

**An Assessment of Information & Assistance Services
For Seniors Needing Long-term Care in North Carolina:
What has changed and what comes next for the Aging Network?**

A Report for the North Carolina Institute of Medicine

Prepared by Ariel E. Hayes
Master of Public Policy Candidate
The Sanford School of Public Policy
Duke University

Faculty Advisor: Sherman James

April 22, 2011

Table of Contents

EXECUTIVE SUMMARY	3
POLICY QUESTION	7
INTRODUCTION	7
ENTRY INTO THE LONG-TERM CARE SYSTEM: BACKGROUND AND RECENT CHANGES	11
TRANSITION FROM INSTITUTIONAL CARE TO A MORE COMPREHENSIVE SYSTEM	11
BABY BOOMERS & THE AGING OF NORTH CAROLINA	14
ROLE OF NORTH CAROLINA’S AGING NETWORK	17
INFORMED DECISION-MAKING IN LONG TERM CARE	19
INFORMATION, REFERRAL AND ASSISTANCE SERVICES	21
BACKGROUND	21
DESCRIPTION OF SERVICES	22
RESEARCH METHODOLOGY	24
IMPLEMENTING THE NCIOM RECOMMENDATIONS	26
SYSTEM DESIGN	26
i. <i>No Wrong Door</i>	26
ii. <i>Agency Decisions at the Local Level</i>	27
iii. <i>Technology</i>	27
COMMUNITY RESOURCE CONNECTIONS INITIATIVE (CRC).....	28
NCCARELINK	30
CHALLENGES WITH I&A PROGRAMS IN NORTH CAROLINA	34
MOVING FORWARD WITH NCIOM RECOMMENDATIONS	41
OBJECTIVE #1: REDUCE THE TIME IT TAKES FOR OLDER ADULTS TO FIND THE SERVICES THEY NEED ..	41
OBJECTIVE #2: MAKE IT EASIER FOR OLDER ADULTS TO IDENTIFY IF THEY NEED INFORMATION OR ASSISTANCE.....	42
OBJECTIVE #3: PROVIDE HIGH-QUALITY ASSISTANCE SERVICES.....	43
OBJECTIVE #4: ENGAGE THE PRIVATE, FOR-PROFIT SECTOR TO REDUCE THE STRAIN ON THE PUBLIC AND NON-PROFIT AGING NETWORK	44
ACKNOWLEDGMENTS	45
BIBLIOGRAPHY	46

Executive Summary¹

Policy Question: How should North Carolina’s Aging Network provide information and assistance services so that all older adults (and their caregivers) looking for long-term care receive appropriate guidance?

Introduction:

Information and Assistance (I&A) programs inform, counsel and connect people seeking long-term care with services that could meet their needs. The Older Americans Act mandated that every Area Agency on Aging (of which there are 17 in North Carolina) establish I&A programs in their region. North Carolina has 42 I&A programs registered with the Division of Aging and Adult Services; more counties offer these services without OAA funds. As the population ages, more people will need a well-informed, local agency is critical to help them navigate the long-term care system and access services. Older adults and their families face such a complicated array of choices and decisions – about not only health care, but also housing, finances, and basic household tasks.

Ten years ago, the North Carolina Institute of Medicine (NCIOM) delivered its report, “A Long-Term Care Plan for North Carolina: Final Report” to the North Carolina Department of Health and Human Services (DHHS). Early in its deliberations, the Task Force concluded “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.”² Once the state was awarded a *Real Choice Systems Grant*, these recommendations became a roadmap for North Carolina, which launched two initiatives to improve seniors’ access to long-term care information and counseling: a web-based resource system called NCcareLink and the regional Community Resources Connections (CRC) program. My assessment focuses on how the Aging Network and its existing I&A programs have responded to these initiatives and worked to create a more accessible and understandable system. This report is especially relevant to counties that are beginning the transformation to a CRC and to state policymakers responsible for NCcareLink. s

Methodology:

I selected eight counties (Alamance, Beaufort, Forsyth, Henderson, Lenoir, Macon, Mecklenburg, and Surry) and contacted the primary agencies that serve older adults. The counties vary by geographic region, diversity, population density, and proportion of adults over 65. I conducted a total of 28 interviews. In each county, my goal was to identify and interview an organization that plays a central role in informing older adults about their options. In five

¹ The research, analysis, and policy alternatives and recommendations contained in this paper are the work of the student who authored the document, and do not represent the official or unofficial views of the Sanford School of Public Policy or of Duke University.

² North Carolina Institute of Medicine. “A Long-term Care Plan for North Carolina: Final Report” 2001, pg3

counties, this was an agency that receives state or county-funding to provide information and assistance.

In addition to the main I&A provider, I interviewed other organizations at the regional and local level that serve the same population. This allowed me to, first, gauge the “No Wrong Door” model by discussing the skills and tools each agency used to make accurate, effective referrals. Secondly, it spoke to a community’s recognition of the designated I&A provider (e.g. how many people are relying on the Senior Center instead of the Council on Aging, and for what reason).

Lastly, to gain some understanding of how other states have addressed the issues, I interviewed employees at Departments of Aging in Oregon, Ohio, and Virginia, which have also established online databases.

Key Findings:

Many of the key findings from my interviews are fundamental and already known to providers and the state.

- 1. The role of the AAA and its staff is not clearly defined.** The potential of AAAs are tremendous, but the history of AAAs in North Carolina has led to weakly defined roles that could impede easy entry into the system. In North Carolina, few people know even what the AAA does. A clearer definition and articulation of roles could help the staff members direct calls efficiently and reduce the number of inappropriate calls in the first place. The state can change its management strategy and level of supervision of the AAAs to promote certain roles and foster greater clarity.
- 2. Everyone in the Aging Network receives calls from older adults.** Both in counties that have formal I&A programs and those that do not, every agency in the Aging Network is regularly contacted by older adults who do not know where to go for information and assistance. Seniors have diverse and often specific needs; when providers respond to these calls, it can be a time-intensive process and, if the provider is not experienced in I&A, may not lead to the best match for the consumer.
- 3. Older adults have trouble identifying their needs.** Older adults recognize one need (e.g. help with light housekeeping) but they may not realize they also are struggling to walk and need to install grab bars in their home to prevent falls. The reason I&A is so valuable is that trained individuals can ascertain this information through phone conversations; it is much harder – but not impossible – to gather the same information online.
- 4. Older adults delay seeking help until they are in dire need.** Information & Assistance programs usually receive calls from older adults only when their functioning has deteriorated to the point where they need immediate assistance. Culture plays an enormous role. It is very difficult for the Aging Network to convince people to call at the first sign of a need, rather than in a crisis. As the demands on the Aging Network

increase, the AAA may have less time and resources to promote services at health fairs or reach out to pastors. Before the system is so strained that there is little or no time for community outreach, the Aging Network needs to find more effective ways to promote their services.

5. **Caregivers are seeking out information online and being directed to many different sites.** Adult children looking for information are likely to begin with a Google search. Even once NCcareLink is fully developed and being promoted by the Aging Network, policymakers need to be aware of the websites that appear at the top of a Google search query, such as private rehabilitation and home healthcare providers. Additionally, online information needs to be integrated with off-line service delivery. People who are searching for information online are often looking for phone numbers of service providers. They may want the phone number to a provider of specific services (e.g. transportation, personal care) or to a public office (e.g. DSS) that can screen for Medicaid eligibility. Either way, these websites will play an important role in directing people to services, so the way services are described and pathways are mapped online needs to match the offline system
6. **Changes to the long-term care system need to allow for county differences, while also moving toward consistency.** Every county has organized their services differently. The CRC pilot projects and expansions demonstrate that every county will interpret and implement programs in their own way. However, it would be unfortunate if these variations prevented counties from sharing insights about what works or created additional confusion for senior citizens and caregivers. Moving forward, the goal for the state is to ensure information is readily available to all aging adults, without prescribing a set of certain set of services that may be unrealistic for or incompatible with a particular county's current organization.

Recommendations

In keeping with the NCIOM's initial recommendation, any new alternatives must advance the three goals that information should be readily available and easily accessed, understandable, and uniform for all in need.

Objective #1: Reduce the time it takes for older adults to find the services they need

1. Identify at least one I&A program in every county.
2. Expand and modify online presence of all Aging Network agencies to make them consistent and senior-friendly.
3. Prioritize good website design over expediency.
4. Work with Aging Network staff to collect and record data on caller demographics (age, race, location) and level of functioning
5. Allow providers the opportunity to see the same software interface that Aging Network agencies are using.

Objective #2: Make it easier for older adults to identify if they need information or assistance

6. Learn from states that have implemented needs assessment tools.
7. Create a .pdf version of the state's needs assessment tool that can be emailed to or downloaded by interested caregivers.

Objective #3: Provide high-quality assistance services

8. Train I&A providers in options counseling.
9. Implement benefits or incentives that help recruit and retain exceptional staff at I&A agencies.

Objective #4: Engage the private, for-profit sector to reduce the strain on the public and non-profit Aging Network

10. Provide training to I&A programs to promote services provided in the private, for-profit sector.
11. Expand or replicate the Forsyth Senior Services' Elder Care Choices program, which provides consultation and referral services to employees as part of subscribing companies' employee benefits packages.

Policy Question:

How should North Carolina's Aging Network provide information and assistance services so that all older adults (and their caregivers) looking for long-term care receive appropriate guidance?

Introduction

It has been 10 years since the North Carolina Institute of Medicine (NCIOM) delivered its report, "A Long-Term Care Plan for North Carolina: Final Report" to the North Carolina Department of Health and Human Services (DHHS). This report, authored by a task force of 40 individuals – with input and assistance from 35 others, laid out the problems facing the state in meeting the long-term care needs of the population. The report highlighted the fragmentation within DHHS, the confusion individuals face finding appropriate services, the shortage of trained professionals and paraprofessionals who provide long-term care, the scarcity of information about the quality of care, and an assessment of whether the current level of services is adequate to meet the populations' needs. In response to these problems, the Task Force made 47 recommendations to simplify the infrastructure and improve the financing, delivery, and quality of long-term care. In part because the Task Force included senior officials in many branches of DHHS with responsibility for implementing the recommendations, the NCIOM report became the roadmap for modernizing the long-term care system. √

Early in its deliberations, the Task Force concluded "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."³ The long-term care system in North Carolina, as described by the Task Force in 2001, involved a "complex...patchwork of programs, services, providers, and state and federal laws" that cause confusion for consumers and unnecessary duplication.⁴

Recommendations 3, 4, 6 and 7 of the NCIOM report pertain to simplifying entry into the system. All were labeled by the NCIOM as high priority recommendations. As defined by the NCIOM, "'entry into the system' refers to consumer pathways into and through long-term care and includes the following types of services: information, referral and assistance; screening; level of service assessment; and care planning."⁵ Table 1 (pg. 7) lists these recommendations.

My thesis first, focuses on how the provision of information, referral and assistance has changed since the NCIOM report and, second, suggests an array of steps that publicly-funded agencies could adopt moving forward. Several of the most significant changes were already outlined in NCIOM update that was published in 2007 (see Table 1, pg. 7). These changes include the establishment of two pilot Aging and Disability Resource Centers (ADRCs) and the launch of a statewide information and assistance web-based resource system called NCcareLink.

³ North Carolina Institute of Medicine. "A Long-term Care Plan for North Carolina: Final Report" 2001, pg3

⁴ North Carolina Institute of Medicine. "A Long-term Care Plan for North Carolina: Final Report" 2001, pg2

⁵ North Carolina Institute of Medicine. "A Long-term Care Plan for North Carolina: Final Report" 2001, pg33

Today, the ADRC pilot program has become the statewide Community Resource Connections (CRC) initiative. Funded through a grant from the Administration on Aging and the Centers for Medicare & Medicaid Services, the CRC program is about “building on existing community infrastructure and realigning systems and processes” to “create a coordinated system of information and access for all people seeking long-term support and services, and to minimize confusion, enhance individual choice, and support informed decision-making.”⁶

There is significant momentum behind the CRC initiative. Several counties have a CRC in place, while most are still in the planning phase. Despite the popularity of the concept, there is considerable confusion about how to deliver all the required functions using only the existing community infrastructure. There are four categories of required functions; the first is information and the second is assistance. The description of these services, as listed by the Office of Long-Term Services & Supports is:

- Awareness & Information
 - Public Education
 - Information on long-term support options
- Assistance
 - Options counseling
 - Benefits counseling
 - Employment options counseling
 - Crisis intervention
 - Planning for the future long-term services needs

My report, by describing existing resources and practices for providing information and assistance, aims to assist counties with providing these services as they adopt a CRC model.

Additionally, my research is relevant for state policymakers responsible for NCcareLink. NCcareLink is an online directory of services designed to help people of all ages in North Carolina find providers that match their needs. It is widely recognized that the website is not yet fully functional. Once the database is more up-to-date, the state plans to introduce an online decision making tool for older adults that will allow them to describe their situation and be matched with the full range of appropriate services. My interviews with other states shed some light on the value of this type of decision aide and could be useful in guiding the implementation of this resource.

⁶ NC OLTS website. http://www.ncdhhs.gov/olts/what/access_adrc.htm

Table 1. NCIOM Recommendations and Comments for Entry into the Long-Term Care System

	Recommendation	2007 Update
1	<p>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).</p>	<p><i>No specific update provided. As this is the overarching goal, the updates below describe the progress.</i></p>
2	<p>The North Carolina DHHS 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 (priority).</p> <p>The uniform portal of entry system should be defined by functions, as opposed to place or agency. Uniform portal of entry characteristics include:</p> <ul style="list-style-type: none"> • 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 out-stationing 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. <p>The state should provide guidelines and parameters for the uniform portal of entry system, but which agency provides the services should be determined locally.</p>	<p>Several steps have been taken to support this recommendation.</p> <p>First, the North Carolina Department of Health and Human Services (DHHS) helped establish two pilot Aging and Disability Resource Centers to help clients understand and identify appropriate long-term care services and supports.</p> <p>In addition, the state has started to develop a statewide information and assistance web-based resource system (NC Care Link).</p> <p>Finally, the Department has helped to simplify the Medicaid application.</p>

3	<p>The Office of Long-Term Care, within the North Carolina 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.</p> <p>The telephone-screening tool shall 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. (Priority)</p>	<p>NC Care Link, once fully implemented, will include a telephone screening tool to help individuals and their families identify appropriate health and human services resources in their communities. While NC Care Link may be able to help steer consumers toward appropriate resources, the NC Care Link telephone screening component will not be a substitute for the level of services screening needed to determine medical eligibility for Medicaid-funded long-term services and supports.</p> <p>Once the uniform level of screening instrument is developed, it can be built into the NC Care Link software so that appropriate agencies can use the tool to screen individuals to obtain the information needed to determine medical eligibility for Medicaid-funded long-term services and supports.</p>
4	<p>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 DHHS, 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 (priority).</p>	<p>Significant progress has been made in developing a web-based information and assistance system that will maintain data on all health and human services programs. The Office of Citizen Services and the Division of Information Resource Management are leading this effort, working closely with the Division of Aging and Adult Services and other state and local stakeholders. DHHS contracted with an information and assistance vendor, North Light, to develop this referral database</p>

Entry into the Long-Term Care System: Background and Recent Changes

The provision and financing of long-term care services is so fragmented and navigating the regulations and policies is so complex, that it's common for policy analysts to say there is no long-term care system. Long-term care encompasses the medical and non-medical services that help an individual maintain an optimal level of functioning.⁷ Primarily, long-term care refers to assistance with daily activities that disabled individuals need, such as bathing, dressing, eating, or other personal care. Long-term care also includes household tasks like meal preparation, cleaning, grocery shopping, financial management, medication management, and transportation. It even includes setting up computerized medication reminders and emergency alert systems, and doing home modifications like building ramps and installing grab bars.⁸ Long-term care can be provided at home, in the community, in assisted living facilities or in nursing homes.

Transition from Institutional Care to a More Comprehensive System

Background

Until the 1990s, a state's long-term care system consisted largely of care in a nursing home. Therefore, "entry into the system" traditionally took place when a person was no longer able to live independently and her caregivers sought help finding an appropriate placement. This historical bias toward institutional care failed to respect the preferences of older adults, the majority of whom want to remain in their homes for as long as possible. Additionally, long-term care provided almost exclusively in nursing homes was a very costly way to deliver care. Since the major source of public funding for long-term services and supports provided in home and community settings is the Medicaid program, states share the responsibility for financing these services. During the late 1980s, Medicaid long-term care costs grew at a rate of 20 to 25 percent per year.⁹ More than four-fifths of that spending went to nursing home care.

The first state expansions of home and community-based services (HCBS) grew out of policymakers' belief that these services would be a way to restrain the growth in publicly funded nursing home costs. In 2009, the median monthly payment for nursing home residents was \$5,243 – more than five times the median amount to support someone at home.¹⁰ Using 1915(c) Medicaid waivers, states can provide services not usually covered by the Medicaid program, as long as these services are required to keep a person from being institutionalized. Services covered under waiver programs include: case management, homemaker, home health aide, personal care, adult day health, habilitation, respite care, "such other services requested by the state as the Secretary may approve," and "day treatment or other partial hospitalization services,

⁷ Special Committee on Aging. *Developments in Aging: 1997 and 1998, Volume 1, Report 106-229*. Washington, DC: United States Senate, 2000.

⁸ Stone RI. "Long-term Care for the Elderly with Disabilities: Current policy, emerging trends, and implications for the twenty-first century" Milbank Memorial Fund, 2000. Available at: <http://www.milbank.org/0008stone/>

⁹ Coleman B, Kassner E & Paek J. "New Directions for State Long-term Care Systems. Volume II: Addressing institutional bias and fragmentation." AARP Publication No. 9606. Washington, DC: Public Policy Institute, 1996.

¹⁰ Kaye HS, Harrington C, LaPlante M "Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?" *Health Affairs* 2010; 29(1):11-21

psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness.”¹¹

In the past 15 years, states have expanded community-based services considerably. In 1994, spending on HCBS was \$8.4 billion and accounted for 19 percent of Medicaid long-term care spending.¹² Ten years later, spending on HCBS had increased to \$31.6 billion - or 36 percent of all Medicaid long-term care expenditures, and in 2008 it rose to \$45.4 billion – 43 percent.¹³ Medicaid spending on institutional care has increased at a much slower rate.¹⁴

The Supreme Court decision in *Olmstead v L.C.* in 1999 gave legal weight to the culturally- and cost-driven shift from institutional care to HCBS. Under the Court’s decision, states are required to provide long term care in the least restrictive setting for each individual.¹⁵

States, however, are struggling to fulfill this obligation. In the past 10 years, North Carolina has devoted considerable resources to interpreting the *Olmstead* ruling and evaluating the most cost-effective and evidence-based methods of home- and community-based care to the elderly. Yet, despite these good intentions, policymakers work within a system where the funding of services still favors institutional care. Nursing home care is a mandatory service that all Medicaid programs must cover. HCBS are optional services, however, and states provide these services through an array of Medicaid waiver programs (such as 1915(c) waivers) and state funded initiatives. Moreover, a state may operate several HCBS waiver programs at once, each offering a distinct package of services and supports to a different group of individuals. North Carolina operates three separate home- and community-based long-term care programs for Medicaid beneficiaries -- each with its own income and functional eligibility criteria.¹⁶ For any waiver program, beneficiaries must be at risk of institutional care; in other words, they need to meet the same eligibility requirements as Medicaid patients receiving care in nursing homes.¹⁷ Additionally, for each waiver, states must specify a limit on the number of people who can receive services. As a result, many people who seek HCBS are placed on a waiting list.¹⁸

¹¹ Smith G, O’Keefe J, Carpenter L et al. “Understanding Medicaid Home and Community-Based Services: A Primer” Washington, DC: U.S. Department of Health and Human Services. October 2000. Available at: <http://aspe.hhs.gov/daltcp/reports/primer.htm>

¹² O’Brien E. “Long-Term care: Understanding Medicaid’s Role for the Elderly and Disabled” Washington, DC: Kaiser Commission on Medicaid and the Uninsured, November 2005

¹³ Keckley PH, Frink B. “Medicaid Long-term Care: The ticking time bomb” Deloitte Center for Health Solutions, 2010

¹⁴ Keckley PH, Frink B. “Medicaid Long-term Care: The ticking time bomb” Deloitte Center for Health Solutions, 2010

¹⁵ Mollot, R, Rudder C, Sobel M, Stone C. “Single Point of Entry for Long Term Care and *Olmstead*: An Introduction and National Perspective for Policy Makers, Consumers and Advocacy Organizations” 2005. Long Term Care Community Coalition

¹⁶ Goins, R.Turner and Gerry Hobbs, “Distribution and Utilization of Home- and Community-Based Long-Term Care Services for the Elderly in North Carolina” *Journal of Aging and Social Policy* 2001; 12(3): 23-41

¹⁷ LeBlanc AJ, Tonner MC, and Harrington C. “Medicaid 1915(c) Home and Community-Based Services Waivers Across the States” *Health Care Financing Review* 2000; 22(2): 159-174

¹⁸ Dean H. Testimony given at the Senate Special Committee on Aging on Long-Term Care Financing and Reform, on behalf of the National Governors Association, 2002.

Implications for Entry into the System

Today “entry into the system” involves far more choices for older adults and their caregivers than when the system consisted of almost total dependence on nursing home care. As defined by the NCIOM Task Force, “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.”

a. Redefining “Entry”

Entry into the system traditionally reflected a movement from a house to an institutional setting. If you lived in the community, you were receiving few public services and were not “in the system”. If, on the other hand, you resided in a nursing home, then you were in the system. That model is incompatible with the goal of the home- and community-based model in which services are provided on a continuum as adults age. The state’s goal is no longer to be the provider of last resort, but to help older adults maintain their independence as long as possible by delivering a more comprehensive array of long-term care services

In this model, states must identify where and when entry into the system takes place. Tai-chi classes at the senior center may not be long-term care, but receiving congregate meals at the same center might be. A key piece in the redesigned model of “entry” is the technological platform that allows providers to share information about older adults. Electronic record-keeping will allow long-term service and support providers to monitor a person’s condition as they apply for transportation assistance, then meals on wheels, then in-home aide etc. It’s plausible that several years could pass between calls for assistance, or just a few months. North Carolina has contracted North Light People Soft to develop this software, which is still under development. The next step is effective implementation that recognizes the need to continually provide information and assistance, screening, and care planning to meet the changing needs of elderly adults. Entry is not a one-time event, but if executed properly, a recurring set of processes that begin before seniors’ functional decline becomes an emergency.

b. Information Needs Have Changed

Choosing a nursing home can be very stressful; however, the process usually involves similar steps. Caregivers first identify nursing homes close to home or to a loved one. Second, caregivers can compare the quality of nursing homes using information about safety inspections, nursing home staffing rates, and other quality measures collected by the government and converted into a ranking of one to five stars (available at: www.medicare.gov/nhcompare). Additionally, hospital discharge planners and regional Long-Term Care Ombudsman are excellent and accessible resources for more information about nursing homes. Finally, a caregiver can visit a Nursing Home and speak with nurses and residents to feel more comfortable with the choice.

The point is not to imply that choosing a nursing home is easy (it can be one of the hardest and emotional decisions a family will make), but rather that the combination of federal data requirements and a finite number of nursing homes in close proximity to family members has

made information about nursing homes readily available and easy for lay audiences to understand.

For families who are considering alternatives to nursing home, there is seemingly an infinite array of care combinations. Information about what to expect and how to choose must be tailored to the individual's situation, which means that score cards and easy-to-understand rankings are out of the question. What makes home and community-based care so difficult is that older people's circumstances – including medical history, cognitive decline, medication regimen, emotional and psychological makeup, family dynamics, support structures, and finances – are unique, and the services they need – and can afford – vary from person to person.

Some of the considerations include:

- Safety: Living independently, older adults are at risk of falling or injuring themselves carrying out basic household chores (cooking, cleaning). Home modifications, like adding grab bars or building ramps, may be necessary.
- Medication management: Nonadherence to medication regimens is a major cause of nursing home placement of frail older adults.¹⁹
- Caregiving: It's a big task being a caregiver. Many people who become responsible for a dependent adult are at risk of neglecting their own health and well-being.

Baby Boomers & the Aging of North Carolina

Background

In North Carolina, the elderly are now about 12 percent of the state's total population, but they are growing as a proportion of the population and are expected to be 18 percent of the state population by 2030, when the youngest baby boomers turn 65.²⁰ That will translate to roughly 22 million North Carolinians over age 65. The demographic shift may outpace the administrative capacity and limited budgets of health and human service agencies. Already substantial waiting lists for aging services could increase dramatically. North Carolina remains a popular location for newly retired adults; between 1995 and 2000, North Carolina had a net migration of 34,290 adults over 60, making it the third most popular choice after Florida and Arizona.²¹

The challenge of caring for older adults is compounded by other demographic shifts. Changes in family structure means that aging adults are less likely to live near their adult children, who may otherwise have helped them age in place. Secondly, the migration of younger adults from rural to urban counties means that some rural counties will have a very high population of older adults with an even more limited tax base with which to provide services. Moreover, rural older adults are more likely to have chronic health conditions and live in poverty than their urban counterparts.²²

¹⁹ Lewis A. Non-compliance: a \$100 billion problem. *The Remington Report* 1997; 5(4):14-5.

²⁰ North Carolina Study Commission on Aging. *Report to the Governor and the 2005 Session of the General Assembly*.

²¹ North Carolina Study Commission on Aging. *Report to the Governor and the 2005 Session of the General Assembly*.

²² Rogers C. "The older population in 21st century rural America." *Rural America*, 2002; 17(3):2-10.

The Baby Boomer generation does have advantages that previous seniors have not. They are, in many cases, wealthier, healthier, and more independent in their golden years than their parents. Additionally, they are technological savvy consumers – in some cases, they’ve played a role in the development and widespread use of technology in society.

Implications for Entry into the System

a) Without change, waiting lists for services will grow.

Baby Boomers will prefer to “age in place” than to move into assisted living facilities or retirement homes. As the demand for home- and community-based services grow, seniors will be forced to either pay out of pocket or add their name to growing waiting lists for home aides, home modification services, adult day care etc. It’s important to recognize both the constraints imposed by Medicaid 1915(c) waivers and the flexibility states have to decide which services and supports will be offered and to customize benefit packages to meet the needs of particular groups. Moving forward, entry into the system needs to include better data collection on the demographics of senior citizens requesting meals, transportation, and personal care services will be important in ensuring that resources are distributed equitably.

b) Baby Boomers are more likely to look online for information about long-term care than seniors today

The digital divide in the U.S. is both geographic and generational. In a May 2010 survey, only 58 percent of adults ages 65-73 and 30 percent of adults age 74 and older responded that they go online, compared with 76 percent of “Older Boomers” (ages 56-65) and 81 percent of “Younger Boomers” (ages 46-55).²³ While use of the Internet is trending upward, and quickly, the Internet is not very popular with or accessible to the current cohort of adults over 74. At present, the long-term care system needs to be accessible by phone, in-person, as well as online.

However, for the younger- and older-boomers, Internet access is more common and Internet use is more frequent. Two-thirds of younger boomers (68 percent) have broadband Internet in their homes, compared to 20 percent of the oldest adults (over 74).²⁴ For this cohort, using the Internet as a primary means of communication may be effective. Additionally, the system could take advantage of Boomers’ use of social networking sites. Social networking use among internet users ages 50 and older nearly doubled from 22 percent in April 2009 to 42 percent in May 2010.²⁵

A majority of Internet users at every age use the Internet to search for health information, with older boomers the most likely to use the Internet for this purpose.

²³ Zickuhr K. “Generations 2010” Pew Internet & American Life Project, 2010. Available at: <http://pewinternet.org/Reports/2010/Generations-2010.aspx>

²⁴ Zickuhr K. “Generations 2010” Pew Internet & American Life Project, 2010. Available at: <http://pewinternet.org/Reports/2010/Generations-2010.aspx>

²⁵ Madden M. “Older Adults and Social Media” Pew Internet & American Life Project, 2010. Available at: <http://www.pewinternet.org/Reports/2010/Older-Adults-and-Social-Media.aspx>

Activity	Ages 46-55 "younger boomers"	Ages 65-73 "older boomers"	Ages 65-73	Ages 74+
Go online	81%	76%	58%	30%
Look for health info online	84%	85%	76%	59%

Even when older adults have reliable online access, they often prefer to talk with a person because they have trouble finding the information they need online. Website content may not be accessible for older adults because the font is too small or the navigation too complex. The NIH Senior Health Project worked with the National Institute on Aging and the National Library of Medicine to develop both a national website for older adults to locate health information (www.nihseniorhealth.gov) and a set of guidelines on how to design an accessible website for older adults.²⁶ Their recommendations pertain to 22 design elements of a website, including type face, writing style, navigation, animation and pull down menus. When incorporated into website design, these guidelines assure the text is readable, increase comprehension of website content, and increase the ease of navigation for older adults.

The Federal government is encouraging states to play a leading role in the development of health information websites. A key foundation of the health reform law that President Obama signed into law last year are health insurance exchanges which would be in operation in 2014 and are intended to make buying a health plan comparable to shopping the Internet for an airline ticket or a hotel room. With the ability to shop for health insurance online and research Medicare plans, Boomers will expect to access reliable information on long-term care online as well.

c) Older adults will delay employing public services by using more assistive technology

Many needs of older adults are amenable to technological solutions. Technology can contribute to the independence and health of senior citizens by modifying their living environment, improving their mobility and cognition, and connecting them with their community, caregivers and healthcare providers.²⁷ The Center for Aging Services Technologies or "CAST," a coalition of more than 400 companies, universities, health care providers and government entities, has defined four-domains of aging-related technologies:

1. Enabling technologies (help seniors to "age in place")
2. Operational technologies (help seniors to function in society)
3. Connective technologies (facilitate communication with caregivers & medical personnel)
4. Telemedicine (allows health professionals or caregiver to monitor, diagnose and/or treat patients from a distance)

Examples of "enabling technologies" include a computerized pillbox that notifies families if loved ones haven't taken their medicine, movement sensors that send information — about when doors were opened, what time a person got into and out of bed, whether there's been any

²⁶ Morrell RW, "http://www.nihseniorhealth.gov: the process of construction and revision in the development of a model web site for use by older adults" *Universal Access in the Information Society* 2005; 4: 24-38

²⁷ U.S. Department of Commerce Technology Administration. "Technology and Innovation in an Emerging Senior/Boomer Marketplace. Prepared for discussion at the 2005 White House Conference on Aging." Washington, DC, December 11, 2005. WHCoA_WhitePaper_12-6-05.pdf

movement in a room for a certain time period – via e-mail, text message or voice mail.²⁸ A senior services organization in New York, with backing from Microsoft and the city’s Department for the Aging, created a “virtual senior center” for about a dozen low-income elderly people.²⁹

Many of these devices have been developed and introduced into the market only recently, so it’s too early to know their impact in supporting independent living. But it’s likely that some older adults will use fewer or delay seeking long-term care services and supports because they are able to afford these technologies. If this is the case, entry into the system will involve a combination of public and private services. It could also lead to a socio-economic divide in care between seniors that heavily disadvantages the most low-income.

Role of North Carolina’s Aging Network

Background

In addition to Medicaid, the Older Americans Act (OAA) provides funding for a range of services and activities provided in the community to older adults. Since its enactment in 1965, the OAA has been the foundation of home and community-based services. It established the federal Administration on Aging and the nationwide Aging Network. OAA-funded programs include: nutrition, in-home care, transportation, disease prevention/health promotion, long-term care ombudsman, senior employment, and services through the National Family Caregiver Support Program (e.g. respite care). In contrast to Medicaid services, for which there are financial or functional eligibility criteria, Older Americans Act-funded services are universal and are available to all adults over age 60. As a result, many of these services have waiting lists, which makes it disadvantageous for older adults to delay inquiring about and signing up for these programs.

To develop and implement the wide array of OAA programs, an amendment to the Older Americans Act in 1973 mandated the creation of State Units on Aging and Area Agencies on Aging in each state. Today, there are 56 State and Territorial Units on Aging and 629 Area Agencies on Aging (AAA).³⁰ They are the backbone of the Aging Network, and oversee over 30,000 public and private service provider organizations.³¹ Funding from the Older Americans Act is provided in a fixed block grant to state units of aging. Each AAA receives a share and enters into contracts with local service providers to deliver programs within their communities.

The growth in home- and community-based services has required increased effort and coordination from the Aging Network. Functions such as planning, budget allocation, operations,

²⁸Stout H. “Technologies Help Adult Children Monitor Aging Parents.” *New York Times* July 28, 2010. Available at: <http://www.nytimes.com/2010/07/29/garden/29parents.html>

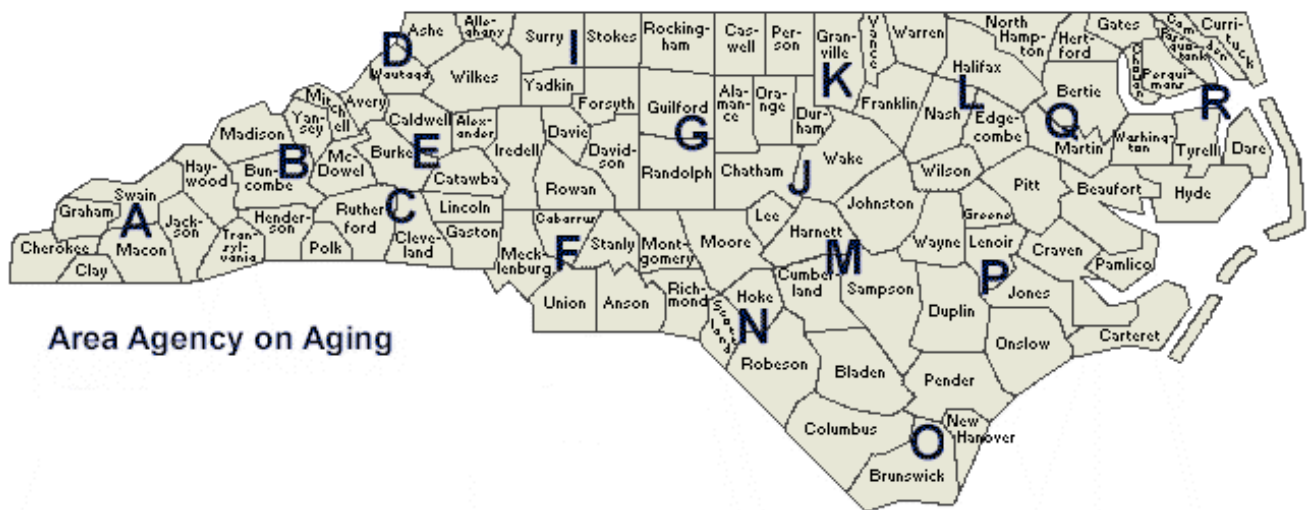
²⁹ Span P. “Being There, Without Leaving Home” *The New Old Age*. (blog). *New York Times*, August 3, 2010. Available at: <http://newoldage.blogs.nytimes.com/2010/08/03/being-there-without-leaving-home/>

³⁰ n4a. “Background Information on AAAs, Title VI Aging Programs and the OAA” Washington, DC: National Association of Area Agencies on Aging, 2010.

³¹ n4a. “Background Information on AAAs, Title VI Aging Programs and the OAA” Washington, DC: National Association of Area Agencies on Aging, 2010.

and quality assurance across the full range of community and institutional long-term care programs often fall to county or regional entities.

North Carolina has 17 AAAs that represent different regions. One AAA can be responsible for overseeing between three and 10 counties; the median is eight. At a minimum, the staff includes an Executive Director, a Finance Officer, a Regional Ombudsman (responsible for advocating on behalf of nursing home residents), a Family Caregiver Specialist, an Aging Coordinator, and an Administrative Assistant. The median number of staff in North Carolina is eight, but staffing ranges from six to 14.



Most AAAs provide two types of direct services: the Family Caregiver Support program and the Ombudsman program. Other direct services include SHIP, health promotion & disease prevention, and legal services. But the AAA contracts out most of the actual operation of services to local human services agencies. About 60 percent of the funding is from the Older Americans Act and 40 percent is state-appropriated funds. No two AAAs are identical in terms of staffing or service provisions.

At the county level, there are a few possible service providers: the Council on Aging, Senior Services, and the Department of Social Services. At a more local level, there are community senior centers that deliver services and plan activities. The majority of counties (n=61) have one senior center, but several counties have two, three, or even four. There are a total of 166 senior centers across the state.³²

Implications for Entry into the System

The AAA really plays a pivotal role in the Aging Network; it's a permanent part of the landscape, its role in program development and administration is recognized by federal legislation that calls on it to perform additional functions, and it's the body that formally

³² DAAS Senior Centers in North Carolina: <http://www.ncdhhs.gov/aging/scenters/srcenter.htm#c1>

connects federal and state missions with local delivery. The system, however, allows and encourages considerable variation in the structure and responsibilities of each AAA. Those that are well-managed can, and often do, deliver technical assistance and guidance to county service organizations, while those with a small and strained staff struggle to provide any support.

As a result, the state must accept and acknowledge that the pathways into long-term care are different in the 17 regions of the state. Furthermore, successful implementation of the No Wrong Door model depends on the ability to the AAA to convene the providers in its region and coordinate their information and assistance services.

Informed Decision-Making in Long Term Care

The transformation that is underway in long-term care – from institutional to home-based care – is about protecting the rights of older adults to make decisions about their care and to achieve quality of life. As much as policymakers make Medicaid expenditures the salient issue, they are very concerned with and committed to a model of care that promotes informed decision-making. One of the objectives of North Carolina’s new Community Resource Connections for Aging and Disability (CRC) initiative is to “enhance individual choice and support informed decision-making”.³³

Informed decision-making occurs when (at a minimum) “an individual understands the nature of the disease or condition being addressed; understands the clinical service and its likely consequences, including risks, limitations, benefits, alternatives, and uncertainties; ... makes a decision consistent with his or her preferences and values or elects to defer a decision to a later time” (pg68).³⁴ Policymakers care about informed decision-making because it is ethically desirable and because it is shown in the literature to increase patients’ active participation in their care and adherence to treatment.³⁵ It also reflects the choice they want for their parents and for themselves.

There are considerable hurdles to achieving informed decision-making and very little research examines these challenges outside of the clinical context. There is a small, but growing body of evidence-based practices designed to help physicians communicate with patients about a medical diagnosis and the treatment options. Almost no literature, however, guides informed decision-making in the context of personal care and social services for people who have lost some degree of functional capacity. Families are confronting a variety of costs, challenges, their own limits as caregivers, and the tradeoff between safety and autonomy.³⁶

Resources that promote informed decision-making exist, but have not been widely adopted. The goal of these decision aids is to encourage thoughtful consideration of the patient’s values,

³³ NC OLTS website: http://www.ncdhhs.gov/olts/what/access_adrc.htm

³⁴ Briss P et al. “Promoting Informed Decisions about Cancer Screening in Communities and Healthcare Systems” *American Journal of Preventive Medicine* 2004; 26(1):67-80

³⁵ Epstein RM, Alper BS, Quill TE. “Communicating Evidence about Participatory Decision Making” *JAMA* 2004; 2359-2366

³⁶ Kane RL, Boston K, Chilvers M. “Helping People Make Better Long-Term-Care Decisions” *The Gerontologist* 2007; 47(2):244-247

certainty, and knowledge by reviewing the benefits and risks of the decision. There are several examples of decision aids. DECISIONDialog is a private service contracted by health insurers that uses decision aids and health coaching to guide their care.^{37 38} The Minnesota Board of Aging created a Long-Term Care Choices Navigator (www.longtermcarechoices.minnesotahelp.info), which has been online and available to the public since May 2006. The Navigator includes an assessment that gauges the client's status related to activities of daily living, income and assets and caregiver supports. Finally, the Dartmouth-Hitchcock Medical Center developed a video decision aid called, "Getting Older, Staying Well: 10 Common Health Concerns and What You Can Do About Them" that addresses four common health concerns: preventing falls, incontinence, hearing problems, and physical activity.³⁹

³⁷ DECISIONDialog. Available at:

<http://www.healthdialog.com/Main/Measurableresults/AllProductsandServices/DECISIONDialog>

³⁸ Woolf SH et al. "Promoting Informed Choice: Transforming Health Care to Dispense Knowledge for Decision Making" *Annals of Internal Medicine* 2005; 143:293-300.

³⁹ DMHC Center for Shared Decision Making, Geriatrics. Available at:

http://www.dhmc.org/webpage.cfm?site_id=2&org_id=108&morg_id=0&sec_id=0&gsec_id=39685&item_id=55468#video

Information, Referral and Assistance Services

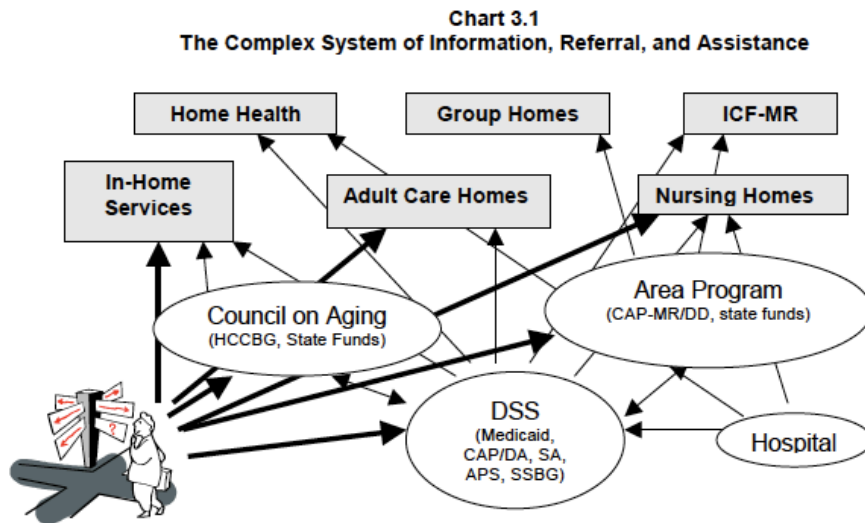
Information, referral and assistance services are one component of entry into the system, and often – but not always – precede screening, service level assessment and care planning.

Background

Information and Assistance (I&A) programs inform, guide, and connect people with services to meet their needs.⁴⁰ The history of state-funded I&A services dates back to the 1973 reauthorization of the Older Americans Act (OAA), which created the Information and Referral Program and mandated that each area agency on aging establish Information and Referral programs (today called Information and Assistance programs) for older adults.⁴¹

This public service, however, never surpassed word of mouth as the most trusted source of information for aging adults and their caregivers. Family, friends, clergy, and doctors were more likely to be consulted about nursing home placement or home health services than the AAA. As the population ages, more people will need a well-informed, local agency is critical to help them find the right mix of services and supports to fit their needs. Older adults and their families face such a complicated array of choices and decisions – about not only health care, but also housing, finances, and basic household tasks – that many seniors may be placed in nursing facilities because they are not aware of all the community-based supports that could help them stay at home.

Many adults do not know about publicly-funded I&A programs and go about accessing services in many ways. The following diagram was taken from the 2001 NCIOM report and is still a fairly accurate depiction of how an individual gets connected with services.



⁴⁰ National Association of State Units on Aging. "VISION 2010: Toward an Aging Information Resource System for the 21st Century" Washington, DC: National Association of State Units on Aging, 1999.

⁴¹ Older Americans Act of 1965 as Amended: 42 U.S.C. 3001. [Public Law 100-175, Section 306. (a)(2)(A) and (a)(4); Section 307. (a)(9)]

Description of Services

Information & Assistance programs provide several services. Primarily, they help older adults assess their needs and then identify appropriate services to meet those needs. An elderly person calls the I&A provider, or visits the office, and either asks about a particular service or explains their situation and need for help. The conversation usually ends when the I&A provider gives the older adult the name and phone number of a service provider, or gets permission to contact the provider on the individual's behalf. The full range of activities for I&A providers include making follow-up calls to consumers, providing counseling, participating in community education, maintaining and updating a directory of services, and engaging in advocacy for the development of new programs.

Because they are often the first point of contact for assistance, I&A programs receive and respond to a broad range of inquiries for older persons. They may be contacted for simple information about the location of a senior center, securing transportation, or the availability of financial assistance for utilities and gas payments. On the other hand, I&A programs also handle complex requests such as those related to housing options and securing services by persons with multiple disabilities. Based on the design of the county system, I&A programs may provide pre-screening for case management services; initial eligibility determination for public benefits; or immediate connection to appropriate agencies for crisis intervention.

The term I&A refers to two distinct services: information and assistance. These services involve different levels of effort on the part of the service provider, both on the call and in recordkeeping. As stated in the North Carolina Administrative Code⁴²:

“‘Information’ includes informing people about programs and services, identifying the types of assistance they need and connecting them to appropriate service providers.

‘Assistance’ is a more intensive service for those persons who require additional help with negotiating the service delivery system. Assistance includes the provision of planning, referral, coordination of services, follow-up and advocacy initiatives on behalf of the older adult or their family, or both, in an effort to ensure that needed assistance is received and that the assistance provided meets identified needs. Assistance may also include a home visit to more clearly identify a client's needs for the purpose of initiating the development of a care plan.”

Practitioners often use the term I&A to describe a variety of programs. The first type is an official program with one or more employees who dedicate most of their time to responding to inquiries. Every county in North Carolina has the choice to use the Home and Community Care Block Grant (HCCBG) funds they receive from their AAA to create this type of program, which

⁴² NCAC 22L .0101 Definitions and Scope of Information and Assistance

is monitored by the North Carolina Division on Aging and Adult Service (DAAS).⁴³ The standards for these programs are laid out in a 44 page document.⁴⁴ I will refer to this as formal I&A.

Currently, 42 out of 100 counties elect to provide I&A with Older Americans Act funding.⁴⁵ According to my interview with Heather Burkhardt, Information and Assistance Program Specialist at the DAAS, “agencies are funded anywhere between \$2,000/year to \$200,000/year.”⁴⁶ Each agency is monitored by its regional AAA every three years.

The second type of I&A is the response that an individual gets when he calls any agency in the Aging Network. All AAA, Council on Aging, and Senior Center staff have some expertise with aging services and will offer information about programs and services if and when they are contacted by an older adult in need. For instance, every person I interviewed, regardless of job title or position, said they receive calls or emails from older adults and their caregivers looking for services. I will refer to these inquiries as informal I&A, and will limit it to information provided by an agency that associates itself with the aging network (e.g. if a person asks a Pastor for information that is word-of-mouth, not informal I&A; however, if someone contacts the Baptist Aging Ministry, that would be an example of informal I&A).

The third type of I&A is information that is provided by the Aging Network on their websites. While numerous agencies in the state have their own websites that provide a description of services or instructions on accessing services, for this report I will primarily focus on NCcareLINK (www.nccarelink.gov), a comprehensive online directory of services to help people in North Carolina of all ages find health and human services, information and referral, and financial assistance. NCcareLink was developed by the Division of Health and Human Services with funding from the federal Administration on Aging (AOA) and CMS.

In addition to these three types of I&A provided by publicly-funded agencies, there are several non-profit agencies who provide I&A services. The largest of these are the 211 systems operated by the United Way in 48 counties in North Carolina. The AARP and Alzheimer’s Association are also active advocacy groups in the state and respected sources of information.

⁴³ Eighteen services can be funded through the Block Grant and they include: adult day/day health care, care management, home delivered meals, home health, housing and home improvement, information and assistance, in-home aide services, respite care, senior companion and transportation.

⁴⁴ North Carolina Division of Aging. Information and Assistance. Effective: July 15, 2002.

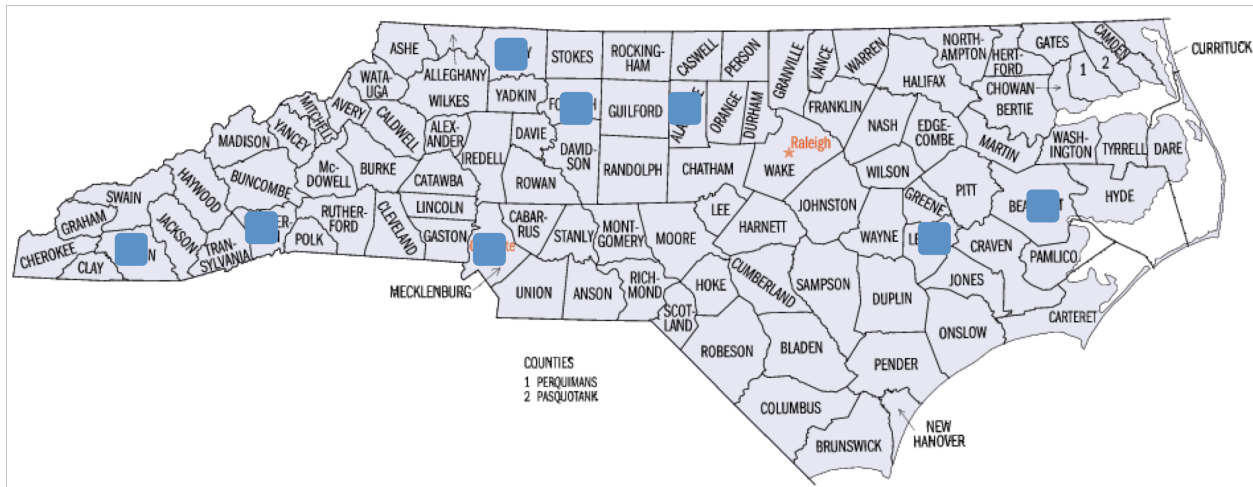
⁴⁵ DAAS website: <http://www.ncdhhs.gov/aging/services/iassist.htm>

⁴⁶ Interview with Heather Burkhardt, February 7, 2011.

Research Methodology

Information and Assistance (I&A) services are provided, officially or unofficially, by every agency in the Aging Network. This includes the regional Area Administration on Aging office, the county Council on Aging or Senior Services office, the county DSS, and local senior centers. To understand how an older adult would navigate the system, I selected eight counties and contacted the primary agencies that serve older adults. The counties vary by geographic region, diversity, population density, and proportion of adults over 65.

From West to East, as marked on the map below, the counties are: Macon County, Henderson County, Mecklenburg County, Surry County, Forsyth County, Alamance County, Lenoir County, and Beaufort County. They include two of the state's largest cities, Charlotte (Mecklenburg County) and Winston-Salem (Forsyth County), several rural counties (Henderson County, Beaufort County, Surry County), and a county with a large retirement community (Henderson County).



I conducted a total of 28 interviews; with one exception, interviews were done over the phone. I used a Bluetooth headset so that I could type the interviewees' responses during the interview. Through this method, I have a nearly complete transcript of each person's comments. Interviews ranged in length from 30 to 70 minutes, though most were under an hour. The interview tool is included as an Appendix to this report.

In total, 12 of the interviews were with employees at regional Area Agencies on Aging (AAA). I interviewed multiple people at the same AAA if the initial contact did not routinely talk with older adults about their options for care. Nine interviews were completed with individuals responsible for county-level service (e.g. staff at Councils on Aging, Senior Services, DSS). Two interviews were completed with Directors of local Senior Centers.

In each county, my goal was to identify and interview an organization that plays a central role in informing older adults about their options. In five counties, this was an agency that

receives state or county-funding to provide information and assistance. In addition to the main I&A provider, I interviewed other organizations at the regional and local level that serve the same population. This allowed me to, first, gauge the “No Wrong Door” model by discussing the skills and tools each agency used to make accurate, effective referrals. Secondly, it spoke to a community’s recognition of the designated I&A provider (e.g. how many people are relying on the Senior Center instead of the Council on Aging, and for what reason).

As an outsider to the communities I was interviewing, I relied on information available through the Division of Aging and Adult Services to identify potential interviewees. The Division has lists of all the Area Agency on Aging staff, all the I&A service providers, and all the senior center directors. In some cases, it was difficult to ascertain a person’s job responsibilities from their job title, and so I learned, as any older adult or caregiver would, by calling and being redirected. Excepting senior centers, 90 percent of the people I contacted responded positively to my request for an interview or referred me to a colleague. More than any other group, senior center directors were the least likely to respond – three out of 15 returned my calls and/or emails.

Agencies in the aging network are known to have a high rate of turnover, and I encountered this problem in three of my interviews. Two of my interviews were with individuals who had been employed at the agency for less than a month. The third interview was with a woman who had been the Director of a Senior Center for a year, and had devoted most of her time to staffing rather than program development or I&A.

I limited the interviews to individuals who work for public agencies; however, I recognize the enormous role that non-profit agencies, religious organizations, and civic organizations also play. With more time, I would have contacted these groups, along with private providers. I also did not interview any older adults or their caregivers about their experience. My concern was that with the time I had available, these interviews were unlikely to be representative of the fragmentation of the system.

Lastly, to gain some understanding of how other states have addressed the issues, I interviewed employees at Departments of Aging in Oregon, Ohio, and Virginia, which have also established online databases.

Implementing the NCIOM Recommendations

System Design

In a system as complicated as long-term care in North Carolina, designing a “uniform portal of entry” – as the NCIOM recommends – is no simple task. As described by the NCIOM Task Force, the primary characteristics of a “uniform portal” include: common information and assistance, screening, and assessment tools, automated information sharing, and simple mechanisms for determining eligibility for services.⁴⁷ In North Carolina, the functions of the “uniform portal” will be carried out by hundreds of agencies, including Departments of Social Services (DSS), Councils of Aging, Senior Centers, Centers for Independent Living and more.

In conceiving this model, the NCIOM Task Force agreed on three critical elements:

1. The portal would be designed in the “No Wrong Door” model so that “individuals would be able to enter the system through multiple agencies.”
2. The decision about which agency provides services should be made at the local level, so there will be wide variation between counties.
3. Development of a “uniform portal” is contingent on the appropriate technology to support sharing confidential information.

Understanding what these components mean for the development of a uniform system is essential to assess the progress the state has made toward this goal. This is especially true because the NCIOM recommendations really influenced the choices that have been made. As Heather Burkhardt at DAAS explained:

“That report came out in 2001 and then 2002 and 2003 were really bad state budget years. And so there was just no chance that any of the stuff we worked on was going to get funded. And then the federal money came down for ADRCs and it was alright, this is our chance to start moving that access chapter and implement those recommendations. We looked at that Entry into LTC section and we’re like, alright, let’s do it. Everything we did in that grant application – I&A, no wrong door, was built on the foundation of that report.”

i. No Wrong Door

North Carolina has adopted a “No Wrong Door” model for entry into long-term care.⁴⁸ Consumers are not required to contact a single, physical location to gain information. Instead, agencies retain responsibility for their particular services while coordinating with each other to integrate access to services.⁴⁹ For example, DSS is responsible for screening adults for Medicaid in-home aide services, while the Council on Aging (COA) administers the meals on wheels

⁴⁷ North Carolina Institute of Medicine, “ pp40

⁴⁸ Interview with Sabrena Lea, Director of the Office of Long Term Services and Supports

⁴⁹ Armour-Garb A. “Point of Entry Systems for Long-Term Care: State Case Studies” Prepared for the New York City Department of Aging, 2004. Available at: http://www.nyc.gov/html/dfta/downloads/pdf/study_ltc.pdf

program. Instead of DSS referring an individual to the COA, DSS would be able to send the information directly to the COA – saving the consumer the step of repeating the assessment process.

For this model to be successful, it means that every agency must ask for similar information, use the same screening instrument, and, and, if appropriate, conduct an assessment of functional capacity, medical and social service needs, and preferences.⁵⁰ Secondly, providers must be able to share this information to reduce repetitive assessments and create a continuum of care.

Another option is the “one-stop shop” model, where a single local or regional agency with multiple locations is designated the point of entry. Several states have designated the area agency on aging (AAA) as the location at which people can find information about services and benefits, be assessed for publicly funded programs, work with care managers, and arrange for services.⁵¹ In Mecklenburg County, the Just1Call program functions as a one-stop information and assistance call service for older adults. The call center provides information on a wide array of services and shares information with DSS to determine Medicaid eligibility.^{52, 53}

ii. *Agency Decisions at the Local Level*

Information and Assistance (I&A) programs have evolved over time and in response to the particular needs and resources of a community. North Carolina has 100 counties that vary considerably by geography, wealth, population density, and diversity. Rural counties often have developed systems that are more informal than urban counties but no less effective. Possibly because of this local variation, the NCIOM Task Force advised “the state should provide guidelines and parameters for the uniform portal of entry system, but which agency provides the services should be determined locally.”

This decision means that the uniform portal will build on the strengths of the current system and allow counties to enhance their current structure rather than replace it. However, it also hinders consumers and providers from sharing information across county lines. Particularly as adult children live in different communities than their aging parents, it can be confusing that DSS has different functions depending on the county.

iii. *Technology*

The majority of the NCIOM Task Force recommendations for a uniform portal of entry depend on the appropriate technology to support confidential information sharing. There is a significant cost to developing and implementing this type of computerized system. North Carolina contracted with North Light People Soft to develop the software. The product was intended to accompany NCCareLink and is still under development. It has not yet been finished or introduced at the local level.

⁵⁰ Reinhard, SC. and Scala, M. “Navigating the Long-Term Maze: New Approaches to Information and Assistance in Three States.” Washington, DC: Institute for the Future of Aging Services, 2001

⁵¹ Reinhard, SC. and Scala, M. “Navigating the Long-Term Maze: New Approaches to Information and Assistance in Three States.” Washington, DC: Institute for the Future of Aging Services, 2001

⁵² Alecxih L, Kuo C. “Just1Call Case Study” ADRC-TAE Issue Brief. Washington DC: The Lewin Group, 2004.

⁵³ Interview with Jackie Hayward, Just1Call Supervisor

Without the software that allows confidential sharing of information, the concept of a uniform portal of entry appears to be temporarily stalled. But a uniform portal of entry requires more than access to a common database of personal health records. A uniform portal of entry requires collaboration and understanding between providers so that referrals are appropriate and every agency trusts the other to follow-up and deliver the requested care. Technology is only a tool – it will not change the mindset people bring to their work or drive the transformation in service delivery.

Ohio is also in the process of developing a no wrong door model for aging services. Deanna Clifford, Program Administrator at the Ohio Department of Aging, described the work that goes into changing behaviors offline.

“Collaboration isn’t a natural process. It takes people outside of their comfort zone, and I really believe that every service delivery system is stretched as far as it can be stretched at this point. We’re trying not to ask people to do things differently, we’re trying to ask them to work together differently. We’ve spent years and years developing silos, and it’s going to take a long time to break down those silos, and helping people to work together. Getting to that point where collaboration can take place has been one of our challenges.”

The collaboration that Clifford describes does not require new technology, but it does require a shared belief in the process and goals of the no wrong door model. The state is asking people to spend considerable time and energy changing the way they do business without providing many concrete incentives. In North Carolina, the common computer system that would allow service providers to save and share patient information has become the incentive that will bring people to the table to begin collaborating. Several interviewees described the frustration at having been promised a system that, years later, is still not available. The delays in development have eroded trust and prevented providers from moving forward in advance of receiving the software.

Community Resource Connections Initiative (CRC)

The Community Resource Connections for Aging and Disabilities initiative (CRC) began with two pilot sites: one in Forsyth (2004) and one in Surry (2005). The state selected these two counties to provide models for both urban and rural counties. The expansion of the CRC initiative officially began in October 2008, with a summit in Raleigh for project grantees and the State CRC Collaborative. Today, the Office of Long-Term Services and Supports reports that the CRC initiative includes six new full programs and five under development. CRC activities involve 30 of North Carolina’s counties and roughly half of the state’s population.⁵⁴

My interviews with Area Agency on Aging staff confirmed that statewide, every region is focused on how to create and implement a CRC model. Interviewees who discussed the CRC sounded genuinely excited about initiative and spoke confidently about the goal: “We want [older adults] to tell their story one time and from there we would be able to connect them to

⁵⁴ Office of Long-term Services and Supports. “Community Resource Connections for Aging and Disabilities Progress Report”. July 15, 2009. Available at: http://www.ncdhhs.gov/olts/whatsnew/CRC_progressreport.pdf

what they need.” When I pressed for more information, these same interviewees expressed doubt and confusion in describing the structure that the new system would take. They indicated that they had just begun discussions and were in very preliminary stages.

The structure of the CRC is a decision that is made by the county or counties involved in the project. They choose a lead agency to coordinate the effort, and then draft Memoranda of Understanding with other providers to create the pathways that an individual will follow to get information and services. In Surry County, the AAA was the lead agency. In Forsyth County, the lead agency is Senior Services. The idea is to change the way that people work with one another, rather than creating new buildings or organizations. Conceptually, it’s a fantastic model that does not cost anything to create. In practice, the idea of putting a new name on programs that have been delivering services for decades can give the impression of “new paint on an old barn.”⁵⁵

One interviewee who is consulting on two CRC projects was upfront about the challenges with implementation:

“The struggle for the state has been to put a new frame around organizations that have been doing this work. They have a strong sense of their own organizational identity already and are a bit resistant to a new framework that they feel is imposed on them by the state with... little or no money to support the additional work. It’s been rough terrain. Sabrena⁵⁶ often says it’s like flying the plane while still building it. It’s been... like pulling an abstract concept down from the clouds and getting people to buy into it. It’s come a long way, but it’s not been easy.”

Counties that are making the most progress with the CRC model have an experienced champion of the Aging Network. Several interviewees spoke highly of the involvement of Dean Burgess, a retired Director of the AAA, who has tremendous knowledge of the community, but is also independent from any organization. Since this initiative does not involve new buildings or new staff, it requires people to be honest about their own weaknesses and to admit where another organization does a service better. In a time when jobs are on the line, it helps to have an independent voice at the table who can see the whole system.

Ultimately, the goal is to improve collaboration – partially through shared access to a web-based portal, but mostly in the person-to-person conversations and referrals. One of the challenges is how counties can report progress or document the baby steps they are taking to overcome the institutional and historical silos of care.

There is little information about how the CRC model has affected older adults in Forsyth and Surry counties. In Surry County, the number of calls tripled in less than two years – from 161 to 502 by Spring 2009. Unfortunately, my interview contacts were unable to shed light on what factors are responsible for the dramatic increase. For the past year, Surry County had a part-time CRC Coordinator. A full-time

Data for Surry and Forsyth County CRCs		
Total Consumer Contacts:		
	<u>Surry</u>	<u>Forsyth</u>
Fall 2007	161	2448
Spring 2008	368	2794
Fall 2008	341	4199
Spring 2009	502	2289
Assistance & Access Delivered: (Follow-Up after initial Contact, Benefits Counseling, Options Counseling, Long-term care futures planning):		
	<u>Surry</u>	<u>Forsyth</u>
Fall 2007	210	3169
Spring 2008	499	3177
Fall 2008	460	2653
Spring 2009	652	3401

⁵⁵ Interview with Sabrena Lea, Director of the Office of Long Term Services and Support

⁵⁶ Sabrena Lea is the Director of the Office of Long Term Services and Support

Coordinator was hired three months ago and in our interview, she was still getting up to speed.

In Forsyth County, the number of consumer contacts has fluctuated with no clear upward trend. Forsyth Senior Services is leading the CRC effort. They have chosen to keep their identity as Forsyth Senior Services and operate the CRC under their umbrella of services. In other counties, the CRC is the umbrella under which Senior Services operate. As a result, older adults in Forsyth are less familiar with the CRC concept. Forsyth's Senior HelpLine, a toll-free number for assistance, was established in 1998 and is operated through the Senior Services. Still, however, people are calling other places before they call HelpLine. The referrals come from "a variety of places. It's the YWCA, YMCA, their church, the Shepherd [Senior] Center, Senior Financial Care." One way in which the CRC has affected the provision of services is in bringing people together. For example, "when the pilot was in progress, a group of a variety of disciplines came together to develop a screening tool. It took them about 18 months, it's 3 pages and that's what is used."

The limited results from pilot projects are not sufficient to demonstrate that the CRC model is the solution to the access problem in long-term care. They also do not represent the variety of forms the CRC program will take as it expands across the state. The unique resources of Forsyth and Surry counties mean that other counties will be unable replicate the design of these first CRC programs. While the program has strong momentum, the economic recession has made the ambitious goal of systems transformation much more difficult.

NCcareLink

NCcareLink is a well-designed, comprehensive health and human services website, but from the perspective of the Aging Network, it is still a work in progress. While the public website is up and running, the state is still working with its vendor, North Light People Soft, to develop the platform for providers. Once developed, this platform will allow agencies to confidentially save and share client information, thus allowing information captured in one call to be accessed by a range of providers.

The main function of NCcareLink is the search tool. Visitors to the site can search for services by keyword or location. In order for the search to work, there needs to be a fully functional resource database supporting the user interface. Developing this database is labor intensive and time consuming. Information about every provider needs to be verified and then manually entered into the system. States often have inclusion criteria to ensure providers are reputable before they include them in the database. Over time, entries need to be modified or deleted to reflect changes. Once the information is in the system, it needs to be coded according to a specific taxonomy so that the entry appears when certain search words are used. Because aging websites are still a recent development, the software developers and public agencies are continually improving the taxonomy. The generational divide increases the challenge: older adults often use different search words than the software programmers. In every state I interviewed, there has been some back and forth between the vendors and the state agencies about the search words.

Funding for NCcareLink came from the *Real Choice Systems Grant* awarded to the state to improve the long-term care system. The grant was \$800,000 for 3 years. According to Heather Burkhardt, “over half of that went to the beginning of NCcareLink.” Though the grant was to help states provide long-term care in home and community settings, North Carolina used the funds to develop a website that would be beneficial to all residents. The website’s content includes services for singles, couples and families, military personnel and veterans, as well as seniors. However, the state did designate the Area Agencies of Aging as responsible for creating and maintaining the database of all services.⁵⁷

North Carolina has designated several Area Agencies on Aging as NCcareLink hubs. At each AAA, one person is assigned the NCcareLink data entry work. This is a mammoth undertaking for one person, especially considering the staff member is doing this work with no background in website development and in addition to her primary role. One interviewee explained, “On a monthly basis, right now, I’m spending 20-30 hours a month [on NCcareLink].” Moreover, there is no grant funding to support this effort, so it becomes a low-priority item. “We don’t get funding for Care Link, so I’m more focused on projects that we have grant support for.”

The interviewees also indicated that no one in the state had much familiarity with the software. With everyone learning about database taxonomy at the same time, many mistakes were made. “We’ve all had to learn together. What I did 3 years ago has changed now. I’ve had to go back 2 or 3 times and change the information in Care Link which is frustrating.” And finally, the staff (most of whom did not volunteer for this role) are overwhelmed by the amount of work still to be done: “We’ve never gotten to the point in our database where I feel like what we have is current...in our region [7 counties] we have hundreds and hundreds of providers.”

One person summed up the situation very well: “If each hub had hired one person and brought that person to Raleigh and trained them so it would all be done the same way then we’d have a really good system. But the way we’re doing it is so low cost that it’s only as good as the amount of time and staff and the capacity that each hub has.”

In Oregon, the Department of Aging faced similar challenges creating the database for www.ADRCofOregon.org. In response, the Department of Aging decided to relieve the AAAs of the responsibility for data entry and control the listings at the state level. Now, the state has a link on their website for providers to enter their own information, which is approved by a full-time resource specialist who also adds the taxonomy. This transition was possible in part because the AAAs in Oregon had already manually entered information for around 7,000 providers. From Oregon’s perspective, it’s advantageous to centralize data entry so there will be more consistency and less duplication. It is still too early to know if there will be significant drawbacks because certain providers never submit their information or because the Department of Aging is overwhelmed by the number of requests to approve.

Virginia’s SeniorNavigator (www.seniornavigator.org) is one of the most comprehensive websites for health and aging information. SeniorNavigator (www.seniornavigator.org) has a

⁵⁷ In 1975, North Carolina created CARE-LINE, a toll free telephone service to provide information and referral (I&R) services, in response to a mandate in the OAA that consumers provide I&R. DHHS decided to establish a service that would serve not only older adults, but all consumers in North Carolina.

database of more than 21,000 providers– more than any other state I interviewed. Importantly, SeniorNavigator is a non-profit organization that is independent of the Department of Aging. Support for SeniorNavigator comes from contributions made by individuals, corporations, and foundations. For instance, information on the website can be sponsored by different corporations. While corporate sponsorship can compromise the objectivity of the information, so far, it has enabled Virginia to be successful in making free information available to all Virginians and in a very user-friendly format.

State	Features	Senior-Friendly	Agency
North Carolina NCcareLink	* Information for people of all ages *Can sign-in to save searches	* Can adjust text size (but hard to find this feature)	NC Department of Health & Human Services
Virginia SeniorNavigator	* Needs Assessment tool * 3 clearly marked search paths * Articles and links on relevant topics	* Can adjust text size * Easy sidebar navigation	SeniorNavigator is a 501c3 not-for-profit
Tennessee Tennessee Connection	* Needs Assessment tool * Toll-Free statewide Long-Term Care information number * “Talk it Over” page lists the Information & Assistance phone number at every AAA * Articles and links on relevant topics	* Can adjust text size * Small sidebar navigation font	Created by the TN Aging and Disability Resource Center program Website by AssistGuide Information Services
<i>Other states that use AssistGuide & have similar websites include: Georgia, Hawaii,</i>			
Florida AAA websites	* Each AAA (n=11) has developed its own website		
Maryland Maryland Access Point	* Very clear: it’s the Consumer Guide to Long-term care * Pop-up box asking for zip code and why you are visiting (information for self, family member, research) * Easy to print the page	* Can adjust text size	* Maryland Health Care Commission

Though the frustration with NCcareLink is understandable, it was discouraging to hear that, after several years, and a considerable financial investment, not a single interviewee said they recommend the website to older adults. These comments are indicative of responses I heard over and over again:

“It’s not working in the community. Providers are not using it as a resource. They’re not updating their information on a regular basis and people don’t know about it.”

“I have not used it, and I have never recommended it. Because I haven’t used it, I feel uncomfortable repeating it, but a lot of people in Human Services say it’s not living up to its potential.”

“It’s not live enough that I can even do anything with it. I’m being told that it will have value down the road. I don’t know enough about it.”

Everyone I interviewed was willing to say that at some point, the technology will become more user-friendly and the website will be an effective tool for older adults looking for services and for providers looking to share information. It was sobering, however, that many interviewees felt that it would take at least five more years for NCcareLink to be fully functional and useable. One interviewee stress that the problem was state leadership:

“I think, ideally, NC Care Link is a great concept. It’s very much needed. A lot of states have it, and they have some good databases out there. I think it’s needed to have one database there to help people across the lifespan and lifecourse, disabled or children whatever. I think it makes sense to have all that information in one place...but until the state and DHHS says this is something we really want to invest in and put some strong leadership with, it’s not going to be an effective tool and it’s not an effective use of our taxpayer dollars.”

Several interviewees were aware of similar websites developed in other states. In particular they had seen an example of a needs assessment tool, which asks older adults a series of multiple choice questions in order to simulate a conversation about their needs. The value of this technology is that older adults are often unaware of the needs they have and the full range of services that are both available and appropriate for them. This type of tool is becoming increasingly common – for instance, Virginia, Minnesota, Ohio, Oregon, and Tennessee all have these options. In fact, North Carolina has already developed a needs assessment tool, but is waiting until NCcareLink is more complete to add it to the website.

Providers’ first impression of NCcareLink has been unequivocally negative. In every interview, people were upfront and unabashed in their criticism and frustration. Moving forward, the state must overcome these attitudes and, in particular, gain the support and confidence of people responsible for maintaining the database.

Challenges with I&A Programs in North Carolina

1. The role of the AAA and its staff is not clearly defined.

The potential of AAAs are tremendous, but the history of AAAs in North Carolina has led to weakly defined roles that could impede easy entry into the system. A clearer definition of roles could help the staff members direct calls efficiently and reduce the number of inappropriate calls in the first place.

The variation in size and scope of AAAs in North Carolina is neither unique to the state nor the problem. All AAAs have incredible flexibility in their structure and service delivery mechanisms. Nationwide, each of the 629 AAAs is a private, nonprofit service organization and most have evolved over time to reflect as much as possible the needs and resources of the community they serve. Virginia, for example, has 25 AAAs – “all different”. As the state acknowledges, “there’s a benefit to that because they fit the needs of the locality.”⁵⁸ They have also been the main source of information for the aging community for a long time.

In North Carolina, few people know what the AAA is. Even interviewees who now work at the AAA said they had never heard of the AAA before applying for their current position – and many of these individuals had been working with older adults for a long time. public awareness of the AAA is minimal. Unlike in other states, the role of the AAA in North Carolina has historically been to contract services. The Ombudsman program was the only type of direct services. However, today some AAAs have begun to provide additional direct services and/or step into the void in counties where there is no “lead” agency to function as the single entry point.

Many AAAs are expanding their service provision in response to new OAA required services. For instance, they are:

- Administering the National Family Caregiver Support Program Respite Care program. This program was established as part of the reauthorization of the OAA in 2000. Every AAA in North Carolina has a Family Caregiver Specialist on staff.⁵⁹
- Coordinating evidence-based health programs. Support for evidence-based programs was added to Title III-D of the OAA as part of the 2006 reauthorization. Now, several AAAs are leading or coordinating regular trainings in their region as part of the Living Healthy Program.

As the AAA becomes more involved in service delivery, a greater number of older adults will see the AAA as a source of information and assistance. If the AAA sees its role as a behind-the-scenes coordinator, rather than a service provider, these informal I&A calls could be a poor use of time. For instance, it was common for AAA staff members (Ombudsman & Family

⁵⁸ Interview with Kathleen Vaughan, March 29, 2011.

⁵⁹ The title of this position varies: Family Caregiver Specialist, Family Caregiver Resource Specialist, Family Support Specialist, Family Caregiver Support Specialist, Caregiver Specialist, Family Caregiver Support Program Coordinator. While the differences are not significant, the lack of consistency suggests disagreement about even the most basic decisions.

Caregiver Specialists) to tell me they take time to research the right service in response to an older adult's phone call. This could delay the time it takes for the older adult to receive services and take away from the main responsibilities of the AAA employee.

Interviewees disagreed about the role the AAA should play in I&A. Some felt calls should be made to county providers. "We'll be just another pass-through. I'd rather they call the county than call me... When we don't provide those services, why would they call here." Another Family Caregiver Specialist thought she provided an objective viewpoint that caregivers would not get if they called service providers directly: "I'm not trying to increase anyone's business or anyone's client list or anything, I'm trying to look at the situation the caregiver has without any kind of agenda and I'm trying to help them think."

The state could make the decision on behalf of all AAAs by requiring family caregiver specialists to participate in "unregistered I&A", which is already a requirement in certain regions. Or, the state could continue to allow regions to define the roles of AAA staff members. Regardless, any decision about entry into the system should be specific about the role of all AAA staff to provide clarification for employees and to prevent them from misleading consumers and other service providers.

Funding plays a role in the ambiguity of the AAA's scope and functions. In 2006, Gayla Woody, the Director of the Centralina AAA, testified before the U.S. Congress. She spoke to the strength of the AAA: "I believe that AAAs can offer tremendous technical assistance to local community planning entities to help them define their mission, determine their process and gather critical information." However, she also explained that she "had the staff resources and time to support two of the nine counties" in her region. Since involvement of the AAA in any county is variable and contingent on both public funding and legally mandated functions, the AAA needs to be proactive about clarifying its roles to citizens so that it is understood when it plays different roles for the counties it serves.

Allowing the AAA's role to be so ambiguous, both to the public at large and even within the Aging Network, is a handicap for simplifying entry into the system. The state can change its management strategy and level of supervision of the AAAs to promote certain roles and foster greater clarity.

2. Everyone in the Aging Network receives calls from older adults

If the AAA is one of the least known agencies in the Aging Network, and its staff members are all receiving calls from older adults, it's an indication that everyone in the Network is being contacted by older adults who do not know where to go for information and assistance.

Among the people I interviewed, several worked full or part-time providing I&A services. Four of the eight counties I chose to interview did have I&A programs registered with DAAS; the providers included DSS, Council on Aging, and Senior Services. Two additional counties, Mecklenburg and Macon, have I&A programs funded by the County Commissioners (so these

are not supervised by DAAS or counted among the 42 counties).⁶⁰ Most of these programs are staffed by licensed social workers.

In counties without formal programs, the demand for information can require changing the way services are provided. For instance, one Senior Center director hired a part-time person for I&A. As she described, “I&A got so big...and I was doing a good job with helping these people and finding the services they needed, but I wasn’t doing an excellent job with the paperwork and follow-up.” In counties where Senior Centers either don’t have the money or flexibility to hire help with I&A, the challenge of keeping up with phone calls, particularly with an aging population, could be significant.

Providing I&A is time-intensive because the needs of older adults are so diverse. People need help paying their rent, utilities, groceries, prescription drugs, and hospital bills. They call to complain of chest pains. At Mecklenburg’s Just1Call, a dedicated helpline for older adults, one social worker reported 60 different requests in one month. The callers to one of the smallest I&A programs come from both ends of the socio-economic spectrum: seniors battling eviction and wealthy retirees remodeling their homes to be senior-friendly. People call to obtain free incontinence supplies, Ensure, and wheelchairs. Experienced I&A providers can predict trends in the types of calls. As gas prices sky-rocket, more older adults call about fuel assistance because they’re on fixed incomes.

With so many different, and often specific, needs, the only way to become really good at making accurate referrals is through experience. Otherwise, people are directed to programs with lengthy waiting lists and their frustration increases. Mecklenburg’s Just1Call requires new staff members to spend a month in training before they begin answering the calls. “It takes so long to train someone because you don’t know what kind of request will be on the other end.”

3. Older adults have trouble identifying their needs

In response to the growing demand for I&A from older adults, and the strain that burden places on various agencies – building a website – like NCcareLink – that can answer some of the straightforward and common information queries makes a lot of sense. The challenge is designing a website that helps consumers distinguish between a simple information search and a more complicated assistance question.

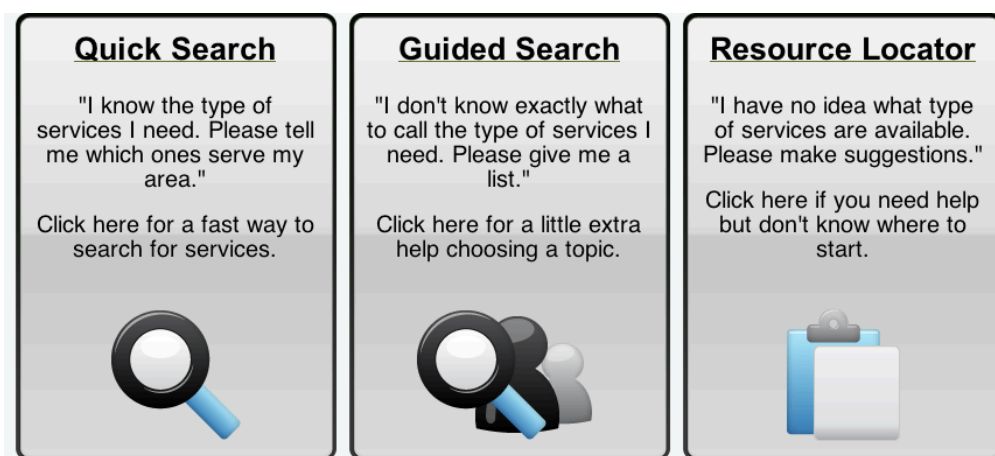
One of the most salient points from my interviews with Aging Network providers is that consumers do not recognize their own needs. “[He] would call in and say “I need this” but in talking to someone you realize that might be secondary to what the real need is. You start talking and find out that they haven’t been refilling their medication because they think food is more important.” The concern is that people identify just one need, when they actually have several unmet needs. For example, if an older woman has difficulty preparing meals, she may also have difficulty walking around her home and be at high risk for falls. The goal is to maintain her independence, so it is important to connect her with more than home-delivered meals. She should be encouraged to go to exercise classes at the senior center or to install grab bars in her house.

⁶⁰ Alexih L, Kuo C. “Just1Call Case Study” ADRC-TAE Issue Brief. Washington DC: The Lewin Group, 2004

The decision about what services are appropriate can only be made through longer and more extensive consultations.

An I&A website can still encourage these conversations in a few ways. The first is to encourage people to call and make the appropriate phone numbers easily accessible. Tennessee has adopted this model. An alternate approach is directing website visitors to an online needs assessment tool, like Minnesota's DecisionNavigator, that asks a series of questions about functioning, memory, health and finances to identify the full range of a person's needs and ability to access services. While many states have developed online assessment tools, Virginia has created perhaps the most effective prompt to direct people, as appropriate to that tool.

Figure 3: From Virginia's SeniorNavigator site



4. Older adults delay seeking help until they are in dire need

Information & Assistance programs usually receive calls from older adults only when their functioning has deteriorated to the point where they need immediate assistance. Culture plays an enormous role. One interviewee described in her region, "a fear of anything that sounds like public assistance, pride, hardwiring from their family upbringing that [we] take care of our own, all of those types of mindsets factor in." Another factor is denial. Most people do not recognize – or do not want to recognize – physical or cognitive decline in themselves, their spouses or their parents until something unexpected happens – like a fall or heart attack. "People always think I'm not that bad and I don't need those services." The perception that long-term care and aging services are only for the very sick has made it impossible for providers to convince the community that they want to help maintain their independence and not take it away.

The result is that it is very difficult for the Aging Network to convince people to call at the first sign of a need, rather than in a crisis. That has not stopped them from trying. "We know from marketers that you have to be hit 7 times before you get it. Constantly we're trying to help folks get information – where to go, who to ask. It's a constant part of what we do." All AAAs said they participate in health fairs. Some interviewees said they reach out to pastors and give

presentations at churches. Forsyth Senior Services has started a partnership with 19 employers where they provide a telephone-based consultation and referral service as part of employees' benefit packages.

Every interviewee said it was rare for older adults to be proactive in getting information about long-term care. The few individuals who did usually were retirees who had just moved to North Carolina or adults who had questions about how to save for long-term care. Several interviewees reported a flurry of calls from adult children after holidays, like Thanksgiving, when the adult children of older adults come to visit. "They don't realize how bad it's gotten" and they call agencies in a hurry to obtain certain services before they go home.

As the demands on the Aging Network increase, the AAA may have less time and resources to promote services at health fairs or reach out to pastors. They may agree with one Family Caregiver Specialist who said: "The time for promotion is tremendous and takes away from quality of care and quality of services delivered... We have to be realistic about what we can do... with waiting lists, trying to get more people on is not a goal. Trying to serve people who have come is the priority." Before the system is so strained that there is little or no time for community outreach, the Aging Network needs to find more effective ways to promote their services.

5. Caregivers are seeking out information online and being directed to many different sites.

My interviews with Aging Network providers gave a glimpse into how caregivers are using the Internet for information about long-term care. Everyone I interviewed reported an increase in emails from adult children caregivers in the past year, though the volume of emails remains quite small. One Family Caregiver Specialist was excited to report that she received twice as many emails in 2010 than 2009, but the total number was still only 48.

Many of the adult children who called the Area Agency on Aging looking for information did so because they visited the same Department of Aging and Adult Services website as I did. This webpage lists the job title and contact information for every AAA staff member by region. This website was not designed for caregivers – it does not explain what the ambiguous job titles mean (e.g. "Aging Coordinator") nor does it suggest a first point of contact. As discussed earlier, providing this information and inadvertently directing people to call staff members at the AAA may not be a good use of resources. In comparison, the TennesseeAging website is more consumer-friendly. It lists only one staff member and clearly identifies the information and assistance phone number for consumers to use.

Toll-free Statewide Long-Term Care Information: 1-866-836-6678

<p>FIRST TENNESSEE AAD Counties include: Carter, Greene, Hancock, Hawkins, Johnson, Sullivan, Unicoi, Washington</p> <p>Kathy T. Whitaker, Director First TN Development District 207 North Boone Street Suite 800 Johnson City, TN 37604-5699 kwhitaker@ftaaad.org Tel: 423-928-0224 Fax: 423-928-5209</p>	<p>Information and Assistance 423-928-3258</p> <p>Web Site: http://www.ftaaad.org</p>
---	---

Adult children looking for information are likely to begin with a Google search. Even once NCcareLink is fully developed and being promoted by the Aging Network, policymakers need to be aware of the websites that appear at the top of a Google search query, such as private rehabilitation and home healthcare providers. By the time NCcareLink is fully functional, most Aging Network agencies will have created their own websites. Already, every AAA and many Councils of Aging, Senior Centers, and transportation providers have their own websites. The state needs to be aware of these sites and the consistency between their content and NCcareLink.

Online information needs to be integrated with off-line service delivery. People who are searching for information online are often looking for phone numbers of service providers. They may want the phone number to a provider of specific services (e.g. transportation, personal care) or to a public office (e.g. DSS) that can screen for Medicaid eligibility. Either way, these websites will play an important role in directing people to services, so the way services are described and pathways are mapped online needs to match the offline system. If the information is vague or uninformative, it will only increase work for people receiving calls. Additionally, providers want to have websites that they trust and to which they can refer callers. Right now, they frequently mail individuals handouts and directories. It would save them time and money, and benefit individuals, if these resources could be accessed electronically instead. Importantly, most older adults will not find reliable information or public websites unless they are promoted off-line. The two systems need to reinforce each other.

6. Changes to the long-term care system need to allow for county differences, while also moving toward consistency

While rural counties often lack the financial and human resources that more densely populated counties have, many interviewees at AAAs expressed the idea that “in the rural counties, folks are more connected in a way.” This observation, from people who oversee services in multiple counties, underlines the importance of giving the AAAs the flexibility to innovate and be responsive to local needs.

The greatest example of community responsiveness is the Beaufort County Resource Connections listserv. Faith-based and non-profit organizations subscribe. When a person walks into DSS or the Senior Center asking for assistance that the agency cannot provide – for example, durable medical equipment, assistance paying the gas bill, or a bicycle with a basket – the request goes out to the listserv. “And someone will come up with a bicycle.”

Every county has organized their services differently. The CRC pilot projects and expansions demonstrate that every county will interpret and implement programs in their own way. However, it would be unfortunate if these variations prevented counties from sharing insights about what works or created additional confusion for senior citizens and caregivers. Moving forward, the goal for the state is to ensure information is readily available to all aging adults, without prescribing a set of certain set of services that may be unrealistic for or incompatible with a particular county’s current organization.

Moving forward with NCIOM Recommendations

The goal of my thesis is to propose recommendations to improve the delivery of information and assistance services in North Carolina. In particular, how can the state provide information quickly and cost-effectively so that I&A staff can devote more time responding to assistance inquiries. In keeping with the NCIOM's initial recommendation, any new alternatives must advance the three goals that information should be readily available and easily accessed, understandable, and uniform for all in need.

Objective #1: Reduce the time it takes for older adults to find the services they need

1. **Identify at least one I&A program in every county.** Currently, 42 counties have an official I&A program that receives OAA funds and complies with DAAS standards. Several more counties have created formal programs that are funded by their County Commissioners. Under this policy option, each county would select an I&A program and report the selection to DAAS, though the program would not have to be a recipient of OAA funds. Multiple counties could select the same I&A program (e.g. AAA). The program should have at least one full-time staff member dedicated to responding to inquiries.

2. **Expand and modify online presence of all Aging Network agencies to make them consistent and senior-friendly.** Each Aging Network website is formatted differently, has different content, and is unlikely to be a) interactive or b) consistent with best practices for senior-friendly websites. Moving forward, the following components should be part of every website:
 - Clearly marked I&A program phone number
 - Focus on the primary needs of older adults: home modifications, financial assistance, meals, transportation, and caregiver assistance (respite care)
 - Buttons to enlarge font size
 - Buttons to print each page
 - Simple, clear web pages that define long-term care and give guidance for planning and paying for long-term care
 - Links to other federal and state websites, including:
 - *NCcareLink.gov*
 - *Medicare.gov/nhcompare* – Quality rankings on nursing homes
 - *Benefitscheckup.org* – A service of the National Council on Aging that helps people find federal and state benefits programs
 - *NIHSeniorHealth.gov* – Health and wellness information for seniors
 - *Own Your Own Future* – CMS toolkit for long-term care

Maryland Access Point is an excellent example.⁶¹

⁶¹ <http://mhcc.maryland.gov/consumerinfo/longtermcare/TransportationAssistance.aspx>

3. **Prioritize good website design over expediency.** The majority of adults over 70 are not regular Internet users. When they want reliable information, they turn to physicians or trusted organizations in their community. It is more important that website content is well-designed than that it is live in the next 36 months. There are advantages to waiting, including giving providers the chance to receive and become comfortable with the complimentary software, waiting until the state can afford to promote the site more broadly, and launching the site in connection with other online health tools, such as the state's health insurance exchange by 2014.
4. **Work with Aging Network staff to collect and record data on caller demographics (age, race, location) and level of functioning.** In the long-run, one of the most effective ways to make information more readily available is to be knowledgeable about the types of information and services for which older adults are searching. Already, there are procedures in place for I&A providers to document calls. At a minimum, these procedures should require employees to collect and record data on caller demographics (age, race, location) and level of functioning. The goal is not to create additional or excessive reporting requirements, but to ensure that these records are used to inform community planners about the needs of older adults. Changes should only be made after extensive consultation with current staff to ensure its compatible with their workflow.
5. **Allow providers the opportunity to see the same software interface that Aging Network agencies are using.** Traditionally, physicians are familiar with only their patient's medical needs. They do not have the time or training to learn about a patient's social support structure or the financial circumstances that affect their ability to access help or care at home. And, they are rarely knowledgeable about the array of public programs and community supports that can benefit their elderly patients. So though they are well-respected and well-positioned to connect older adults with services, they are usually poorly informed. By allowing them to access the same information as the AAA, Council of Aging, and DSS, they may be able to learn about their patient's pathways into the system and more effectively advocate for future patients. Initial participation may be low, but encouraging participation at the same time many providers are adopting electronic medical records could increase their responsiveness and avoid duplication down the road.

Objective #2: Make it easier for older adults to identify if they need information or assistance

6. **Learn from states that have implemented needs assessment tools.** There is little data on the impact of needs assessment tools on senior citizens or providers that serve them. Before the state unveils its own needs assessment tool – which will likely occur once the taxonomy is complete and the database is nearly up-to-date – it should learn as much as possible from states that have already implemented these tools, such as Minnesota. The tool should be modified given the experience of these states to maximize its ability to effectively direct people to the appropriate resources (information directory or assistance counseling).

7. **Create a .pdf version of the state’s online needs assessment tool that can be emailed to or downloaded by interested caregivers.** The online needs assessment tool asks a range of questions about older adults’ physical, cognitive, and emotional well-being, some of which adult children may be ill-equipped to answer when they first visit NCcareLink. By making the tool accessible as a .pdf, adult children can use it to start a conversation offline with their parents about their condition and circumstances. They can also share the completed document with physicians and include them in the identification of both impairments and possible supports.

Objective #3: Provide high-quality assistance services

8. **Train I&A providers in options counseling.** In the CRC initiative, assistance services have been divided into five components: options counseling, benefits counseling, employment options counseling, crisis intervention, and planning for the future. Options counseling is the most similar to assistance services as they are currently provided; it is counseling that puts long-term care choices in “the context of the consumer’s needs, preferences, values, and individual circumstances.”⁶² Unlike traditional assistance services, options counseling is considered a process and may require providers to build relationships with people to understand their preferences and needs. Options counseling is a time-intensive process, but for those individuals who are facing a critical decision or major change in their living arrangement, it is particularly valuable.

Several states, including Oregon and Nevada, have recently partnered with academic institutions to develop training modules on options counseling for the Aging Network. North Carolina should provide similar trainings to I&A providers to ensure that the counseling people receive is of the highest quality. While this counseling is not fundamentally different from services already delivered by many, promoting options counseling and making it a formal requirement allows the state to reinforce the concepts of informed decision-making, to ensure the quality and consistency of counseling, and to work with I&A staff to clarify the distinction between information calls and assistance calls. Being able to differentiate between customers and the type of help they need is essential in improving the efficiency this service and targeting resources appropriately.

9. **Implement benefits or incentives that help recruit and retain exceptional staff at I&A agencies.** Providing high-quality information and assistance requires staff members to be passionate and exceeding knowledgeable; and, in this field, knowledge is usually a function of experience. There are examples of agencies that have employed and retained really excellent people; however, too many agencies in the Aging Network experience frequent turnover that impedes institutional learning and eliminates the possibility of experienced I&A staff. Strategies to retain high-

⁶² Aging and Disability Resource Center Technical Assistance Exchange. Options Counseling Topic Overview.

quality staff during a budgetary crisis include improving the office culture, providing flexibility, and empowering employees to act on their ideas.

Objective #4: Engage the private, for-profit sector to reduce the strain on the public and non-profit Aging Network

10. **Provide training to I&A programs to promote services provided in the private, for-profit sector.** The exploding population of older adults is viewed by some in the private sector as an opportunity. The market for technologies and services that promote wellness, mobility, autonomy and social connectivity is growing, rapidly. These products, which include wireless pillboxes that transmit information about patients' medication use, as well as new financial services, can promote health and independence, thereby delaying entry into long-term care or reducing the utilization of public services. As a result, the state should offer trainings on the topic of assistive devices and encourage promotion of these services by the public and non-profit sector.

11. **Expand or replicate the Forsyth Senior Services' Elder Care Choices program, which provides consultation and referral services to employees as part of subscribing companies' employee benefits packages.** Adult children who are taking care of their aging parents may be a more receptive audience for outreach about information and assistance programs than older adults themselves. Employers in North Carolina have been receptive to Forsyth's program, which has grown over the past 14 years. By recruiting employers to participate, the Aging Network can increase its influence among a large cohort rather than doing individual outreach at health fairs. However, this strategy will miss people whose adult children live out of state.

Acknowledgments

Researching and writing this report has been a rewarding experience – in large part, because of the dedication and compassion of the individuals who agreed to be part of this project. The people I interviewed were generous with their time and earnest in their remarks. I am also lucky to have benefited from the guidance of my advisor, Professor Sherman James, and the members of my committee, Professors Jim Johnson, Peter Ubel and Elizabeth Vigdor. Their input was both constructive and encouraging.

I am appreciative to Pam Silberman, President of the North Carolina Institute of Medicine, and Judy Walton, Waiver Development Chief at the NCDHHS Division of Medical Assistance, for encouraging me to look at entry into the system and to revisit the recommendations the NCIOM Task Force drafted in 2001.

I want to acknowledge my parents both for the questions they asked of me as I worked on this report and the caregiving they provided to their own aging parents, all of whom received the care in they needed in the comfort of their homes. Caregiving is fraught with challenges – access to information and assistance should not be among them. Lastly, I have a constant, trusted source of support for whom I am incredibly thankful.

Bibliography

- Alecxih L, Kuo C. “Just1Call Case Study” ADRC-TAE Issue Brief. Washington DC: The Lewin Group, 2004.
- Armour-Garb A. “Point of Entry Systems for Long-Term Care: State Case Studies” Prepared for the New York City Department of Aging, 2004. Available at: http://www.nyc.gov/html/dfta/downloads/pdf/study_ltc.pdf
- Briss P et al. “Promoting Informed Decisions about Cancer Screening in Communities and Healthcare Systems” *American Journal of Preventive Medicine* 2004; 26(1):67-80
- Coleman B, Kassner E & Pack J. “New Directions for State Long-term Care Systems. Volume II: Addressing institutional bias and fragmentation.” AARP Publication No. 9606. Washington, DC: Public Policy Institute, 1996.
- Dean H. Testimony given at the Senate Special Committee on Aging on Long-Term Care Financing and Reform, on behalf of the National Governors Association, 2002.
- Epstein RM, Alper BS, Quill TE. “Communicating Evidence about Participatory Decision Making” *JAMA* 2004; 2359-2366
- Goins, R. Turner and Gerry Hobbs, “Distribution and Utilization of Home- and Community-Based Long-Term Care Services for the Elderly in North Carolina” *Journal of Aging and Social Policy* 2001; 12(3): 23-41
- Kane RL, Boston K, Chilvers M. “Helping People Make Better Long-Term-Care Decisions” *The Gerontologist* 2007; 47(2):244-247
- Kaye HS, Harrington C, LaPlante M “Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?” *Health Affairs* 2010; 29(1):11-21
- Keckley PH, Frink B. “Medicaid Long-term Care: The ticking time bomb” Deloitte Center for Health Solutions, 2010
- LeBlanc AJ, Tonner MC, and Harrington C. “Medicaid 1915(c) Home and Community-Based Services Waivers Across the States” *Health Care Financing Review* 2000; 22(2): 159-174
- Lewis A. Non-compliance: a \$100 billion problem. The Remington Report 1997; 5(4):14-5.
- Madden M. “Older Adults and Social Media” Pew Internet & American Life Project, 2010. Available at: <http://www.pewinternet.org/Reports/2010/Older-Adults-and-Social-Media.aspx>

Mollot, R, Rudder C, Sobel M, Stone C. “Single Point of Entry for Long Term Care and *Olmstead*: An Introduction and National Perspective for Policy Makers, Consumers and Advocacy Organizations” Long Term Care Community Coalition, 2005.

Morrell RW, “<http://www.nihseniorhealth.gov>: the process of construction and revision in the development of a model web site for use by older adults” *Universal Access in the Information Society* 2005; 4: 24-38

n4a. “Background Information on AAAs, Title VI Aging Programs and the OAA” Washington, DC: National Association of Area Agencies on Aging, 2010.

National Association of State Units on Aging. “Vision 2010: Toward an Aging Information Resource System for the 21st Century” Washington, DC: National Association of State Units on Aging, 1999.

North Carolina Study Commission on Aging. *Report to the Governor and the 2005 Session of the General Assembly*.

O’Brien E. “Long-Term care: Understanding Medicaid’s Role for the Elderly and Disabled” Washington, DC: Kaiser Commission on Medicaid and the Uninsured, November 2005

Older Americans Act of 1965 as Amended: 42 U.S.C. 3001. [Public Law 100-175, Section 306. (a)(2)(A) and (a)(4): Section 307. (a)(9)]

Reinhard, SC. and Scala, M. “Navigating the Long-Term Maze: New Approaches to Information and Assistance in Three States.” Washington, DC: Institute for the Future of Aging Services, 2001

Rogers C. “The older population in 21st century rural America.” *Rural America*, 2002; 17(3):2-10

Smith G, O’Keefe J, Carpenter L et al. “Understanding Medicaid Home and Community-Based Services: A Primer” Washington, DC: U.S. Department of Health and Human Services. October 2000. Available at: <http://aspe.hhs.gov/daltcp/reports/primer.htm>

Span P. “Being There, Without Leaving Home” The New Old Age. (blog). *New York Times*, August 3, 2010. Available at: <http://newoldage.blogs.nytimes.com/2010/08/03/being-there-without-leaving-home/>

Special Committee on Aging. *Developments in Aging: 1997 and 1998, Volume 1, Report 106-229*. Washington, DC: United States Senate, 2000.

Stone RI. “Long-term Care for the Elderly with Disabilities: Current policy, emerging trends, and implications for the twenty-first century” Milbank Memorial Fund, 2000. Available at: <http://www.milbank.org/0008stone/>

Stout H. “Technologies Help Adult Children Monitor Aging Parents.” *New York Times* July 28, 2010. Available at: <http://www.nytimes.com/2010/07/29/garden/29parents.html>

Woolf SH et al. “Promoting Informed Choice: Transforming Health Care to Dispense Knowledge for Decision Making” *Annals of Internal Medicine* 2005; 143:293-300.

Zickuhr K. “Generations 2010” Pew Internet & American Life Project, 2010. Available at: <http://pewinternet.org/Reports/2010/Generations-2010.aspx>