1,668**	**1,054**	**1,738**	**1,098**	**1,813**	**1,146**
Davie	144	91	153	96	157	99
Forsyth	1,318	833	1,364	862	1,426	901
Stokes	206	130	221	140	231	146
Crossroads	**970**	**613**	**1,032**	**652**	**1,080**	**682**
Iredell	508	321	550	348	585	370
Surry	301	190	310	196	315	199
Yadkin	161	102	172	109	179	113
Cumberland	**1,371**	**867**	**1,437**	**908**	**1,496**	**946**
Davidson	**650**	**411**	**689**	**435**	**714**	**451**
Duplin-Sampson	**419**	**265**	**440**	**278**	**449**	**283**
Duplin	190	120	200	126	204	129
Sampson	229	145	240	152	245	155
Durham	**945**	**598**	**1,003**	**634**	**1,067**	**675**
Edgecombe-Nash	**619**	**391**	**652**	**412**	**671**	**424**
Edgecombe	221	140	221	140	216	136
Nash	399	252	431	273	456	288
Foothills	**1,040**	**657**	**1,074**	**679**	**1,093**	**691**
Burke	366	231	377	238	387	245
Caldwell	342	216	348	220	349	221
McDowell	183	116	191	121	196	124
Guilford	**1,795**	**1,134**	**1,884**	**1,191**	**1,958**	**1,237**
Johnston	**493**	**312**	**554**	**350**	**603**	**381**
Lee-Harnett	**593**	**375**	**648**	**410**	**693**	**438**
Harnett	378	239	414	262	447	283
Lee	215	136	234	148	246	155
Lenoir	**245**	**155**	**244**	**154**	**241**	**153**
Mecklenburg	**2,996**	**1,894**	**3,298**	**2,084**	**3,624**	**2,290**
Neuse	**759**	**480**	**804**	**508**	**838**	**530**
Carteret	274	173	296	187	312	197
Craven	398	252	419	265	437	276
New River	**715**	**452**	**732**	**462**	**730**	**461**
Onslow	**745**	**471**	**808**	**511**	**879**	**555**
O-P-C	**919**	**581**	**997**	**630**	**1,055**	**667**
Chatham	209	132	229	144	241	152
Orange	562	355	614	388	656	414
Person	147	93	154	97	158	100

PROJECTED PERSONS 18-64 WITH MENTAL RETARDATION/DEVELOPMENTAL DISABILITY BY AREA MENTAL HEALTH, DEVELOPMENTAL DISABILITIES AND SUBSTANCE ABUSE PROGRAM

	2000		2005		2010	
	Disabling MR/DD	1+ ADL/ IADL	Disabling MR/DD	1+ ADL/ IADL	Disabling MR/DD	1+ ADL/ IADL
Pathways	**1,470**	**929**	**1,518**	**959**	**1,552**	**981**
Gaston	800	505	817	516	828	524
Lincoln	272	172	294	186	312	197
Piedmont	**1,842**	**1,164**	**2,005**	**1,267**	**2,145**	**1,356**
Cabarrus	549	347	603	381	648	410
Rowan	544	344	584	369	617	390
Stanly	236	149	245	155	254	161
Union	513	324	572	361	625	395
Pitt	**603**	**381**	**660**	**417**	**717**	**453**
Randolph	**567**	**358**	**612**	**387**	**646**	**408**
RiverStone (Halifax)	**219**	**138**	**223**	**141**	**221**	**139**
Roanoke-Chowan	**294**	**186**	**300**	**190**	**294**	**186**
Rockingham	**394**	**249**	**401**	**254**	**402**	**254**
Rutherford- Polk	**320**	**202**	**331**	**209**	**336**	**212**
Rutherford	253	160	261	165	264	167
Sandhills	**794**	**502**	**846**	**534**	**869**	**549**
Moore	281	178	310	196	320	202
Richmond	189	120	191	121	191	121
Smoky Mountain	**684**	**432**	**713**	**451**	**716**	**452**
Haywood	219	139	224	142	224	141
Southeastern	**1,178**	**745**	**1,308**	**826**	**1,402**	**886**
Brunswick	304	192	343	217	369	233
New Hanover	705	446	772	488	824	521
Pender	169	107	193	122	209	132
Southeastern Regional	**974**	**615**	**1,008**	**637**	**1,011**	**639**
Columbus	216	137	223	141	218	138
Robeson	479	303	500	316	512	323
Scotland	149	94	153	97	153	97
Tideland	**374**	**236**	**380**	**240**	**370**	**234**
Beaufort	185	117	190	120	188	119
Trend Area	**446**	**282**	**478**	**302**	**484**	**306**
Henderson	329	208	357	226	364	230
VGFW	**620**	**392**	**665**	**420**	**705**	**445**
Franklin	203	128	225	142	246	156
Granville	170	107	182	115	196	124
Vance	178	112	185	117	189	119
Wake	**2,888**	**1,825**	**3,291**	**2,080**	**3,682**	**2,327**
Wayne	**518**	**328**	**540**	**341**	**557**	**352**
Wilson-Greene	**376**	**238**	**389**	**246**	**392**	**248**
Wilson	299	189	306	193	307	194

NOTES: "Disabling MR/DD" refers to mental retardation or developmental disability that affects ability to perform age-appropriate tasks, such as working or going to school.

"1+ ADL/IADL" refers to MR/DD conditions causing a need for assistance with at least one ADL or IADL task.

County-specific projections are presented only for those counties with at least 25,000 residents aged 18 and older as of April 2000. Many program areas include only one county.

PROPOSED PERSONNEL FOR THE NORTH CAROLINA OFFICE OF LONG-TERM CARE

- *Director of the Office of Long-Term Care*: As part of executive management team, responsible for working with the department management to develop policy, philosophy, strategies, and organizational direction to provide for a system of long-term care service delivery that crosses division lines. Serves as liaison between the Governor's office, the North Carolina Department of Health and Human services (DHHS) Secretary's office, and key agencies in the development and implementation of long-term care program initiatives. Provides leadership to respond to legislative and DHHS initiatives. Heads the Office of Long-Term Care.

- *Human Resources Planning Supervisor III*: Provides staff assistance to department management in developing, implementing, and reviewing DHHS operational and long range planning systems in the planning and administration of human services programs. Analyzes program-related information from a large number of sources and integrates this information into cohesive program plans and recommendations. Assures adequate involvement of consumers, providers, and agencies in design and implementation of long-term care policies. Assures organized use of state's university systems for policy analysis and evaluation.

- *Human Services Planner/Evaluator IV* (2 positions): Designs, conducts, and administers projects/studies related to all aspects of long-term care. Plans, coordinates, and evaluates the work of interdivisional performance teams. Develops planning systems, assists in the development of integrated operational plans, administers the data/information collection and analysis processes, and prepares and presents reports for the planning periods across divisions. Structures a program evaluation process for a broad spectrum of programs and demonstration projects to test new long-term care programs or policies, and designs the data collection instruments and tools. Maintains contact with other members of the Office of Long-Term Care, DHHS staff, and the general public. Assures that federal and state mandates, legislation, and regulations are incorporated in planning and program goals.

- *Statistician II*: Performs advanced technical and professional work in the evaluation and analysis of program data for the Office of Long-Term Care, including gathering, assembly, and evaluation of information at the state- and county-level about the use of and need for long-term care services. Provides statistical support and data evaluation for demonstration projects, and may recommend areas for investigation to improve quantity and quality of information available for decision-making. Writes interpretive reports and summaries of the data, presents findings in oral and written form, and maintains liaisons with other agencies and programs for acquisition and dissemination of information that can aid policy and program planning and evaluation.

- *Administrative Officer III*: Planning, program development, and implementation of operational policies and procedures for the Office of Long-Term Care, including plans for fiscal resources, budget development, staff recruitment, training, and review. Administers contracts and grants for the Office of Long-Term Care

- *Staff Development Specialist III*: Designs, coordinates, and conducts training, and administers continuing education programs. Assists in formulating policies and procedures affecting the Office of Long-Term Care. Maintains contact with staff at all levels and disciplines within organizations, universities, technical institutes, and other potential providers of training resources and continuing education in order to develop training materials/programs or to contract for delivery of specific training programs related to long-term care issues in the state of North Carolina and assures coordination of relevant DHHS training activities.

- *Information and Data Systems Liaison II*: Performs system analyses to define the needs of the Office of Long-Term Care and for systems information and systems development within DHHS related long-term care matters. Determines and establishes policies relating to the automation of user functions. Evaluates new applications or changing applications from the user perspective, tests new applications or enhancements, and trains others in the use of new or changing application systems.

- *Information and Communication Specialist III*: Coordinates the sharing of information among divisions, with the county commissioners, and the general public. Also responsible for design and maintenance of the website for the Office of Long-Term Care, and serves as DHHS spokesperson for long-term care affairs.

- *Social Research Associate II*: Plans, organizes, implements, and evaluates research and educational programs and projects related to the mission of the Office of Long-Term Care. Oversees all phases of the program, using subject matter knowledge and knowledge of research and evaluation techniques to ascertain the progress and quality of the work; establishes the overall plan, research methods, and staffing needs for projects; reviews and evaluates research projects and research findings and determination of results. Supervises the implementation of training or developmental programs resulting from project research. Writes grants related to long-term care issues.

APPENDIX C

INSTRUMENTS TECHNICAL WORK GROUP MEMBERSHIP

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APPENDIX D

COMPARISONS OF AVAILABILITY OF SERVICES

Table 1 Comparison of Nursing Home Beds and Adult Care Home Beds per 1000 of the Population Aged 65 and Older

Table 2 Comparison of Community Alternatives Program for Disabled Adults (CAP/DA) and Medicaid Personal Care Services (PCS) Clients Served per 1000 of Medicaid Eligible Aged and Disabled Population

Table 3 Comparison of Adult Day Care/Adult Day Health - Home and Community Care Block Grant (HCCBG) and Adult Day Care - Social Services Block Grant (SSBG) Clients Served per 1000 of Population Aged 60 and Older

Table 4 Comparison of Home Delivered Meals - Home and Community Care Block Grant (HCCBG) and Meals - Social Services Block Grant (SSBG) Clients Served per 1000 Population Aged 60 and Older

Table 5 Comparison of In-Home Aides Clients Served - Home and Community Care Block Grant (HCCBG) and Social Services Block Grant (SSBG) per 1000 of Population Aged 60 and Older

Table 6 Comparison of Nursing Home Beds and Community Alternatives Program for Disabled Adults (CAP/DA) Clients Served per 1000 of Eligible Population

TABLE 1

COMPARISON OF NURSING HOME BEDS AND ADULT CARE HOME BEDS PER 1000 OF THE POPULATION AGED 65 AND OLDER

County Name	Population Aged 65 and Older	Nursing Home Beds per 1000 Aged 65 and Older	Adult Care Home Beds per 1000 Aged 65 and Older	County Name	Population Aged 65 and Older	Nursing Home Beds per 1000 Aged 65 and Older	Adult Care Home Beds per 1000 Aged 65 and Older
ALAMANCE	19508	42.09	39.68	JOHNSTON	13731	32.77	45.15
ALEXANDER	4071	44.95	16.21	JONES	1293	61.87	8.51
ALLEGHANY	2050	43.90	50.73	LEE	7411	31.57	46.28
ANSON	3855	41.76	0	LENOIR	8826	37.62	43.39
ASHE	4646	38.74	16.36	LINCOLN	7516	33.26	35.66
AVERY	2598	49.27	15.40	MACON	7074	38.17	7.35
BEAUFORT	6897	42.05	26.10	MADISON	3308	54.41	16.32
BERTIE	3024	46.96	26.79	MARTIN	3951	38.98	41.76
BLADEN	4755	40.80	58.89	MCDOWELL	6598	33.34	58.05
BRUNSWICK	12345	25.44	6.97	MECKLENBURG	60133	51.12	33.76
BUNCOMBE	32527	51.68	42.03	MITCHELL	2940	43.20	11.90
BURKE	12329	36.99	34.80	MONTGOMERY	3298	46.39	50.64
CABARRUS	15855	37.65	57.21	MOORE	17101	33.92	33.57
CALDWELL	10421	39.34	36.46	NASH	11435	36.64	27.37
CAMDEN	951	42.06	6.31	NEW HANOVER	20802	34.08	41.39
CARTERET	9790	41.88	23.80	NORTHAMPTON	3796	39.25	55.58
CASWELL	3629	37.75	67.79	ONSLOW	8405	42.71	56.16
CATAWBA	17284	38.71	26.04	ORANGE	10136	43.71	32.06
CHATHAM	7456	45.60	24.81	PAMLICO	2387	40.22	0
CHEROKEE	4785	37.62	12.54	PASQUOTANK	5057	52.60	52.60
CHOWAN	2700	62.96	24.44	PENDER	6048	35.22	17.03
CLAY	1832	43.67	6.55	PERQUIMANS	2168	35.98	27.21
CLEVELAND	13538	40.18	41.44	PERSON	4941	40.48	26.11
COLUMBUS	7793	37.60	22.71	PITT	12626	43.40	49.50
CRAVEN	11821	39.42	42.13	POLK	4377	50.49	8.68

County Name	Population Aged 65 and Older	Nursing Home Beds per 1000 Aged 65 and Older	Adult Care Home Beds per 1000 Aged 65 and Older	County Name	Population Aged 65 and Older	Nursing Home Beds per 1000 Aged 65 and Older	Adult Care Home Beds per 1000 Aged 65 and Older
CUMBERLAND	23254	34.23	38.66	RANDOLPH	16343	38.55	34.57
CURRITUCK	2238	37.98	0	RICHMOND	6609	41.76	51.29
DARE	3518	35.82	0	ROBESON	12450	42.41	49.88
DAVIDSON	18826	37.66	21.14	ROCKINGHAM	13636	39.97	37.55
DAVIE	5029	39.37	31.42	ROWAN	19323	41.14	31.00
DUPLIN	6492	38.82	61.31	RUTHERFORD	9594	43.78	63.37
DURHAM	19614	67.91	61.69	SAMPSON	8161	38.23	38.23
EDGECOMBE	6956	45.57	39.39	SCOTLAND	4004	49.70	39.46
FORSYTH	38420	49.92	47.92	STANLY	8277	49.05	23.68
FRANKLIN	5657	45.61	47.73	STOKES	5493	58.62	32.22
GASTON	23023	42.22	32.92	SURRY	10959	39.42	39.88
GATES	1438	48.68	0	SWAIN	2037	58.91	24.55
GRAHAM	1361	58.78	22.04	TRANSYLVANIA	6346	37.35	12.61
GRANVILLE	5474	43.84	35.99	TYRRELL	640	46.88	0
GREENE	2536	45.35	20.50	UNION	11176	31.94	31.50
GUILFORD	50371	44.19	36.93	VANCE	5393	43.02	37.83
HALIFAX	8097	42.61	21.24	WAKE	47585	40.66	42.01
HARNETT	10354	41.63	54.38	WARREN	3655	38.30	51.71
HAYWOOD	11053	39.90	29.77	WASHINGTON	2022	41.54	0
HENDERSON	19448	42.27	26.07	WATAUGA	4883	38.09	20.89
HERTFORD	3299	48.80	53.65	WAYNE	13071	36.19	53.17
HOKE	3035	30.31	24.71	WILKES	9461	44.08	24.63
HYDE	898	89.09	0	WILSON	9343	40.14	47.52
IREDELL	15714	35.83	45.18	YADKIN	5754	42.93	29.37
JACKSON	4609	41.22	30.16	YANCEY	3126	44.79	9.28
				STATE AVERAGE	**9818.73**	**42.76**	**31.61**

Sources: Nursing Home Beds data from the State Medical Facilities Plan 2000 (Draft), May 1999
Homes for the Aged and Family Care Home data from Division of Facility Services, 1999

TABLE 2

COMPARISON OF COMMUNITY ALTERNATIVES PROGRAM FOR DISABLED ADULTS (CAP/DA) AND MEDICAID PERSONAL CARE SERVICES (PCS) CLIENTS SERVED PER 1000 OF MEDICAID ELIGIBLE AGED AND DISABLED POPULATION

County Name	Medicaid Eligible Aged & Disabled	CAP/DA Clients Served per 1000 Medicaid Aged & Disabled	PCS Clients Served per 1000 Medicaid Aged & Disabled	County Name	Medicaid Eligible Aged & Disabled	CAP/DA Clients Served per 1000 Medicaid Aged & Disabled	PCS Clients Served per 1000 Medicaid Aged & Disabled
ALAMANCE	4367	14.43	46.71	JOHNSTON	5602	8.39	31.42
ALEXANDER	1131	66.31	66.31	JONES	720	87.50	86.11
ALLEGHANY	645	106.98	62.02	LEE	2141	49.98	71.93
ANSON	1800	55.00	66.67	LENOIR	4112	22.86	94.36
ASHE	1654	113.66	39.30	LINCOLN	2013	21.36	5.46
AVERY	990	200.00	129.29	MACON	1454	63.27	24.07
BEAUFORT	2990	47.49	65.55	MADISON	1424	14.04	33.71
BERTIE	2241	89.25	159.30	MARTIN	2114	35.00	95.55
BLADEN	2962	44.23	126.60	MCDOWELL	1868	21.95	70.66
BRUNSWICK	3048	24.61	68.90	MECKLENBURG	16091	27.90	25.85
BUNCOMBE	8253	23.87	17.81	MITCHELL	1077	80.78	138.35
BURKE	3553	73.46	38.00	MONTGOMERY	1472	33.97	51.63
CABARRUS	3758	112.83	26.88	MOORE	2682	22.74	23.86
CALDWELL	3073	76.80	32.54	NASH	4832	18.00	66.23
CAMDEN	260	42.31	15.38	NEW HANOVER	5871	22.65	63.36
CARTERET	2088	61.78	38.31	NORTHAMPTON	2237	21.46	120.25
CASWELL	1395	70.25	62.37	ONSLOW	3405	47.28	73.72
CATAWBA	3956	38.17	15.67	ORANGE	2020	50.50	36.14
CHATHAM	1503	40.59	64.54	PAMLICO	702	69.80	105.41
CHEROKEE	1821	81.82	22.52	PASQUOTANK	1800	26.67	30.56
CHOWAN	948	62.24	22.15	PENDER	1916	75.16	64.72
CLAY	504	81.35	29.76	PERQUIMANS	662	39.27	40.79
CLEVELAND	4622	36.13	24.88	PERSON	1804	26.61	52.11
COLUMBUS	5323	24.80	157.43	PITT	6362	16.50	117.10
CRAVEN	3795	41.63	54.81	POLK	646	71.21	0.00

County Name	Medicaid Eligible Aged & Disabled	CAP/DA Clients Served per 1000 Medicaid Aged & Disabled	PCS Clients Served per 1000 Medicaid Aged & Disabled	County Name	Medicaid Eligible Aged & Disabled	CAP/DA Clients Served per 1000 Medicaid Aged & Disabled	PCS Clients Served per 1000 Medicaid Aged & Disabled
CUMBERLAND	9577	16.60	67.56	RANDOLPH	3753	49.83	22.65
CURRITUCK	522	55.56	28.74	RICHMOND	3136	9.89	60.59
DARE	547	27.42	12.80	ROBESON	9807	43.64	113.59
DAVIDSON	4698	20.01	34.70	ROCKINGHAM	4718	80.54	41.75
DAVIE	1028	120.62	8.75	ROWAN	4213	49.85	35.13
DUPLIN	3244	37.61	67.20	RUTHERFORD	3082	31.15	31.15
DURHAM	6391	17.84	50.54	SAMPSON	3835	8.87	102.48
EDGECOMBE	4781	14.22	78.85	SCOTLAND	2601	40.37	86.89
FORSYTH	8586	16.77	63.59	STANLY	2204	40.83	56.26
FRANKLIN	2622	36.61	73.61	STOKES	1603	43.67	44.92
GASTON	7850	16.31	27.77	SURRY	3479	45.99	50.88
GATES	587	97.10	30.66	SWAIN	948	90.72	12.66
GRAHAM	677	116.69	23.63	TRANSYLVANIA	1101	67.21	41.78
GRANVILLE	2028	18.24	71.50	TYRRELL	332	39.16	69.28
GREENE	1016	47.24	94.49	UNION	2660	20.68	19.92
GUILFORD	12297	23.58	57.98	VANCE	3371	13.35	64.08
HALIFAX	5950	12.44	71.09	WAKE	11518	26.57	42.19
HARNETT	3861	27.97	60.87	WARREN	1652	21.79	83.54
HAYWOOD	2583	40.26	5.03	WASHINGTON	978	42.94	58.28
HENDERSON	3152	35.22	2.54	WATAUGA	1161	73.21	18.95
HERTFORD	2210	47.51	199.10	WAYNE	5877	10.55	81.67
HOKE	1455	51.55	57.04	WILKES	3337	76.42	36.56
HYDE	509	60.90	76.62	WILSON	4332	31.63	48.48
IREDELL	3618	36.76	52.79	YADKIN	1407	52.59	51.88
JACKSON	1525	81.97	35.41	YANCEY	1210	56.20	95.87
				STATE AVERAGE	**3153.36**	**47.49**	**57.01**

Source: CAP/DA and PCS data from the Division of Medical Assistance, SFY 1999

TABLE 3

COMPARISON OF ADULT DAY CARE/ADULT DAY HEALTH - HOME AND COMMUNITY CARE BLOCK GRANT (HCCBG) AND ADULT DAY CARE - SOCIAL SERVICES BLOCK GRANT (SSBG) CLIENTS SERVED PER 1000 OF POPULATION AGED 60 AND OLDER

County Name	Population Aged 60 and Older	Adult Day Care/ Adult Day Health Clients Served per 1000 Aged 60 and Older: HCCBG	Adult Day Care Clients Served per 1000 Aged 60 and Older: SSBG	County Name	Population Aged 60 and Older	Adult Day Care/ Adult Day Health Clients Served per 1000 Aged 60 and Older: HCCBG	Adult Day Care Clients Served per 1000 Aged 60 and Older: SSBG
ALAMANCE	25105	1.31	0	JOHNSTON	18500	0	1.03
ALEXANDER	5523	0	0	JONES	1740	0	0
ALLEGHANY	2611	0	3.83	LEE	9818	0	0.20
ANSON	4897	0	0	LENOIR	11639	0.34	0
ASHE	6138	1.63	0.33	LINCOLN	10187	0	0
AVERY	3398	0	0	MACON	8740	2.40	0.46
BEAUFORT	9139	0	0	MADISON	9090	0	0
BERTIE	3971	4.78	0.25	MARTIN	4337	0	0
BLADEN	6226	0	0	MCDOWELL	5244	0	0
BRUNSWICK	16980	0.41	0.12	MECKLENBURG	80644	1.13	0.04
BUNCOMBE	41686	0.82	0.46	MITCHELL	3817	0	0
BURKE	16487	0.97	0	MONTGOMERY	4324	0	0
CABARRUS	21043	2.71	0.24	MOORE	21312	0.38	0
CALDWELL	14045	0.57	0.28	NASH	15132	2.25	0
CAMDEN	1296	3.09	0	NEW HANOVER	27539	1.34	0.18
CARTERET	13241	0	0	NORTHAMPTON	4952	1.82	0.20
CASWELL	4779	0	0	ONSLOW	11877	0.34	0
CATAWBA	23250	1.72	0.09	ORANGE	13569	0	0.52
CHATHAM	9600	0	0	PAMLICO	3159	0	0
CHEROKEE	6163	2.60	0	PASQUOTANK	6368	2.51	0
CHOWAN	3423	0.29	0	PENDER	8249	0	0
CLAY	2333	0	0	PERQUIMANS	2848	1.76	0
CLEVELAND	18000	1.67	0	PERSON	6497	0	0
COLUMBUS	10435	0	0	PITT	16387	0.85	0.12
CRAVEN	15575	0.90	0	POLK	5387	0	0

County Name	Population Aged 60 and Older	Adult Day Care/ Adult Day Health Clients Served per 1000 Aged 60 and Older: HCCBG	Adult Day Care Clients Served per 1000 Aged 60 and Older: SSBG	County Name	Population Aged 60 and Older	Adult Day Care/ Adult Day Health Clients Served per 1000 Aged 60 and Older: HCCBG	Adult Day Care Clients Served per 1000 Aged 60 and Older: SSBG
CUMBERLAND	32949	0.61	0	RANDOLPH	21804	0.50	0.18
CURRITUCK	3034	0.33	0	RICHMOND	8585	0	0
DARE	4964	0	0	ROBESON	16881	0	0.36
DAVIDSON	25443	1.06	0.28	ROCKINGHAM	17977	0	0
DAVIE	6622	0	0	ROWAN	24749	1.45	0.08
DUPLIN	8708	0.11	0.46	RUTHERFORD	12506	0.56	0
DURHAM	25683	0.27	0.19	SAMPSON	10780	2.23	0
EDGECOMBE	9112	4.06	0.11	SCOTLAND	5325	3.19	0.94
FORSYTH	50260	0.78	0.22	STANLY	10764	0	0
FRANKLIN	7608	0.26	0.39	STOKES	7639	0	0.26
GASTON	30516	0	0.62	SURRY	14519	0	0
GATES	1928	0	0	SWAIN	2693	0	0
GRAHAM	1829	0	4.37	TRANSYLVANIA	8100	1.48	1.36
GRANVILLE	7339	0	0.55	TYRRELL	816	0	0
GREENE	3385	0	0	UNION	15752	0.83	0
GUILFORD	66182	1.39	0.06	VANCE	7045	0	0
HALIFAX	10561	1.23	0.47	WAKE	66104	1.03	0.11
HARNETT	13810	0.87	0.51	WARREN	4658	0.21	0.21
HAYWOOD	14405	1.80	0	WASHINGTON	2637	0	0
HENDERSON	24386	0.53	0.04	WATAUGA	6588	0	0
HERTFORD	4233	0	0.71	WAYNE	18092	0	0.06
HOKE	4153	0	0	WILKES	12717	0	0
HYDE	1172	0	0	WILSON	12408	0	0.97
IREDELL	21155	0.66	0.19	YADKIN	7548	0	0.40
JACKSON	6133	1.96	0	YANCEY	4077	0	0.49
				STATE AVERAGE	**13030.34**	**0.66**	**0.23**

Sources: HCCBG services data from the Division of Aging, SFY 1999
SSBG services data from the Division of Social Services, SFY 1999

TABLE 4

COMPARISON OF HOME DELIVERED MEALS - HOME AND COMMUNITY CARE BLOCK GRANT (HCCBG); AND MEALS - SOCIAL SERVICES BLOCK GRANT (SSBG) CLIENTS SERVED PER 1000 POPULATION AGED 60 AND OLDER

County Name	Population Aged 60 and Older	Home Delivered Meals Clients Served per 1000 Aged 60 and Older: HCCBG	Meals Clients Served per 1000 Aged 60 and Older: SSBG	County Name	Population Aged 60 and Older	Home Delivered Meals Clients Served per 1000 Aged 60 and Older: HCCBG	Meals Clients Served per 1000 Aged 60 and Older: SSBG
ALAMANCE	25105	44.57	1.12	JOHNSTON	18500	24.59	0
ALEXANDER	5523	9.23	0	JONES	1740	22.99	0
ALLEGHANY	2611	36.00	0	LEE	9818	7.54	0
ANSON	4897	38.19	0	LENOIR	11639	6.36	0
ASHE	6138	35.03	0	LINCOLN	10187	0	0
AVERY	3398	20.89	0	MACON	8740	12.01	0
BEAUFORT	9139	26.15	0	MADISON	9090	5.39	0
BERTIE	3971	22.16	0	MARTIN	4337	35.28	0
BLADEN	6226	11.08	0	MCDOWELL	5244	58.54	0
BRUNSWICK	16980	23.14	0	MECKLENBURG	80644	23.59	0
BUNCOMBE	41686	14.78	0	MITCHELL	3817	45.32	0
BURKE	16487	13.04	0	MONTGOMERY	4324	20.35	0
CABARRUS	21043	0	0	MOORE	21312	7.41	0
CALDWELL	14045	7.19	0	NASH	15132	12.03	0
CAMDEN	1296	29.32	0	NEW HANOVER	27539	16.34	0
CARTERET	13241	3.40	0	NORTHAMPTON	4952	13.73	0
CASWELL	4779	29.50	0	ONSLOW	11877	9.35	0
CATAWBA	23250	16.86	0	ORANGE	13569	0	0
CHATHAM	9600	13.02	0	PAMLICO	3159	22.16	0
CHEROKEE	6163	19.47	0	PASQUOTANK	6368	16.49	0
CHOWAN	3423	15.48	0	PENDER	8249	30.91	0
CLAY	2333	39.86	0	PERQUIMANS	2848	26.33	0
CLEVELAND	18000	10.00	0	PERSON	6497	18.78	0
COLUMBUS	10435	11.31	0	PITT	16387	24.59	0
CRAVEN	15575	8.67	0	POLK	5387	29.33	0

County Name	Population Aged 60 and Older	Home Delivered Meals Clients Served per 1000 Aged 60 and Older: HCCBG	Meals Clients Served per 1000 Aged 60 and Older: SSBG	County Name	Population Aged 60 and Older	Home Delivered Meals Clients Served per 1000 Aged 60 and Older: HCCBG	Meals Clients Served per 1000 Aged 60 and Older: SSBG
CUMBERLAND	32949	9.56	0	RANDOLPH	21804	19.26	0
CURRITUCK	3034	14.50	0	RICHMOND	8585	18.75	0
DARE	4964	12.09	0	ROBESON	16881	11.49	0
DAVIDSON	25443	12.14	0	ROCKINGHAM	17977	18.19	0
DAVIE	6622	24.16	0	ROWAN	24749	0	0
DUPLIN	8708	15.85	0	RUTHERFORD	12506	22.23	0
DURHAM	25683	20.56	0.43	SAMPSON	10780	13.17	0
EDGECOMBE	9112	8.67	0	SCOTLAND	5325	11.08	0
FORSYTH	50260	19.48	2.53	STANLY	10764	37.44	0
FRANKLIN	7608	14.98	0	STOKES	7639	41.10	0
GASTON	30516	10.16	0	SURRY	14519	18.94	0
GATES	1928	30.60	0	SWAIN	2693	29.71	0
GRAHAM	1829	53.03	0	TRANSYLVANIA	8100	18.52	0
GRANVILLE	7339	47.96	0	TYRRELL	816	41.67	0
GREENE	3385	18.61	0	UNION	15752	35.23	0
GUILFORD	66182	19.36	0	VANCE	7045	31.80	0
HALIFAX	10561	16.95	0	WAKE	66104	21.62	0
HARNETT	13810	26.29	0	WARREN	4658	31.56	0
HAYWOOD	14405	10.14	0.62	WASHINGTON	2637	22.37	0
HENDERSON	24386	26.37	0	WATAUGA	6588	30.81	0
HERTFORD	4233	13.70	0	WAYNE	18092	29.79	0
HOKE	4153	9.39	0	WILKES	12717	24.61	0
HYDE	1172	21.33	0	WILSON	12408	15.55	0
IREDELL	21155	14.04	0	YADKIN	7548	23.18	0
JACKSON	6133	22.34	0.82	YANCEY	4077	41.94	0
				STATE AVERAGE	**13030.34**	**20.90**	**0.06**

Sources: HCCBG services data from the Division of Aging, SFY 1999
SSBG services data from the Division of Social Services, SFY 1999

Table 5
Comparison of In-Home Aides Clients Served - Home and Community Care Block Grant (HCCBG) and Social Services Block Grant (SSBG) per 1000 of Population Aged 60 and Older

County Name	Population Aged 60 and Older	In-Home Aides Clients Served per 1000 Aged 60 and Older: HCCBG	In-Home Aides Clients Served per 1000 Aged 60 and Older: SSBG	County Name	Population Aged 60 and Older	In-Home Aides Clients Served per 1000 Aged 60 and Older: HCCBG	In-Home Aides Clients Served per 1000 Aged 60 and Older: SSBG
ALAMANCE	25105	1.83	0.16	JOHNSTON	18500	15.46	5.24
ALEXANDER	5523	16.30	3.62	JONES	1740	16.67	10.92
ALLEGHANY	2611	40.60	5.36	LEE	9818	0	2.65
ANSON	4897	12.87	0	LENOIR	11639	13.23	3.35
ASHE	6138	20.69	0.33	LINCOLN	10187	2.55	1.77
AVERY	3398	26.78	0.29	MACON	8740	6.75	0.57
BEAUFORT	9139	7.88	6.13	MADISON	9090	1.76	2.20
BERTIE	3971	8.56	0.76	MARTIN	4337	18.45	1.15
BLADEN	6226	12.37	3.53	MCDOWELL	5244	16.40	0
BRUNSWICK	16980	2.89	3.42	MECKLENBURG	80644	12.62	0.48
BUNCOMBE	41686	4.68	0.86	MITCHELL	3817	17.55	8.38
BURKE	16487	10.31	0.42	MONTGOMERY	4324	12.95	0.69
CABARRUS	21043	3.18	1.52	MOORE	21312	6.62	0.23
CALDWELL	14045	5.41	1.71	NASH	15132	7.27	0.86
CAMDEN	1296	6.17	0	NEW HANOVER	27539	4.25	0.11
CARTERET	13241	5.36	0.38	NORTHAMPTON	4952	9.69	9.49
CASWELL	4779	10.04	0	ONSLOW	11877	11.11	0
CATAWBA	23250	2.37	0.90	ORANGE	13569	4.20	0.15
CHATHAM	9600	8.85	2.29	PAMLICO	3159	14.56	13.93
CHEROKEE	6163	6.81	4.54	PASQUOTANK	6368	2.83	0
CHOWAN	3423	9.06	0	PENDER	8249	2.67	0.48
CLAY	2333	13.72	12.00	PERQUIMANS	2848	6.67	0
CLEVELAND	18000	3.56	0.50	PERSON	6497	8.62	0.77
COLUMBUS	10435	4.89	0	PITT	16387	3.78	0.43
CRAVEN	15575	4.69	2.89	POLK	5387	4.08	0

County Name	Population Aged 60 and Older	In-Home Aides Clients Served per 1000 Aged 60 and Older: HCCBG	In-Home Aides Clients Served per 1000 Aged 60 and Older: SSBG	County Name	Population Aged 60 and Older	In-Home Aides Clients Served per 1000 Aged 60 and Older: HCCBG	In-Home Aides Clients Served per 1000 Aged 60 and Older: SSBG
CUMBERLAND	32949	7.44	2.25	RANDOLPH	21804	4.86	0.05
CURRITUCK	3034	12.52	1.32	RICHMOND	8585	15.84	0.12
DARE	4964	18.73	19.14	ROBESON	16881	9.66	0.71
DAVIDSON	25443	5.11	0.63	ROCKINGHAM	17977	6.17	0.06
DAVIE	6622	13.14	1.06	ROWAN	24749	5.01	2.02
DUPLIN	8708	30.55	0.23	RUTHERFORD	12506	2.32	2.96
DURHAM	25683	6.11	1.05	SAMPSON	10780	3.90	1.48
EDGECOMBE	9112	22.28	0.22	SCOTLAND	5325	11.83	0.56
FORSYTH	50260	10.27	2.55	STANLY	10764	12.91	2.23
FRANKLIN	7608	10.25	0.13	STOKES	7639	1.44	7.59
GASTON	30516	10.06	0.39	SURRY	14519	10.74	0
GATES	1928	24.38	21.27	SWAIN	2693	19.31	0
GRAHAM	1829	22.96	2.19	TRANSYLVANIA	8100	9.51	0
GRANVILLE	7339	20.44	0.27	TYRRELL	816	51.47	0
GREENE	3385	3.84	3.84	UNION	15752	11.36	2.79
GUILFORD	66182	4.41	0.76	VANCE	7045	16.04	2.98
HALIFAX	10561	10.51	1.52	WAKE	66104	1.98	1.54
HARNETT	13810	8.54	0.22	WARREN	4658	21.04	0.21
HAYWOOD	14405	5.48	2.15	WASHINGTON	2637	21.24	2.28
HENDERSON	24386	7.18	3.28	WATAUGA	6588	31.72	3.34
HERTFORD	4233	7.32	1.42	WAYNE	18092	21.17	0.33
HOKE	4153	11.56	1.20	WILKES	12717	9.91	0.16
HYDE	1172	22.18	7.68	WILSON	12408	7.41	0.81
IREDELL	21155	8.37	0.52	YADKIN	7548	28.62	0
JACKSON	6133	19.08	0.33	YANCEY	4077	12.51	0.74
				STATE AVERAGE	**13030.34**	**11.41**	**2.24**

Sources: HCCBG services data from the Division of Aging, SFY 1999
SSBG services data from the Division of Social Services, SFY 1999

TABLE 6

COMPARISON OF NURSING HOME BEDS AND COMMUNITY ALTERNATIVES PROGRAM FOR DISABLED ADULTS (CAP/DA) CLIENTS SERVED PER 1000 OF ELIGIBLE POPULATION

County Name	Population Aged 65 and Older	Nursing Home Beds per 1000 Aged 65 and Older	Medicaid Eligible Aged & Disabled	CAP/DA clients served per 1000 Medicaid Aged & Disabled	County Name	Population Aged 65 and Older	Nursing Home Beds per 1000 Aged 65 and Older	Medicaid Eligible Aged & Disabled	CAP/DA clients served per 1000 Medicaid Aged & Disabled
ALAMANCE	19508	42.09	4367	14.43	JOHNSTON	13731	32.77	5602	8.39
ALEXANDER	4071	44.95	1131	66.31	JONES	1293	61.87	720	87.50
ALLEGHANY	2050	43.90	645	106.98	LEE	7411	31.57	2141	49.98
ANSON	3855	41.76	1800	55.00	LENOIR	8826	37.62	4112	22.86
ASHE	4646	38.74	1654	113.66	LINCOLN	7516	33.26	2013	21.36
AVERY	2598	49.27	990	200.00	MACON	7074	38.17	1454	63.27
BEAUFORT	6897	42.05	2990	47.49	MADISON	3308	54.41	1424	14.04
BERTIE	3024	46.96	2241	89.25	MARTIN	3951	38.98	2114	35.00
BLADEN	4755	40.80	2962	44.23	MCDOWELL	6598	33.34	1868	21.95
BRUNSWICK	12345	25.44	3048	24.61	MECKLENBURG	60133	51.12	16091	27.90
BUNCOMBE	32527	51.68	8253	23.87	MITCHELL	2940	43.20	1077	80.78
BURKE	12329	36.99	3553	73.46	MONTGOMERY	3298	46.39	1472	33.97
CABARRUS	15855	37.65	3758	112.83	MOORE	17101	33.92	2682	22.74
CALDWELL	10421	39.34	3073	76.80	NASH	11435	36.64	4832	18.00
CAMDEN	951	42.06	260	42.31	NEW HANOVER	20802	34.08	5871	22.65
CARTERET	9790	41.88	2088	61.78	NORTHAMPTON	3796	39.25	2237	21.46
CASWELL	3629	37.75	1395	70.25	ONSLOW	8405	42.71	3405	47.28
CATAWBA	17284	38.71	3956	38.17	ORANGE	10136	43.71	2020	50.50
CHATHAM	7456	45.60	1503	40.59	PAMLICO	2387	40.22	702	69.80
CHEROKEE	4785	37.62	1821	81.82	PASQUOTANK	5057	52.60	1800	26.67
CHOWAN	2700	62.96	948	62.24	PENDER	6048	35.22	1916	75.16
CLAY	1832	43.67	504	81.35	PERQUIMANS	2168	35.98	662	39.27
CLEVELAND	13538	40.18	4622	36.13	PERSON	4941	40.48	1804	26.61
COLUMBUS	7793	37.60	5323	24.80	PITT	12626	43.40	6362	16.50
CRAVEN	11821	39.42	3795	41.63	POLK	4377	50.49	646	71.21

County Name	Population Aged 65 and Older	Nursing Home Beds per 1000 Aged 65 and Older	Medicaid Eligible Aged & Disabled	CAP/DA clients served per 1000 Medicaid Aged & Disabled	County Name	Population Aged 65 and Older	Nursing Home Beds per 1000 Aged 65 and Older	Medicaid Eligible Aged & Disabled	CAP/DA clients served per 1000 Medicaid Aged & Disabled
CUMBERLAND	23254	34.23	9577	16.60	RANDOLPH	16343	38.55	3753	49.83
CURRITUCK	2238	37.98	522	55.56	RICHMOND	6609	41.76	3136	9.89
DARE	3518	35.82	547	27.42	ROBESON	12450	42.41	9807	43.64
DAVIDSON	18826	37.66	4698	20.01	ROCKINGHAM	13636	39.97	4718	80.54
DAVIE	5029	39.37	1028	120.62	ROWAN	19323	41.14	4213	49.85
DUPLIN	6492	38.82	3244	37.61	RUTHERFORD	9594	43.78	3082	31.15
DURHAM	19614	67.91	6391	17.84	SAMPSON	8161	38.23	3835	8.87
EDGECOMBE	6956	45.57	4781	14.22	SCOTLAND	4004	49.70	2601	40.37
FORSYTH	38420	49.92	8586	16.77	STANLY	8277	49.05	2204	40.83
FRANKLIN	5657	45.61	2622	36.61	STOKES	5493	58.62	1603	43.67
GASTON	23023	42.22	7850	16.31	SURRY	10959	39.42	3479	45.99
GATES	1438	48.68	587	97.10	SWAIN	2037	58.91	948	90.72
GRAHAM	1361	58.78	677	116.69	TRANSYLVANIA	6346	37.35	1101	67.21
GRANVILLE	5474	43.84	2028	18.24	TYRRELL	640	46.88	332	39.16
GREENE	2536	45.35	1016	47.24	UNION	11176	31.94	2660	20.68
GUILFORD	50371	44.19	12297	23.58	VANCE	5393	43.02	3371	13.35
HALIFAX	8097	42.61	5950	12.44	WAKE	47585	40.66	11518	26.57
HARNETT	10354	41.63	3861	27.97	WARREN	3655	38.30	1652	21.79
HAYWOOD	11053	39.90	2583	40.26	WASHINGTON	2022	41.54	978	42.94
HENDERSON	19448	42.27	3152	35.22	WATAUGA	4883	38.09	1161	73.21
HERTFORD	3299	48.80	2210	47.51	WAYNE	13071	36.19	5877	10.55
HOKE	3035	30.31	1455	51.55	WILKES	9461	44.08	3337	76.42
HYDE	898	89.09	509	60.90	WILSON	9343	40.14	4332	31.63
IREDELL	15714	35.83	3618	36.76	YADKIN	5754	42.93	1407	52.59
JACKSON	4609	41.22	1525	81.97	YANCEY	3126	44.79	1210	56.20
					STATE AVERAGE	**9818.73**	**42.76**	**3153.36**	**47.49**

Sources: Nursing Home Beds data from the State Medical Facilities Plan 2000 (Draft), May 1999
CAP/DA data from the Division of Medical Assistance, SFY 1999

LONG-TERM CARE ENHANCEMENT FUNDS LEGISLATION PROPOSED BY THE LEGISLATIVE STUDY COMMISSION ON AGING

Whereas, North Carolina's population of adults age 65; and older currently totals one million and is expected to increase by 34% to over one million six hundred thousand by the year 2020; and

Whereas, nurse aids and other aide workers provide about 90% of all the paid long term care needed by older disabled adults whether at home or in facilities; and

Whereas, this workforce is essential to quality care and preserving the dignity of persons who need help with the very basic and personal tasks that many of us take for granted; and

Whereas, between 1996 and 2006, nurse aides and other paraprofessional aides are among the occupations with the fastest and largest job growth; and

Whereas, demand for these workers will continue to grow well beyond 2006 as a result of aging baby boomers who will put further increased demand on the State's long term care system; and

Whereas, North Carolina is experiencing aide shortages of crisis proportion in all long-term care settings including home care, assisted living facilities and nursing homes; and

Whereas, 58% of North Carolina's nurse aide registrants are not working as nurse aides and have substantially higher average annual earnings and more stable employment that they would have were they working as nurse aides; and

Whereas, our State's low unemployment rate is only one factor contributing to the severe shortage of aide workers; and

Whereas, there are other major factors that contribute to high turnover rates including low wages and few paid benefits in spite of very physically demanding work and lack of a career path that recognizes attainment of increased skills,

Now, therefore, the North Carolina General Assembly enacts:

Sec. 1(a). There is appropriated from the General Fund to the Department of Health and Human Services the sum of $_____- for the 2001-2002 fiscal year and the sum of $_____ for the 2002-2003 fiscal year. These funds shall be used to match federal Medicaid funds to provide a ___ percentage labor enhancement payment for Medicaid reimbursed long-term care services. These funds shall be in addition to funds provided for routine inflationary increases in Medicaid reimbursements for long-term care services. The funds appropriate in this section shall be used only to increase wages or benefits for long-term care aide workers, or to provide for shift differential payments for long-term care aides who work during hard-to-fill working hours or shifts.

Sec. 1(b) funds appropriated in this section shall be allocated in accordance with the following:

(1) The amount of the labor enhancement benefit shall be allocated equitably among the various care settings.

(2) Long-term care facilities and agencies that receive labor enhancement funds shall have the flexibility to determine whether labor enhancement funds are used for wages, benefits or shift differentials, or any combination thereof.

(3) If labor enhancement funds are used to enhance wages, the long-term care facility or agency shall determine which aides receive wage increases and the amount of the increase provided. The determination shall be based on local market wage demands, rewarding longevity of service by the worker, and other wage related needs of the agency or facility.

(4) Long-term care facilities and agencies that receive labor enhancement funds shall, as a condition of receiving the funds, submit reports and information required by the Department for the purpose of verifying use of the labor enhancement funds. Reports and information provided by facilities and agencies shall include for each facility and agency information needed to determine annual labor turnover rates in the agency or facility, including data on pre-labor enhancement turnover rates and turnover rates at the end of each fiscal year for which labor enhancement funds are received.

Sec. 1(c) Not later than January 15, 2002, the Department of Health and Human Services shall report to the joint Legislative Commission on Governmental Operations and to the Legislative Study Commission on Aging on the use of labor enhancement funds appropriate under this section. The report shall include detailed information on:

(1) The amount of funds used for wages, for benefits, and for shift differentials.

(2) Comparative information on average hourly wages paid to aides and turnover rates by setting (e.g., home care, assisted living, nursing home) for fiscal year 1999-2000 through fiscal year 2002-2003.

Sec. 2.(a) The Department of Health and Human Services, Division of Facility Services, shall develop and implement a Carolina Educates Caregivers program (“Program”) for aides working in long-term care. The purpose of the Program is to facilitate the development of a stable, well-trained labor force to provide long term care services. To this end, the Program will provide bonuses, tuition, and other financial assistance and incentives to support continuing education and professional development for long-term care aides. The Program shall provide on-going support to educate long term care workers and shall be modeled after the TEACH program for child care workers. For purposes of this section, long term care includes home care agencies, assisted living facilities, and nursing homes. The Department may contract for assistance with the development and implementation of the Program with a public or private non-profit organization that does not represent one or more long term care provider groups and that has expertise in low-wage or health care workforce recruitment and retention issues.

Sec. 2(b). There is appropriated from the General Fund to the Department of Health and Human Services the sum of one million four hundred six thousand twenty-nine dollars ($1,406,029) for the 2001-2002 fiscal year, and the sum of two million ninety-seven thousand three hundred one dollars ($2,097,301) for the 2002-2003 fiscal year. These funds shall be used as follows:

(1) $1,406,029 for the development and implementation of the Carolina Educates Caregivers Program established pursuant to this section.
(2) $2,097,301 to provide bonuses, tuition, and other financial assistance and incentives to support continuing education and professional development for long term care aides.

Not more than __% of the funds appropriated for each fiscal year may be used for administrative expenses and start-up costs to implement and operate the program. Funds unexpended and unencumbered at the end of each fiscal year shall revert to the General Fund.

Sec. 2(c). Not later than January 15, 2002 the Department shall report to the Legislative Study Commission on Aging on the implementation status of the Carolina Educates Caregivers Program.

Sec. 2(d). The Department of Health and Human Services shall develop a career ladder and associated new curricula requirements and job category qualifications for long term care aide workers. The purpose of the career ladder is to provide a career path for aide workers that recognizes the attainment of additional skills and broadens the pool of potential workers by providing additional job opportunities for persons who may not currently consider long term care as a career option. The Department shall work with appropriate State organizations such as the North Carolina Board of Nursing, the Center for Nursing, the Community College system, long term care provider organizations, and others to consider the need to re-engineer current job categories of aide workers and develop new job categories of licensed and unlicensed personnel as needed to meet current and future care needs of long term care clients and patients.

Sec. 2(e). There is appropriated from the General Fund to the Department of Health and Human Services the sum of one hundred thousand dollars ($100,000) for the 2001-2002 fiscal year for the development of a career ladder as provided in this section.

Sec. 3(a). The Department of Health and Human Services shall compile and evaluate demographic, turnover, and wage and benefit data for the long term care aide workforce across long term care settings. This compilation and evaluation shall be ongoing in order to provide the information necessary to track the impact of efforts to increase the supply and stability of the long term care aide workforce and to provide data from which additional efforts can be considered.

Sec. 3(b). There is appropriated from the General Fund to the Department of Health and Human Services the sum of fifty thousand dollars ($50,000) for the 2001-2002 fiscal year, and the sum of fifty thousand dollars ($50,000) for the 2002-2003 fiscal year. These funds shall be used for data collection and compilation required under this section. The Department may contract with the North Carolina Institute on Aging for this data collection and analysis activity.

Sec. 4. The Legislative Research Commission may study workforce issues pertaining to the long term care aide workforce. In conducting the study the Commission may consider State and national efforts to address a crisis in developing and maintaining a stable, well-trained work force of workers providing long-term care services. The Commission may also propose actions the State may need to take to ensure that the State's long term care workforce capacity meets the long term care needs of an increasing aging population. In appointing study committee members, the Speaker of the House of Representatives and the President Pro Tempore of the Senate may consider including public members who represent the long term care industry, long term care consumer advocates, and individuals employed as nurse aides in this State.

Sec. 5. This act becomes effective July 1, 2001.

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INCREASE CAP INCOME LIMITS LEGISLATION PROPOSED BY THE LEGISLATIVE STUDY COMMISSION ON AGING

Sec. 1. Effective October 1, 2001, the Department of Health and Human Services shall increase the income eligibility limit for the Community Alternatives Program to three hundred percent (300%) of income eligibility for federal Supplemental Security Income (SSI) benefits. The Department shall allow individuals to deduct the same amount in maintenance allowance to support the recipient's spouse in the community as allowed for individual's in nursing homes.

Sec. 2. There is appropriated from the General Fund to the Department of Health and Human Services the sum of $____ for the 2001-2002 fiscal year and the sum of $____ for the 2002-2003 fiscal year. These funds shall be used to implement the increase in CAP eligibility as provided for in Section 1 of this Act.

Sec. 3. This act becomes effective October 1, 2001.

PRIVATE LONG-TERM CARE INSURANCE OUTREACH LEGISLATION PROPOSED BY THE LEGISLATIVE STUDY COMMISSION ON AGING

Sec. 1 (a) The Department of Insurance, in conjunction with the Department of Health and Human Services' Division on Aging and Division of Mental Health, Developmental Disabilities, and Substance Abuse Services and other appropriate entities or groups, shall implement outreach efforts to inform the public about long-term care funding or payment options. The efforts shall include information on the following:

(1) What long-term care services are covered by Medicare or Medicaid.
(2) What services must be paid for in whole or in part by the individual.
(3) The average premium cost for private long-term care insurance and what services the long-term care insurance covers.
(4) Any other information that might be useful to consumers in planning for and securing long-term care services.

(b) Outreach efforts shall be targeted to:

(1) Employers.
(2) Persons who comprise the "baby boomer" generation.
(3) Financial advisors.
(4) Certified Public Accountants.
(5) Banks.
(6) Advocacy groups and associations that represent senior citizens and persons with disabilities.
(7) The legal profession.
(8) Any other identified as having an interest in information about long-term care.

(c) Outreach strategies shall include:

(1) Community education, including integration into pertinent community college curricula on estate and financial planning.
(2) The Internet.
(3) Mass media.
(4) Information about the Seniors Health Insurance Program (SHIIP) in the Department of Insurance.

Sec. 2. Not later than March 1, 2002, the Department of Insurance shall report on the implementation of long-term care outreach efforts to the Senate and House of Representatives appropriations subcommittees on General Government and Health and Human Services, and to the Fiscal Research Division of the Legislative Services Office.

Sec. 3. There is appropriated from the General Fund to the Department of Insurance, the sum of two hundred sixty-eight thousand dollars ($268,000) for the 2001-2002 fiscal year, an the sum of $268,000 for the 2002-2003 fiscal year to implement the long-term care outreach efforts required by this act.

This act becomes effective July 1, 2001.

EXAMPLES OF LOCAL INITIATIVES IN LONG-TERM CARE

LOCAL INITIATIVES

Western NC Help Link
Simplified Access, Electronic Information and Referral, Case Assistance, Information Sharing Across Agencies, Case Management Across Agencies, and Regional Planning

- Agencies from 26 counties will eventually participate in an electronic information and referral network (IRis based); currently operational in Buncombe county
- 211 information line
- Client, service and referral information is shared among providers
- Community-Based Case Management services offered to clients who need more intensive follow-up or management than an agency is able to provide itself

ACCES (Accessing Cleveland County Elder Services, Inc.)
County Planning, Simplified Access, Case Assistance, and Case Management

- Information and referral by Senior Center (not automated)
- Case assistance by LIVE!
- County coordination through ACCES committee; strong cooperation by service providers minimizes fragmentation
- Case management services provide health education information and referral
- County Commissioners allocated funds to develop a single case management system
- Initial funding from Kate B. Reynolds Charitable Trust; Hospital provides physical space

Charlotte-Mecklenberg Aging Coalition (CMAC)
Simplified Access, Electronic Information and Referral, Case Assistance, Common Intake Tool, and Case Management

- An Access Management Organization (AMO) style center planned with comprehensive screening and case management planned
- A call center—"Just1Call"-- with trained Info Specialists and Resource Coordinators, located in DSS
- Satellite locations planned
- IRis electronic database
- Intake tool based on Duke's SOS

Wake County—Resources For Seniors
Simplified Access, Electronic Information and Referral, Case Assistance, Common Intake Tool, and Case Management

- In Wake County, the department of health, mental health, and social services consolidated into a single agency, Human Services
- County contracts with Resources for Seniors (RFS) to provide publicly funded services
- RFS provides most aging services
- RFS provides extensive marketing to inform community how to access services through RFS
- RFS uses IRis for intake, follow-up and reporting; web-based database
- CAP/DA and RAI-HC assessment tools used

Forsyth County
Simplified Access, Electronic Information and Referral, Case Assistance, Common Intake Tool, and Case Management

- In 1990, Senior Services formed "living at home" division, to provide information and referral, case assistance and case management (including in-home assessments)—a CAP/DA model with funding from Kate B. Reynolds Charitable Trust
- First "living at home" model—providing case management and community-based services to high risk older adults
- In 1993, major interagency agreement with health deptartment contracting with Senior Services for CAP/DA program
- Senior Services information and referral source (Helpline); electronic information and referral not IRis based but use Elder Care software

Alamance County
Simplified Access, Case Assistance, Case Management, and County Planning

- Planning began in 1990, formed the Alamance County Planning Committee on Services for older adults, now known as Elder Care
- Public officials, senior advisors, religious leaders, corporate leaders, service agency, community, and consumer representatives involved
- Developed clinical pathways to determine need, medical management, and Medicaid eligibility
- Use Duke SOS
- Initial funding from Kate B. Reynolds Charitable Trust

Guilford County
Simplified Access, Electronic Information and Referral, Case Assistance, Case Management, Info Sharing Across Agencies, and County Planning

- Planning directed to building an infrastructure for aging and disability services
- Leadership board of county commissioners, departments of social services, health and mental health, universities, corporations, foundations, medical care systems, nursing homes and adult care homes, service providers, and volunteers
- Deal with advocacy, planning, policy development, education, resource development, data systems, financing, research, and quality assurance
- Insure access through electronic information and referral, case assistance, care management, screening, assessment, and tracking
- Staff to staff contact with confidentiality policy
- Have pathways, protocols and key indicators

Piedmont Triad Council Of Governments Area Agency On Aging
Simplified Access, Electronic Information and Referral, Case Assistance, Common Intake Tool, and Regional Planning

- Four of the six Region G counties, with United Way of Greensboro and Moses Cone Hospital, led to design a universal resource database of services
- Database serves as a first step to access
- IRis based database on web; intake on IRis with Duke's SOS
- Lead agency in each county collects data; United Way of Greensboro enters data
- Includes pathways and protocols for information and case assistance

Eastern North Carolina
Electronic Information and Referral, Common Screening Tool, Case Assistance, Information Sharing Across Agencies, and Regional Planning

- Mid-East Commission Area Agency on Aging lead agency
- Developed web-based automated resource directory (IRis based) for 16 county area—the health and human service providers in Regions Q and R
- Enhanced and automated version of Duke's SOS for screening and tracking; currently used in one county—Pitt
- Kate B. Reynolds Charitable Trust funding for Aging at Home project

Wilmington/New Hanover
Simplified Access, Electronic Information and Referral, Case Assistance, Common Intake Tool, and County Planning

- New Hanover County community planning initiative named Project R.O.A.R. (Raising Older Adults Rights).
- Cape Fear Area Agency on Aging and New Hanover County DSS lead agencies.

State-County Special Assistance (SA) Demonstration Project

- The demonstration project, authorized by the General Assembly, is designed to help eligible individuals who need adult care home level of care to live at home with the aid of the SA income supplement, in-home services, and family/informal support.
- A DSS case manager assesses and monitors the individual's ability to live at home, the types of in-home services needed, the availability of family or other informal support, and how SA payments are used to enable the person to live at home.
- The SA payment is used to pay for minor home repairs, installation of ramps or rails, rent for safe housing, or other necessary costs of living at home safely. Medicaid, SSBG, Home and Community Care Block Grant, and other funding sources are used to provide in-home services such as Personal Care Services, Home Delivered or Congregate Meals, durable medical equipment, case management, as examples.
- The demonstration project will operate through June 2001 and is limited to 400 individuals living in the 22 counties participating in the project.
- The automated RAI-HC assessment instrument is being used for the assessment and service planning components of the project.

Resident Evaluation Services Pilot

- Resident Evaluation Services is a new program established by the General Assembly. County DSS staff will assess all Special Assistance applicants and recipients to
  - determine whether adult care home level of care is needed;
  - identify individuals with mental illness, developmental disabilities, or substance abuse problems so that they can be referred to area mental health agencies or other qualified mental health professionals for diagnosis and treatment or habilitation; and
  - provide technical assistance to adult care homes on assessing and developing care plans for residents using the RAI assessment and care planning instrument.
- A six-month pilot is planned for March 2001-September 2001. The pilot will include county DSS agencies, area mental health agencies, and a sample of adult care homes in the 25 pilot counties. Statewide implementation is planned for phase-in during calendar year 2002.
- The pilot will test use of the automated RAI-ACH assessment instrument by DSS agencies and ACHs as a web-based application. Area mental health agencies will also have access to the RAI-ACH assessment information via the web application. In conjunction with this project, Catherine Hawes and Elise Bolda are developing the assessment protocols (CAPS) needed for care planning purposes.
- Initially, assessment data collected by county DSS agencies will be used to establish level of care criteria for adult care homes for Special Assistance applicants and recipients. The long-range plan is for the RAI assessment instrument to replace the FL-2.

FREQUENTLY USED ACRONYMS

ADL	Activity of Daily Living
CAP/DA	Community Alternatives Program for Disabled Adults
CAP-MR/DD	Community Alternatives Program for Persons with Mental Retardation or Developmental Disabilities
DFS	The North Carolina Division of Facility Services
DHHS	The North Carolina Department of Health and Human Services
DMA	The North Carolina Division of Medical Assistance
DMHDDSAS	The North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services
DOA	The North Carolina Division of Aging
DSS	The North Carolina Division of Social Services
FPL	Federal Poverty Level
FFY	Federal Fiscal Year
HCCBG	Home and Community Care Block Grant
HCFA	Health Care Financing Administration
HIPAA	Health Insurance Portability and Accountability Act
IADL	Independent Activity of Daily Living
ICF-MR	Intermediate Care Facility for the Mentally Retarded
LPN	Licensed Practical Nurse
LTC	Long-Term Care
MR/DD	Mental Retardation or Developmental Disability
MSA	Medical Savings Account
N.C.G.S.	North Carolina General Statute
NC IOM	The North Carolina Institute of Medicine
NLTCS	National Long-Term Care Survey
PCS	Personal Care Services
RFP	Request for Proposals
RN	Registered Nurse
SA	State-County Special Assistance
SAB	Special Assistance for the Blind
SFY	State Fiscal Year
SHIIP	Seniors Health Insurance Information Program
SIPP	Survey of Income and Program Participation
SSBG	Social Services Block Grant
SSI	Supplemental Security Income
UNC	University of North Carolina
UNC-CH	University of North Carolina at Chapel Hill

ASSESSMENT AND CARE PLANNING TOOLS

MDS	Minimum Data Set
RAI	Resident Assessment Instrument
RAI-AC	Resident Assessment Instrument-Acute Care
RAI-ALNC	Resident Assessment Instrument- Assisted Living North Carolina
RAI-AL	Resident Assessment Instrument-Assisted Living
RAI-HC	Resident Assessment Instrument-Home Care
RAI-MH	Resident Assessment Instrument-Mental Health
RAI-PAC	Resident Assessment Instrument-Post Acute Care
FL-2	State mandated tool for Nursing Home and Adult Care Home Admissions
NC SNAP	North Carolina Support Needs Assessment Profile
OASIS	Outcome and Assessment Information Set
PASARR	Preadmission Screening and Annual Resident Review
SOS	Service and Service Outcome Screen