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Long-Term Care: Are We Ready to Meet Expected Needs and Demand?

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Tarheel Footprints in Health Care

Recognizing unusual and often unsung contributions of individual citizens who have made health care for North Carolinians more accessible and of higher quality

Bonnie M. Cramer, MSW

Chair, National Board of Directors, AARP

For more than three decades, the name Bonnie Cramer has been a household word for the dedicated, highly energetic, and articulate spokesperson representing the interests of older adults and long-term care issues in North Carolina. Throughout a long and distinguished career in state government, she has held a number of key positions in the field of aging services. For 10 years, she served with the Division of Aging in the North Carolina Department of Health and Human Services and was director of the Division during the period when home- and community-based services were being developed in the state. She also served as director of the Office of Long-Term Care Policy and the assistant director of the Division of Facility Services, the regulatory agency overseeing both health and long-term care services and providers. She ended her career in state government with an appointment to the Office of State Budget and Management.

In 2008, after several years on the AARP National Board of Directors, she assumed the position of chair of the 23-member Board to the Association, a term that will end in May of 2010. She had previously achieved considerable national attention as a member of the Board of Directors of the National Association of State Units on Aging and as a member of the advisory committee for the National Center on Elder Abuse.

Bonnie Cramer began her career in health and human services after receiving a master's degree in social work at the University of North Carolina at Chapel Hill. Her first job was in the field of child protective services, a position she refers to as "one of the most difficult, emotionally draining things I've ever done." After working in this field for several years, she was lured to the field of aging and long-term care and took a position as deputy director of the state's Division on Aging.

Bonnie has always been a strong advocate for the needs of older adults, especially those with disabilities, whose dependence on the availability of quality programs and providers of technical care and social support is critical to their functional independence. Her understanding of the daily challenges of persons with these disabilities is facilitated by her own struggle with the pain and disability associated with severe rheumatoid arthritis. Most people who have encountered her in one of her many arenas of public policy activity would hardly be aware of any limitations caused by her disability. But those who know her well realize what she goes through daily just to overcome its potentially limiting impact.

In her two years as AARP National Board Chair, she has become one of the most effective and visible voices for older adults and is a frequent spokesperson for older Americans before committees of the US Congress. In North Carolina, she is always among the first to speak out in support of new and innovative approaches to serving the needs of older adults when the state has a window of opportunity, such as with the recent 646 waiver initiative, which serves those populations dually eligible under both Medicare and Medicaid. Although she is "retired" from her career in North Carolina state government, her expertise and experience are highly valued and sought by current leaders in these fields.

The editors of the *North Carolina Medical Journal* are pleased to recognize this special contributor to the health and welfare of our state's (and the nation's) older adult population in this issue of the *Journal*. We are deeply grateful to Bonnie Cramer for all she has done for North Carolinians throughout her professional career, and we wish to recognize her for exceptional national leadership in this field. She has brought great credit to our state through these many efforts.

Contributed by Gordon H. DeFriese, emeritus professor of social medicine and epidemiology at the University of North Carolina at Chapel Hill and president emeritus of the North Carolina Institute of Medicine.

Practices for Sale

Bringing Medical, Dental, and Health-Care Related Buyers and Sellers Together.

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Medical Space for Lease	**Cary, NC**	**For Lease**	**$5,200 per mo**	**All Inclusive**
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Urgent Care	**Raleigh, NC**	**$875,000**	**$1,005.000**	**$1,880,000**
Extended hour practice with 6 plus exam rooms, X-Ray and the capacity to grow even more. The patient volume supports two providers on-going plus two mid-levels can also have a full schedule. This practice is on a heavily traveled road in Wake County and has very impressive gross and profit margins.				
Urgent Care	**Raleigh, NC**	**$135,000**	**$1,550,000**	**$1,685,000**
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Women's Practice	**Wake County, NC**	**$725,000**	**$1,750,000**	**$2,475,000**
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2 Urgent Cares	**Cary Area, NC**	**$350,000**	**Leased**	**$350,000**
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Internal Medicine	**Durham County, NC**	**$176,000**	**$165,000**	**$341,000**
This practice is a mainstay of the community. Retiring physician is willing to stay for a few days per week to mentor and help with transition. Treating internal as well as gastrological patients with some owner financing possible.				
Urgent Care	**Greensboro, NC**	**$350,000**	**Leased**	**$350,000**
Upscale practice serving patients in the Triad for about 15 years. Medical equipment includes digital X-Ray.				
Internal Medicine	**Greenville, NC**	**$600,000**	**$160,000**	**$760,000**
This primary care practice is a medical cornerstone of the community, serving metropolitan Greenville and surrounding areas. Impressive 40 patients per day with owner financing up to $250,000 for the qualified MD.				
Urgent Care	**Johnson County, NC**	**$185,000**	**Leased**	**$185,000**
Established practice with exceptional layout. Beautiful free standing practice building with rent of $5,650 per mo.				
Walk-In Clinic	**Onslow County, NC**	**$460,000**	**Leased**	**$460,000**
Beautiful practice in the Jacksonville area with predictable 45 to 50 patients per day. Use of digital X-Ray, and well equipped. Highly visible from the street and tastefully appointed inside. Some owner financing.				
Primary Care	**Jacksonville, NC**	**$290,000**	**Leased**	**$290,000**
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Treating patients for over 12 years, this upscale practice is nestled in a medical community with aesthetically pleasing amenities. Patient daily totals are 30 to 45 per day, with a lot of room for growth.				
Urgent Care	**Angier, NC**	**$198,500**	**Leased**	**$198,500**
Excellent location, well equipped, super staff and ready for the new owner. Steady patient volume of 35 to 55 per day				
Med Building Sell/Lease	**Smithfield, NC**	**N/A**	**$936,000**	**$936,000**
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PEER-REVIEWED ARTICLE

A Conceptual Model Exploring the Relationship Between HIV Stigma and Implementing HIV Clinical Trials in Rural Communities of North Carolina

Sohini Sengupta, PhD, MPH; Ronald P. Strauss, DMD, PhD; Margaret S. Miles, RN, PhD, FAAN; Malika Roman-Isler, PhD, MPH; Bahby Banks, MPH; Giselle Corbie-Smith, MD, MSc

Abstract

Background: *HIV/AIDS disproportionately affects minority groups in the United States, especially in the rural southeastern states. Poverty and lack of access to HIV care, including clinical trials, are prevalent in these areas and contribute to HIV stigma. This is the first study to develop a conceptual model exploring the relationship between HIV stigma and the implementation of HIV clinical trials in rural contexts to help improve participation in those trials.*

Methods: *We conducted focus groups with HIV service providers and community leaders, and individual interviews with people living with HIV/AIDS in six counties in rural North Carolina. Themes related to stigma were elicited. We classified the themes into theoretical constructs and developed a conceptual model.*

Results: *HIV stigma themes were classified under the existing theoretical constructs of* perceived, experienced, vicarious, *and* felt normative *stigma. Two additional constructs emerged:* causes *of HIV stigma (e.g., low HIV knowledge and denial in the community) and* consequences *of HIV stigma (e.g., confidentiality concerns in clinical trials). The conceptual model illustrates that the* causes *of HIV stigma can give rise to* perceived, experienced*, and* vicarious *HIV stigma, and these types of stigma could lead to the* consequences *of HIV stigma that include* felt normative *stigma.*

Limitations: *Understanding HIV stigma in rural counties of North Carolina may not be generalizeable to other rural US southeastern states.*

Conclusion: *The conceptual model emphasizes that HIV stigma—in its many forms—is a critical barrier to HIV clinical trial implementation in rural North Carolina.*

Keywords: *HIV; AIDS; stigma; clinical trials; minority groups; research participation*

The epidemiology and demographics of HIV/AIDS have evolved over the last 25 years in the United States, resulting in the highest rates of new infection among minority populations, particularly among African American and Latino populations. In addition, there has been a shift in new HIV/AIDS cases from large northeastern and western metropolitan areas to the southeast, where over 43% of residents live in rural areas.[1,2] The southeast represents

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six southern states, including North Carolina, that are disproportionately affected by the AIDS epidemic. In North Carolina, 68% of the total number of AIDS cases reported in 2007 were African Americans and 8% were Latinos.[3]

The rise of the AIDS epidemic in southeastern rural areas may be exacerbated by poverty and lack of access to HIV prevention and care that is more readily available in US urban areas.[1,2] Such socioeconomic conditions create an environment that can engender HIV stigma and allow it to flourish. An extensive body of literature exists that identifies HIV stigma as a complex sociocultural barrier that negatively affects preventive behaviors, including condom use and HIV test-seeking behaviors; care-seeking behaviors relating to diagnosis and compliance; quality of care for people living with HIV/AIDS (PLWHA); and perception and treatment of PLWHA among family, friends, partners, health care providers, and the larger community.[4,5] For example, in urban areas, HIV stigma was three times more likely to be associated with reduced access to care among low-income, HIV-infected individuals even after controlling for sociodemographic characteristics and biomarkers for HIV infection.[6] For African Americans and Latinos living with HIV/AIDS in one of the southeastern states, stigma and shame have been identified as themes affecting medication adherence.[7] These studies' findings are of particular importance because lack of access, or delayed access to care, may result in more advanced stages of HIV disease at clinical presentation and/or increased resistance to first-line antiretroviral therapies.

While qualitative and quantitative studies have demonstrated an association between HIV stigma and access to HIV care among racial/ethnic minority groups, little work has been done on the impact of HIV stigma on access to clinical trials. HIV clinical trials have been, and continue to be, a source of care for PLWHA, especially PLWHA who have no health insurance coverage. Racial/ethnic minority groups, however—particularly African Americans and Latinos—have been disproportionately underrepresented in HIV research and clinical trials despite formal policies and concerted efforts on the frontline to increase their inclusion as subjects in clinical trials.[8,9] If HIV stigma is a barrier to HIV prevention and care services in impoverished and rural minority communities, it may also affect HIV clinical trial participation in these communities as well. Applying theory to understand the relationship between HIV stigma and HIV clinical trial participation in rural US communities will be useful in expanding our understanding of health disparities in HIV care access and utilization.

In recent years, theoretical frameworks have been posed to explore the complexity of HIV stigma and its impact in communities. The simplest theoretical framework breaks down HIV stigma into perceived stigma, experienced stigma, and internalized stigma.[4] *Perceived stigma* is how PLWHA feel that they are being negatively treated by partners, family, friends, health care providers, and members of their community because of their HIV status. *Experienced stigma* is an act of discrimination towards PLWHA that includes denial of health care, education, or employment, or isolation from family members. *Internalized stigma* is the negative self-image PLWHA may have resulting from perceived and/or experienced stigma.

An alternative framework assumes that HIV stigma begins at the societal level where inequalities in social, political, and economic power enable stigmatization.[5] In this framework, HIV stigma can be manifested by labeling, negatively stereotyping, separating PLWHA from non-infected community members based on other discredited attributes (e.g., being an injection drug user or a commercial sex worker), and by racism and sexism. In this understanding, the most direct level of HIV stigma is experienced stigma, which can be acts of discrimination by non-stigmatized individuals or acts of discrimination toward PLWHA at the institutional level (e.g., being fired for having HIV).

Another useful theoretical framework incorporates both perceived and experienced stigma at the individual and community levels, in addition to internalized stigma.[10] Moreover, this framework includes two new concepts of HIV stigma: felt normative stigma and vicarious stigma. *Felt normative stigma* is a protective mechanism for PLWHA against experiencing stigma (e.g., passing as a member of the non-stigmatized community). *Vicarious stigma* happens when PLWHA hear stories of experienced stigma and these stories become real to them, even though they may not have directly experienced discrimination themselves.

Our study is one element of a larger community-based project called Project EAST (Education and Access to Services and Testing) that is examining individual, provider, and community level factors that influence participation of rural racial/ethnic minorities in HIV/AIDS research, and which will test the feasibility of implementing HIV/AIDS clinical trials in local communities. The first phase of Project EAST utilized qualitative methods to obtain preliminary data about community views of HIV/AIDS and to ascertain the feasibility of clinical trial implementation in rural, minority communities. One mode of implementation that was highlighted was using a mobile unit to increase rural communities' access to clinical trials. Issues of HIV stigma were dominant and emergent themes in this inquiry. Thus, the purpose of the current study—using the existing theoretical constructs for HIV stigma as a guide—was to develop a conceptual model that explored the relationship between HIV stigma and related identified themes, and how these themes may affect the implementation of HIV clinical trials in rural counties of North Carolina.

Methods

Sample

According to the 2000 US Census Bureau, almost 32% of the population in North Carolina lives in what is defined as a "rural area."[11] We conducted focus groups with HIV service providers and community leaders, and individual in-person interviews with PLWHA in six of these predominantly rural counties in North Carolina, representing two three-county communities. Moreover, these six counties were also selected due to their moderate HIV prevalence, based on HIV/AIDS surveillance at the end of 2007, ranging from 0.5%-1%.[3] In qualitative methodology, sample size and power depend on purposeful selection of participants to achieve an information-rich and heterogeneous sample that represents the target populations of interest;[12] in our case, we were interested in sampling HIV service providers, community leaders, and PLWHA from each of the six North Carolina counties.

To achieve data saturation,[13] we conducted a total of 11 focus groups with 4-10 participants in each focus group. The majority of these focus groups were stratified by community leader vs. HIV service providers and by county, but the exceptions included: one focus group with Spanish-speaking community leaders from one three-county community in which over 40% of the PLWHA are Latinos, one combination community leader/provider focus group from one county, and one provider focus group representing three of the counties. HIV service providers were defined as those who provide direct care or services to PLWHA, and community leaders were defined as those who could have an influence in engaging their respective communities in HIV/AIDS clinical trials.

Similarly, we recruited between five to eight PLWHA study participants from each of the six counties for a total of 35 individual PLWHA in-person interviews to achieve data saturation. PLWHA were recruited through local HIV/AIDS case management and clinical care programs in each of the participating counties. Inclusion criteria included self-identifying as African American or Latino, ability to speak English or Spanish, and residing in one of the six counties.

Data Collection

The Project EAST design, methods of recruitment, data collection, and data analysis were approved by the University of North Carolina (UNC) Biomedical Institutional Review Board and the UNC General Clinical Research Center on August 29, 2006.

Instrument

Separate semi-structured interview guides were developed for the focus groups and the PLWHA interviews. For both, semi-structured interview guides consisted of parallel *a priori* conceptual domains that included:

- community and personal views about HIV/AIDS,
- views about HIV research or HIV clinical trials,
- views about how to bring HIV clinical trials into rural communities, and
- views about different mechanisms (including a mobile van) to conduct HIV clinical trials.

For the PLWHA interviews, additional, *a priori* conceptual domains included: *disclosure* and *preferences relating to participation in HIV clinical trials*. Questions and probes were developed for each of the *a priori* conceptual domains, and those that elicited HIV stigma or related themes are listed in Table 1.

Recruitment

HIV service provider and community leader potential focus group participants were recruited by a community outreach specialist from each three-county community. Each community outreach specialist developed a master list of potential participants for the community leader groups by identifying individuals from political, educational, grassroots, economic, media, religious, and social welfare-related community segments. A similar master list was comprised for service providers that included physicians, case managers, health educators, and other clinical practitioners. Each community outreach specialist made phone contact with a purposive sample of leaders to ensure a cross-representation across community segments and provider types for data collection.

Focus groups were convened at a centrally-located facility within each three-county region and were conducted

Table 1.
Selected Conceptual Domains and Questions/Probes in the Semi-Structured Interview Guide

Conceptual Domain	Questions/Probes in Interview Guide
Community and personal views about HIV/AIDS and PLWHA	1. What do people in your community think about HIV/AIDS? 2. How are PLWHA treated in the community? 3. Are certain HIV-positive groups more discriminated against than others?
Barriers to bringing HIV clinical trials into rural communities	What makes it difficult to bring HIV clinical trials into communities?
Views about a mobile van	What about using a mobile van in your community as a way for people who are HIV-positive to enroll and participate in clinical trials?
Additional Questions Asked to PLWHA	
Disclosure	Who have you not told that you have HIV? *Probe: Why didn't you tell them?*
Preferences on where to participate in HIV clinical trials	Would it be easier or better for you to participate in an HIV clinical trial here in your community or would you prefer to go to University, A, B, or C? *Probe for rationale.*

by a facilitator and notetaker. Each meeting was digitally recorded, and each lasted an average of 90 minutes. At the beginning of a focus group, written informed consent was obtained, followed by a question and answer discussion using the semi-structured interview guide, and demographic information was collected from each of the participants at the end. A financial incentive of $20 as well as a meal were provided to focus group participants. Focus group data were collected over a period of three and a half months.

PLWHA potential participants were contacted by their case manager or the community outreach specialist to explain the study. Each interview was digitally recorded and lasted an average of 45 minutes. At the beginning of an interview, written informed consent was obtained, followed by a question and answer discussion using the semi-structured interview guide, and demographic information was collected from each of the participants at the end. A financial incentive of $20 was given to all PLWHA participants.

Data Analysis

All focus group and PLWHA interviews were electronically transcribed into Microsoft Word documents by a professional transcriptionist. Accuracy of the transcription was verified by a member of the research team, and any identifying information within the interviews was redacted to protect the confidentiality of participants. The transcribed interviews were imported into the qualitative software program, Atlas.ti, v.5.2. The first phase of qualitative data analysis involved identifying themes from the questions asked and developing a codebook that reflected a thematic coding structure underlying both *a priori* conceptual domains/questions and emerging conceptual domains. Separate codebooks were developed for the focus group and PLWHA interview transcripts. Codes for each theme were assigned to text using Atlas.ti by a pair of coders per transcript, and 100% inter-coder reliability was established by having the coders resolve any coding differences between them. The codebooks went through a series of iterations to produce final versions that could be used for the interpretative phase of data analysis. Using this approach, the first phase of the analytical process yielded discrete and systematically coded textual data.

In the second phase of data analysis, we extracted coded textual data reflecting HIV stigma themes and categorized them under the existing theoretical constructs—perceived stigma (from PLWHA or community), experienced stigma, internalized stigma, felt normative stigma, and vicarious stigma—identified in the literature. Stigma-related themes that did not fall neatly under the existing theoretical constructs were classified under "other" to denote potential emerging themes that could be associated with HIV stigma. These data were reviewed to identify their co-occurrences, and a conceptual framework was then developed that explored the possible relationships between HIV stigma, its related themes, and how these themes may affect local implementation of HIV clinical trials in rural North Carolina communities.

Results

Sociodemographics

Tables 2 and 3 present the sociodemographics of focus group and individual interview participants. The majority of community leader focus group participants were African American or Latino (82.5%), female (72.5%), and had completed some college or graduate school (92.5%). Similarly, service provider participants were primarily African American or Latino (69.4%), female (72.2%), and had completed some college or graduate school (94.4%). For PLWHA participants, the majority were African American (88.6%), had a high school education or less (88.6%), were on antiretroviral therapy (88.6%), and had annual incomes less than $5,000 (54.3%). Related to being on antiretroviral therapy, 57% of those interviewed were "in-care," meaning that they had gone to their medical appointments within the past six months.

HIV Stigma-Related Themes Grouped by Theoretical Construct and Their Co-Occurrences

Table 4 (page 118) presents the HIV stigma themes that were elicited from the interview guide questions and our

Table 2.
Sociodemographics of Focus Group Participants

Demographics	Community Leaders (n = 40)	HIV Service Providers (n = 36)
Age	Mean 43.4 (SD = 11.18)	Mean 40.6 (SD = 11.28)
Race/Ethnicity		
African American	26 (65.0%)	21 (58.3%)
Latino	7 (17.5%)	4 (11.1%)
White	5 (12.5%)	11 (30.6%)
Multi-Racial/Ethnic	2 (5.0%)	—
Gender		
Male	11 (27.5%)	10 (27.8%)
Female	29 (72.5%)	26 (72.2%)
Education		
HS/GED or less; other training	3 (7.5%)	2 (5.6%)
Some or completed college	21 (52.5%)	22 (61.1%)
Some or completed graduate school	16 (40.0%)	12 (33.3%)

classification of these themes under existing theoretical constructs; we included an "other" category for HIV stigma-related themes that did not fall neatly into the existing constructs. Nine HIV stigma themes were elicited from the question, *What do people in your community think about HIV/AIDS?*; five themes from, *How are PLWHA treated in the community?*; five themes from, *Are certain HIV-positive groups more discriminated against than others?*; three themes from, *What makes it difficult to bring HIV clinical trials into communities?* (this included one related theme probing participants about using mobile vans); three themes from, *Who have you not told that you have HIV?*; and three themes from, *What are your reasons for non-disclosure*? We then organized each of these themes under the existing HIV stigma theoretical constructs of perceived stigma (PS), experienced stigma (ES), internalized stigma (IS), felt normative stigma (FNS), vicarious stigma (VS), and other by placing an "X" under the constructs in which we felt they best fit. Some of the stigma themes were classified under more than one construct.

Table 3.
Sociodemographics of Individual Interview Participants

Demographics	PLWHA (n = 35)
Age	Mean 42.9 (SD = 9.135)
Race/Ethnicity	
African American	31 (88.6%)
Latino	4 (11.4%)
Gender	
Male	21 (60.0%)
Female	14 (40.0%)
Marital Status	
Married/living with partner	10 (28.6%)
Separated/divorced/widowed	12 (34.3%)
Never married	13 (37.1%)
Education	
High school or less; technical	31 (88.6%)
Some or completed college	4 (11.4%)
Health Insurance[a]	
Private	1 (2.4%)
Public (Medicare, Medicaid, Other)	27 (65.9%)
None	13 (31.7%)
Receiving HIV Care	
Yes	20 (57.1%)
No	15 (42.9%)
Currently on Antiretrovirals	
Yes	31 (88.6%)
No	3 (8.6%)
Don't know	1 (2.9%)
Participated in Clinical Trial	
Yes	7 (20.0%)
No	27 (77.1%)
Don't know	1 (2.9%)
Household Income	
< $5K	19 (54.3%)
≥ $5K to $20K	11 (31.4%)
> $20K to $40K	2 (5.7%)
> $40K to $60K	1 (2.9%)
Not reported	2 (5.7%)

a. Some respondents had more than one source of health insurance, making the total n for "Health Insurance" greater than the sample size of n = 35.

Many of the themes elicited when asking about community and personal views about HIV/AIDS were categorized as "other" given that, while they may be associated with HIV stigma, they were not HIV stigma themes by themselves. We categorized these themes as either causes or consequences of HIV stigma. For example, perceptions of those who are at risk for HIV infection co-occurred with judgments of who is or is not a "sinner" (a perceived stigma theme). Thus, perceptions of who is at risk (or of which groups get infected) could be considered a cause for negative stereotyping associated with perceived stigma (labeling at-risk groups or PLWHA as "sinners"). Isolation of PLWHA and local health care providers' negative attitudes and interactions with PLWHA were both felt and experienced and, thus, we classified these themes under perceived and experienced stigma. The theme relating to PLWHA saying they have another disease seemed to be more related to felt normative stigma.

More direct questions asking about HIV stigma—how PLWHA are treated or which HIV-infected groups are discriminated against more than others—elicited HIV stigma themes that could be classified under experienced stigma and under vicarious stigma in cases where PLWHA participants believed that certain HIV-infected groups were stigmatized more than others, even if that perception was not based on their own experiences.

Asking PLWHA about disclosure of their HIV status identified the extent of non-disclosure to even close family members. These themes were classified in the "other" category since non-disclosure among PLWHA could be a consequence of two reasons that we classified under vicarious stigma—fear of being treated badly or the uncertainty of how others may react to their diagnosis. The third reason PLWHA do not disclose—wanting to keep their status confidential—was categorized into felt normative stigma.

Lastly, our questions asking about barriers to HIV clinical trial implementation in rural communities, and about the mobile unit specifically, elicited themes

Table 4.
HIV Stigma-Related Themes Grouped by Theoretical Construct

Interview Guide Questions	HIV Stigma Themes Elicited	HIV Stigma Theoretical Constructs[a]					
		PS	ES	IS	FNS	VS	Other
What do people in your community think about HIV/AIDS?	▪ Lack of HIV education						X
	▪ Denial about HIV/AIDS						X
	▪ Perceptions of who is at-risk						X
	▪ Fear of HIV transmission						X
	▪ People not aware of their HIV status						X
	▪ Certain groups considered “sinners”	X					
	▪ PLWHA say they have other disease				X		
	▪ PLWHA feel/are isolated	X	X				
	▪ Local health care providers think/act negatively toward PLWHA	X	X				
How are PLWHA treated in the community?	▪ Treated badly, considered “bad” person		X				
	▪ Subjected to violence		X				
	▪ How PLWHA treated changes when people discover their HIV status		X				
	▪ Do not want to be near PLWHA	X	X				
	▪ Denied employment/housing		X				
Are certain HIV-positive groups more discriminated against than others?	▪ Homosexuals/gays		X			X	
	▪ Those perceived to be HIV-positive because of how they look		X			X	
	▪ “Promiscuous” women or sex workers		X			X	
	▪ Drug users		X			X	
	▪ African Americans		X			X	
What makes it difficult to bring HIV clinical trials into communities?	▪ Others will find out who is participating in HIV clinical trials						X
	▪ Clinical trial venues will be known as places to go for HIV research/care						X
	▪ Only participate in HIV clinical trial if site was outside of their town						X
What about using a mobile van in your community as a way for people who are HIV-positive to enroll and participate in clinical trials?	▪ Not good because the mobile van will be known as the “HIV bus”						X
Who have you not told that you have HIV?[b]	▪ No one knows						X
	▪ Family members						X
	▪ Friends						X
What are your reasons for non-disclosure?[b]	▪ Fear of being treated badly					X	
	▪ Uncertainty how others will react					X	
	▪ Wanted to keep HIV status confidential				X		

a. PS = Perceived stigma; ES = Experienced stigma; IS = Internalized stigma; FNS = Felt normative stigma; VS = Vicarious stigma; and Other = Emerging category(ies) of stigma, or related to stigma.

b. Questions were asked to persons living with HIV/AIDS (PLWHA) only.

that primarily co-occurred with protecting confidentiality about their HIV status. In Table 4, we classified these themes as "other" and felt that these themes could be a consequence of many of the HIV stigma themes classified under the constructs of perceived, experienced, vicarious, and felt normative stigma.

While examples of internalized stigma probably existed in these rural communities, it is unclear from our textual data that any of the HIV stigma or HIV stigma-related themes should be classified as such. Therefore, we did not classify any of our HIV stigma themes under internalized stigma.

Conceptual Model Exploring the Impact of HIV Stigma on Local Implementation of HIV Clinical Trials

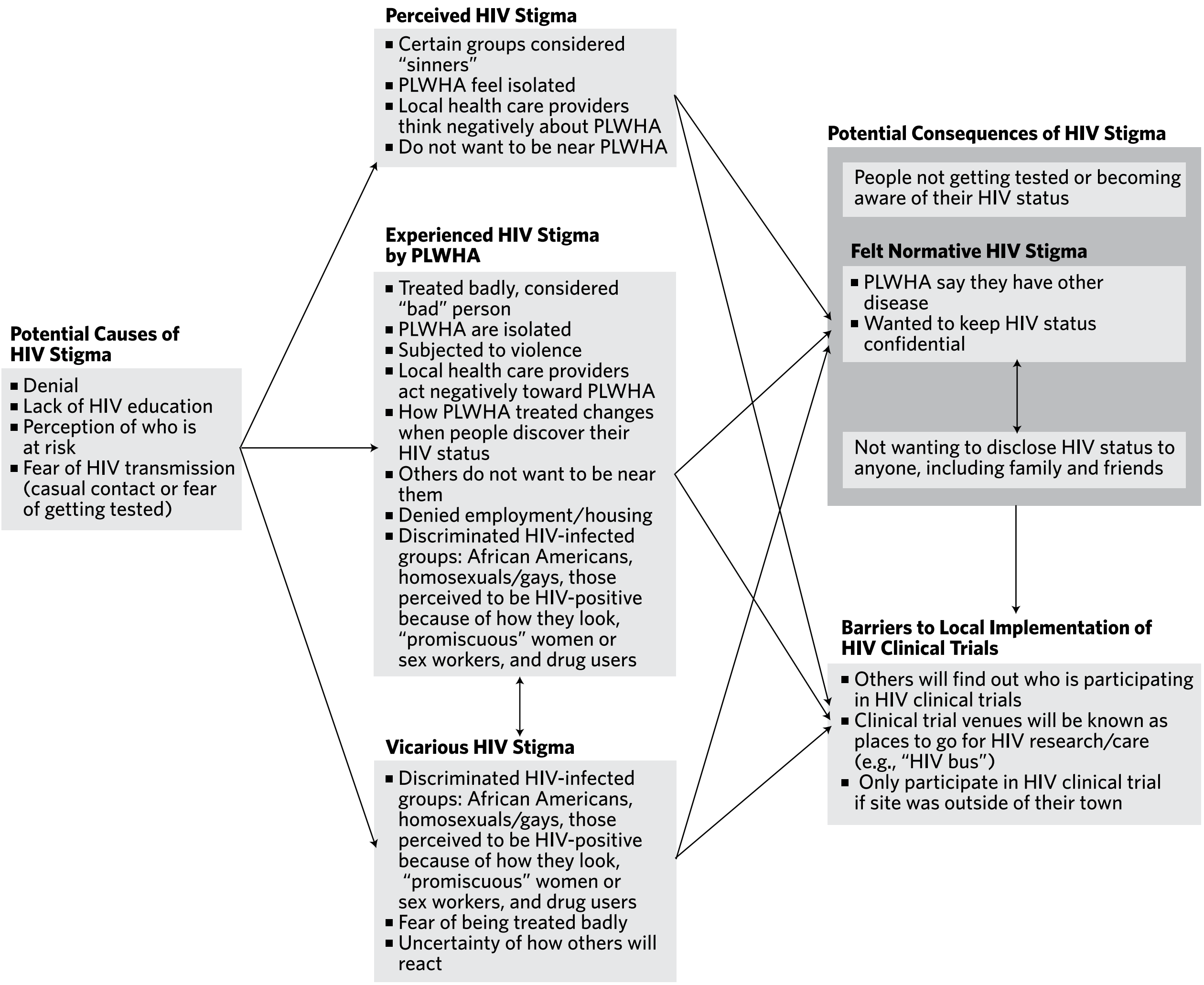
The conceptual model was developed to explore the possible relationships between HIV stigma themes and local implementation of HIV clinical trials. In reviewing co-occurrences between the themes from Table 4, Figure 1 was developed. The following quotes highlight some of the co-occurrences that were demonstrated, providing some indication of the causes of perceived HIV stigma:

> *[In the community, people feel] those who get HIV are the sinners and immoral, and the bad...those who are not worthy of our attention. It is a subject that never enters the church. The church does not know how to talk about it. It is something we are not going to see.* (Community leader focus group participant)

> *It's more of ignorance than anything else and it's just so hard to actually enlighten people because they think that when you say the word AIDS you just sneezed on them... So, they don't want to hear the word. You can't really talk about it amongst people.* (PLWHA participant)

In the first quotation, the church is highlighted as a place in the community that can engender causes of HIV stigma—lack of education, denial that HIV is a problem, perception of

Figure 1.
Exploring HIV Stigma and Its Potential Impact on Local Implementation of HIV Clinical Trials



who is at risk—that, in turn, could affect perceptions about HIV, particularly about who contracts the disease (e.g., "sinners"). The second quotation demonstrates how denial in the community can result in PLWHA feeling isolated (i.e., not having anyone to talk to about living with HIV/AIDS).

The next quotation is about how PLWHA can be treated, demonstrating the relationship between causes of HIV stigma (e.g., fear of HIV transmission and lack of HIV education) and both perceived and experienced stigma:

> *It's not a community that would support it [HIV/AIDS] and by them not being fully aware of the study of it [HIV/AIDS] they'll shun you, they're scared to be in your midst. They won't allow you into their homes and they'll very seldom shake your hand because lack of knowledge of it, they think 'cause they shake your hand they could catch it or if they hug you they could catch it.* (PLWHA participant)

Moreover, asking participants about how PLWHA are treated and which HIV-infected groups are most stigmatized, gauged the extent to which compound or layered stigma—which can be a facet of either experienced or vicarious stigma—plays a role in rural communities' experiences with discrimination toward PLWHA (or those who are perceived to be PLWHA) because of their membership or perceived membership in other discriminated groups. The following quotation reflects the relationship between perceptions of who is at risk (cause) and HIV-infected groups that are discriminated against (experienced or vicarious stigma):

> *And he act bi-sexual. He act gay. No offense to anyone, but he really didn't get into how he got it but I'm thinking, you know, by [being] gay or him just being bi-sexual would put him at risk.* (PLWHA participant)

Felt normative stigma and lack of disclosure are related consequences of HIV stigma for PLWHA in the following quotation example:

> *And it was always the same story. People would rather die and cover it up [HIV/AIDS] than to expose themselves to ridicule, 'cause there's nobody to actually counsel them.* (PLWHA participant)

Lack of disclosure could also be directly affected by causes of HIV stigma, such as lack of knowledge about HIV among loved ones within the community:

> *My family and friends and my church family because they're, like I said, unknowledgeable of it [HIV/AIDS] so I keep it hid…I would let whoever know not to bring it up around my family or whoever because they…it's lack of knowledge of it.* (PLWHA participant)

Since the first phase of our project was to understand the feasibility of implementing HIV clinical trials in rural communities—using either a standing clinic or mobile unit—some of our questions focused on what may make it difficult to implement clinical trials locally. The themes elicited from this inquiry were considered to be more reflective of the consequences of HIV stigma and associated with non-disclosure. As an example, the following quotation illustrates the concern over protecting confidentiality when using a mobile van to conduct HIV clinical trials:

> *I guess it would be okay for people if they really didn't mind people knowing what was going on. 'Cause I don't see how, I mean to me that's going back to confidentiality. I mean if there's a van parked somewhere…I could hear people now, "what is that van for?" or "why you going to that van?" And so it's just like you're opening yourself up. So me personally, I wouldn't [go].* (PLWHA participant)

A community leader focus group participant echoed similar issues with using a mobile van:

> *Once it comes in once or twice…people are going to know the van…And then if they know oh that's [the] AIDS [van] well…"Why is he getting in that? He must have AIDS. Let's go tell the neighbors."*

For some, local implementation of HIV clinical trials may not be feasible because of potential breaches in confidentiality. When asked about their preferences of where to go to participate in HIV clinical trials, a PLWHA participant stated:

> *I would prefer to go to University [A] 'cause I wouldn't want to participate in nothing in my own, oh no, not in my own community, no sir…Because folks talk so much and ohhh, I could see my name around, oh no…I would go out of town where nobody didn't know me…And then I wouldn't have to worry about it being exposed.*

Not reflected in Figure 1, but important because it identifies countering strategies, community leaders, providers, and PLWHA identified some ways in which HIV stigma could be addressed and combated should HIV clinical trials be implemented locally in rural communities. The following examples were elicited from a question asking about views of a mobile van as a mechanism to conduct HIV clinical trials locally:

> PLWHA: *Testing. I think it [mobile van] should do blood pressure. I think it should do a lot of other things because then that way people won't stay focused just on HIV… if they do other testing it would make it justified for me to walk up to the van and get some pills from you or, or*

> *get a box from you and say I went and got tested…And it wouldn't mean so much exposure…*
>
> Providers: *Just a fear of people finding out that van's parked there and what it's here for, 'cause it won't take long. That's why I said if you do it with other services… You could bundle the services…Like medical…or wellness screening…You've got to say something different than say, 'hey I'm the HIV bus.'*
>
> Community leaders: *The community as a whole doesn't even know what the true purpose of that van is…You really have to camouflage…It has an ulterior motive and you also have to have an underground mode of communications for the people that you want to get in, to go to it…so there's no stigma attached.*

Discussion

Although the multifaceted concept of HIV stigma is not new in the field of HIV/AIDS, we never expected the problem of HIV stigma to still be so prominent in US communities in the 21st century. Using existing theoretical constructs, we explored the types of HIV stigma evident in rural, minority communities of North Carolina, but this is the first study to use the guided framework to develop a conceptual model exploring HIV stigma and its potential impact on HIV clinical trial implementation in rural communities. In general, the guided theoretical framework was useful in classifying HIV stigma themes under the constructs of *perceived stigma*, *experienced stigma*, *vicarious stigma*, and *felt normative stigma*. It was not clear, however, if some of the HIV stigma themes—specifically those from PLWHA interviews—could have been classified under *internalized stigma* given that their expression in the textual data did not necessarily reflect PLWHA self-blame or their agreement with the negative attitudes the community may have had about them. We did not consider internalized stigma to be a problem *a priori* and, for this reason, did not ask PLWHA with follow-up probes if they agreed or believed in some of the stigmatizing views reported in their communities. This could be considered a study limitation given that it would be important to understand the extent of internalized stigma in the community for the purposes of targeted stigma reduction interventions at the PLWHA level.

The relationships among *perceived stigma*, *experienced stigma*, *vicarious stigma*, and *felt normative stigma* were significant. In our conceptual model, we were hypothesizing that *felt normative stigma* was more of a consequence of the other HIV constructs *(perceived stigma, experienced stigma, vicarious stigma)*, thus creating possible scenarios where PLWHA are passing as persons who are not infected or have some other non-stigmatized disease (e.g., if PLWHA have significant weight loss, they tell their community they have cancer). *Felt normative stigma* also has implications for local HIV clinical trial implementation because there is a great deal of fear among PLWHA surrounding how to protect the confidentiality of their HIV status from the community. Using a mobile van to conduct clinical trials engendered several concerns relating to how PLWHA, who might benefit from clinical trials, do so without their community finding out they are HIV positive. The next stage of this research will tackle the feasibility of mobile vans or stand-alone clinics as possible mechanisms to conduct HIV clinical trials in rural settings.

While the existing theoretical constructs were useful to classify some of our HIV stigma themes, we could not use this approach with all of our stigma-related themes, particularly the themes that arose from asking the questions about community/personal views on HIV/AIDS and the difficulties of implementing HIV clinical trials locally. For the themes elicited from the community/personal views on HIV/AIDS, we classified the majority as causes of HIV stigma because we felt that issues relating to lack of HIV/AIDS education, or denial that HIV is a problem, do not represent HIV stigma examples by themselves, but have been shown to be associated with HIV stigma.[14,15] We hypothesized, however, that people not getting HIV testing could be a consequence of HIV stigma. Similarly, lack of disclosure to the community, family, or friends, or the issues of confidentiality relating to HIV clinical trials participation were classified as consequences given that these themes do not, by themselves, represent HIV stigma. It is important to address these confidentiality concerns as a component of any intervention that we develop since they have implications for the willingness of PLWHA to participate in local HIV clinical trials, and broader implications for the elimination of health care disparities in HIV care access.

Lastly, the ultimate goal in our project is to develop a mechanism (e.g., mobile van) for conducting HIV clinical trials in local, rural communities. To overcome the issue of possible breaches in confidentiality, both PLWHA and focus group participants advocated going to great lengths to hide or mask clinical trials with other types of services. Thus, if we were to take this recommendation, we could offer a combination of health care services, including HIV clinical trials, on a mobile unit or within a stand-alone clinic, as a means to protect confidentiality of individuals who are seeking HIV clinical trial services. The purposeful masking of HIV services could be a potential problem from a research ethics standpoint, but we would adhere to the principles underlying research integrity and ethics to make implementing local HIV clinical trials a viable option.

As with all studies, this study has its limitations. While we were interested in determining if there were racial/ethnic differences in the feasibility of conducting HIV clinical trials in rural communities, the textual data from the Latino participants (either from one focus group or the four individual interviews) did not suggest any relationships between HIV stigma and HIV clinical trials. Rather, other barriers to HIV clinical participation for Latino PLWHA were elicited that included being undocumented immigrants and separated from their families, dual issues that generally can affect accessing health services for Latinos in the US[16] but did not co-occur with our HIV stigma themes. It is possible that, given our very small subsets of Latino participants, we were not able to capture these data with the interview guide questions we asked.

Another study limitation has to do with generalizeability. HIV stigma demonstrated in these communities in rural North Carolina may be comparable to HIV stigma in other southeastern communities, but this cannot be assumed from these findings. It does appear, however, that HIV stigma in rural North Carolina may be higher than what is reported in US metropolitan areas, particularly for men who have sex with men.[17] Furthermore, we found that the pervasiveness of HIV stigma is uncannily similar to that reported in China or other relatively resource-poor countries/regions in the world.[9,18-20] Future research is warranted to apply our conceptual model to other demographically similar rural US communities, as well as distinctly different communities in the US and other nations as a way to increase the external validity of the HIV stigma themes identified in this study.

HIV stigma continues to be a daunting challenge in US rural communities that seek to bridge the gap in health disparities and access to care, including making HIV clinical trials accessible. Nevertheless, our study findings suggest that efforts to address HIV stigma in rural US settings may be crucial if health disparities are to be addressed. The conceptual model developed will be useful for planning, developing, and implementing HIV stigma reduction interventions at the community and individual levels. **NCMJ**

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PEER-REVIEWED ARTICLE

Reasons for Visits to Emergency Departments for Medicaid and State Children's Health Insurance Program Patients: United States, 2004

Nelson Adekoya, DrPH

Abstract

Objective: *To describe the primary reason for visits to hospital emergency departments (EDs) by patients whose expected source of payment was Medicaid/State Children's Health Insurance Program (SCHIP). The primary reason for an ED visit is particularly important because it reflects the patients' perspective of the problem that necessitated a visit to the ED.*

Study Design: *Retrospective study.*

Methods: *Data for 2004 from the National Hospital Ambulatory Medical Care Survey (NHAMCS) were analyzed for reasons for ED visits. NHAMCS is a national probability sample survey of visits to hospital EDs and outpatient departments of non-federal, short-stay, and general hospitals in the United States. Data are collected annually and are weighted to generate national estimates.*

Results: *An estimated 24.5 million visits were made to hospital EDs in 2004 by patients whose expected method of payment was Medicaid/SCHIP (annual rate = 795 visits/1,000 Medicaid/SCHIP enrollees). Medicaid/SCHIP enrollees aged 25–44 years recorded the highest visit rate at 1,281 visits/1,000 persons. The rate of visits for African American Medicaid/SCHIP enrollees was 36% higher than that of whites (1,016 vs. 746 visits, respectively/1,000 persons). Nine of the 10 leading reasons for ED visits are similar for both Medicaid/SCHIP enrollees and the general population. Among Medicaid/SCHIP enrollees, the leading reason for visits include fever (54 visits/1,000 persons), stomach pain (37 visits/1,000 persons), and cough (35 visits/1,000 persons). For the general population, the leading reasons for visits include stomach pain (19 visits/1,000 persons), chest pain (19 visits/1,000 persons), and fever (14 visits/1,000 persons). For patients with an expected payment source other than Medicaid/SCHIP, 7 of the 10 leading reasons for visits are similar to Medicaid/SCHIP enrollees. For this category, the leading reason for visits are chest pain (18 visits/1,000 persons), stomach pain (16 visits/1,000 persons), and fever (10 visits/1,000 persons).*

Conclusion: *Although Medicaid/SCHIP enrollees shared the same leading reasons with the general population in their visits to EDs, they had higher rates of visits for these reasons. It is possible that the general population is making a higher proportion of visits for the same reasons to settings other than EDs, relative to the Medicaid population. Differences in the age distribution of these populations could also be a factor in the observed visit rates.*

Keywords: *emergency departments; reason for visits; National Hospital Ambulatory Medical Care Survey; Medicaid; SCHIP*

Emergency department (ED) usage is a key indicator of the performance of the health care system. ED use can be used to evaluate health policies that affect access to care as well as prevent illness and injuries. Medicaid/State Children's Health Insurance Program (SCHIP) are two federal/state programs for low-income people or populations that are categorically eligible for services. Nationally, Medicaid/SCHIP recipients are of particular concern because one of every five visits to EDs is made by persons enrolled in these programs.[1] During 1994–2004, enrollees in the programs increased from an estimated 14 million to 31 million.[2] In addition, Medicaid expenditures account for the largest and fastest growing category of state expenditures, representing 21.9% in 2004.[3] Proposals being considered in the US Congress have called for cuts of up to $10 billion over five years; funding reductions in Medicaid could enlarge state deficit gaps and force states and localities to make program cuts and increase taxes.[3]

Anecdotal reports have described Medicaid/SCHIP recipients and their use of health services.[4,5] For example, in their study of access to pediatric care and ED, Johnson and Rimsza indicated that children covered by Medicaid

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were less likely to use the ED than children with private insurance.[4] However, Phelps and colleagues, in their study of factors associated with ED utilization for nonurgent pediatric problems, showed that those with Medicaid insurance were more likely to view the ED as the usual site of care.[5] Nationwide, ED visit rates were higher among Medicaid/SCHIP enrollees in comparison with Medicare, those with no insurance, and those with private insurance.[1] Nationally, ED visits remain a major public health concern because estimated visits increased from 93.4 million in 1994 to 110 million visits in 2004.[1] Reasons for the continuing rise in ED visits remain elusive,[6,7] and not all the increases in ED visits can be attributable to increases in the US population.

Medicaid enrollees have been reported to comprise a disproportionate share of ED visits for asthma, chronic obstructive pulmonary disease, congestive heart failure, diabetes, and hypertension,[8] and enrollees have been cited as responsible for a high rate of inappropriate use of EDs.[9] Previous research[8] has been limited to the ambulatory care–sensitive conditions to gain knowledge into preventable hospitalizations, and the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics' (NCHS) publications[1,10] currently does not specifically address reasons for visits among the Medicaid population. To fill in part of the gap in what we know about emergency room use, the author analyzed the emergency department component of the National Hospital Ambulatory Medical Care Survey (NHAMCS-ED) to obtain information about what the most common symptoms are that present in the ED for Medicaid patients.

Methods

Data for this report are derived from the 2004 NHAMCS-ED survey and were collected from December 29, 2003 through December 26, 2004.[1] NHAMCS-ED, an annual survey conducted by CDC's NCHS, is a national probability sample survey of visits to hospital emergency and outpatient departments of non-federal, short-stay, and general hospitals in the United States.[1] NHAMCS uses a four-stage probability design of primary sampling units, hospitals that had EDs, emergency service areas within EDs and clinics, and patient visits within emergency service areas and clinics.[1]

In the 2004 survey, 457 emergency service areas participated. A total of 452 of the emergency service areas responded fully, yielding a response rate of 97% and an overall unweighted two-stage sampling response rate of 89%.[1] At each sampled ED, staff were asked to complete encounter forms for a systematic random sample of patient visits occurring during a randomly assigned four-week reporting period. Up to three reasons for an ED visit could be reported, using the patient's own words if possible. Text entries were converted to "reason for visit codes" by using a system developed by the American Medical Records Association under the auspices of CDC/NCHS.[11] Reason for visit is particularly important because it reflects the patients' concern that necessitated a visit. In addition, this information assists in patient triage (resource allocation), quality assurance, and ED management. In 2004, a total of 36,589 patient record forms were completed at EDs.[1]

Data are weighted to generate national estimates by using three estimation processes: inflating reciprocals of the sampling selection probabilities, adjusting for non-response, and applying a population weighting ratio adjustment.[1] This multistage estimation procedure produces unbiased estimates. A total of 8,707 patient record forms for which Medicaid/SCHIP was listed as the expected source of payment were identified. The primary reason-for-visit field recorded per patient at visit was used in this analysis.

Visit rates were calculated by age group, sex, race, census region, and for leading reason for visit for Medicaid/SCHIP enrollees. A comparative table, reflecting leading reasons for visits, is presented for Medicaid/SCHIP enrollees, general population, and patients with an expected payment source other than Medicaid/SCHIP. Denominators for the calculation of rates were provided by CDC/NCHS.[12] Appropriate 95% confidence intervals for the rates were determined by calculating the relative standard errors for the estimates of visits, using the coefficients provided by NCHS.

Data presented in this research include Medicaid and the State Children's Health Insurance Program (SCHIP) visits to emergency departments. Medicaid and SCHIP were combined because in approximately one-third of states, SCHIP is a Medicaid expansion program; in another one-third, SCHIP is a stand-alone program; and in the last third, it is a combination of both. Charges paid in part or in full by this plan include payments made directly to the hospital and payments reimbursed to the patient. In addition, these charges include those covered under a Medicaid-sponsored prepaid plan or SCHIP.

Results

Total Visits for Medicaid/SCHIP Enrollees

An estimated 24.5 million visits met the definition of Medicaid/SCHIP as a primary source of payment (see Table 1). This number represents 22% of the estimated 110 million ED visits in 2004. Eighty-nine percent of Medicaid/SCHIP enrollee visits relate to initial visits, and 7% were follow-up visits. ED visit rate for Medicaid/SCHIP enrollees was significantly higher than ED visits nationwide (795 vs. 382 visits, respectively/1,000 persons).

Although children under the age of 15 had the highest percentage of visits (40%), adults aged 25–44 had the highest rate of visits (1,281 visits/1,000 persons). The rate of visits for females was slightly higher than the rate for males (822 vs. 757 visits, respectively/1,000 persons). Whites made approximately 63% of ED visits; however, the visit rate was significantly higher among African Americans than among whites (1,016 visits vs. 746 visits, respectively/1,000 persons). An estimated 10 million ED visits occurred at southern US hospitals (41%), but the highest rate of ED visits was recorded

Table 1.
Number and Rate of Visits to Hospital Emergency Departments (EDs) for all Payment Categories and for Those With an Expected Pay Source of Medicaid/SCHIP, National Hospital Ambulatory Medical Care Survey (NHAMCS) — United States, 2004

Characteristic	Estimated number of visits for all payments to EDs	Rate of visits to EDs/1,000 persons for all payment methods[a] (95% confidence interval)	Estimated number of Medicaid/ SCHIP-paid visits to EDs	Rate of visits to EDs/1,000 persons covered by Medicaid/ SCHIP[b] (95% confidence interval)	Estimated number of non-Medicaid/ SCHIP-paid visits to EDs	Rate of visits to EDs/1,000 persons not covered by Medicaid/ SCHIP[c] (95% confidence interval)
Age group (years)						
0–14	22,942,000	378 (324–432)	9,882,667	637 (602–637)	13,050,000	289 (273–305)
15–24	17,931,000	441 (393–489)	4,280,869	903 (853–953)	13,650,000	381 (360–402)
25–44	32,105,000	391 (351–431)	6,226,771	1,281 (1,211–1,351)	25,871,000	335 (316–354)
45–64	21,506,000	306 (276–336)	3,321,014	1,026 (975–1,077)	18,184,000	272 (257–287)
≥ 65	15,732,000	454 (410–498)	778,239	322 (306–338)	14,954,000	465 (439–491)
Sex						
Female	59,896,000	406 (366–446)	14,590,659	822 (781–863)	45,307,000	350 (331–369)
Male	50,320,000	357 (323–391)	9,898,901	757 (719–795)	40,420,000	316 (299–333)
Race[d]						
White	81,762,000	352 (316–370)	15,417,370	746 (709–783)	66,344,000	310 (293–327)
African American	24,898,000	689 (595–783)	8,173,934	1,016 (965–1,061)	16,724,000	603 (570–636)
Region						
South	41,150,000	397 (323–471)	10,044,853	868 (825–911)	31,105,000	341 (322–360)
Midwest	26,806,000	414 (377–488)	5,440,782	908 (863–953)	21,365,000	337 (318–356)
Northeast	22,274,000	414 (334–494)	5,203,061	966 (863–953)	17,071,000	358 (338–378)
West	19,986,000	301 (245–357)	3,800,864	483 (459–507)	16,185,000	293 (277–309)
Total	110,216,000	382 (347–417)	24,489,560	795 (755–835)	85,726,000	333 (314–352)

a. Denominator is the noninstitionalized civilian population and includes the Medicaid/SCHIP population.

b. Denominator is persons covered by Medicaid/SCHIP.

c. Denominator is persons not covered by Medicaid/SCHIP

d. Data not displayed for other race category (does not meet reporting requirement).

in the northeast (966 visits/1,000 persons). The lowest rate of visits was in the west (483 visits/1,000 persons).

Medicaid Enrollees' Five Leading Reasons for ED Visits (see Tables 2 and 3, pages 126 and 127)

Fever: Seven percent of ED visits for this population related to fever, and 92% of fever-related visits were among those under 15 years of age. Fever is the single highest reason for ED visits among those under 15 years of age, representing 16% of their visits (99 visits/1,000 persons). Variation in rates of fever-related visits existed by race, sex, and geographic region. The fever-related visit rate was higher among African Americans compared with whites (65 vs. 51 visits, respectively/1,000 persons). The visit rate for females was 70% higher than for males (46 vs. 27 visits, respectively/1,000 persons). The south recorded the highest visit rate compared with other regions (78 visits/1,000 persons).

Stomach and abdominal pain: This condition represented 5% of total visits, with the highest visit rate among persons aged 25–44 years (84 visits/1,000 persons). The visit rate was higher among African Americans as compared with whites (44 vs. 37 visits, respectively/1,000 persons) and among females (49 visits/1,000 persons).

Cough: Four percent of visits were related to cough, and the highest rate of visits was among youth under the age of 15 (49 visits/1,000 persons). Eight percent of visits among those under the age of 15 related to cough. For all Medicaid/SCHIP enrollees, visit rates were higher among African Americans than whites (40 vs. 36 visits, respectively/1,000 persons) and higher among females than males (49 vs. 9 visits, respectively/1,000 persons).

Chest pain: Visits relating to chest pain represented 4% of Medicaid/SCHIP enrollee ED visits. Adults aged 45–64 years recorded the highest visit rate (96 visits/1,000 persons). Sixty percent of visits were among whites, but the visit rate was higher among African Americans than whites (44 vs. 27 visits, respectively/1,000 persons). Females recorded the highest percentage of visits (64%) and had a higher visit rate than males (37 vs. 11 visits, respectively/1,000 persons).

Vomiting: Visits relating to vomiting represent 3% of visits, with 75% of visits recorded among youth aged under 15 years of age. For youth under the age of 15, vomiting visits represents 6% of ED visits among Medicaid/SCHIP enrollees. The highest rate of visits was among youth aged under 15 years of age (40 visits/1,000 persons). As with the majority of other conditions, the visit rate was higher among African Americans compared with whites (40 vs. 24/1,000 persons). Females had the highest rate of visits compared with males (21 vs. 15 visits, respectively/1,000 persons). By region, the northeast had the highest rate of visits (34 visits/1,000 persons).

National Data Versus Medicaid Specific Visit Data

As presented in Table 2, after examining nationwide and Medicaid/SCHIP enrollee-specific visits, most of the 10 important reasons for visits are similar for the two payment-type groups: fever, abdominal pain, cough, chest pain, vomiting, headache, ear infection, sore throat, and back symptoms. The 10 leading reasons represent about one-third of Medicaid/SCHIP enrollee visits and 29% among the general population. However, visit rates were markedly higher among Medicaid/SCHIP enrollees for each reason of visit.

Table 2.
Ten Leading Primary Reasons for Visits to Emergency Departments (EDs) for United States and Medicaid/SCHIP Enrollees per 1,000 Persons, NHAMCS — United States, 2004

Primary reason for visit	Estimated visits (%)	Rate of visits/ 1,000 persons
United States, Total[a]		
Chest pain	5,550,000 (5.0)	19
Stomach and abdominal pain	5,356,000 (4.9)	19
Fever	4,167,000 (3.8)	14
Headache	2,895,000 (2.6)	10
Back problems	2,838,000 (2.6)	10
Cough	2,702,000 (2.5)	9
Shortness of breath	2,553,000 (2.3)	9
Vomiting	2,524,000 (2.3)	9
Sore throat	1,811,000 (1.6)	6
Earache or ear infection	1,706,000 (1.5)	6
All other reasons	78,118,067 (70.9)	382
Medicaid/SCHIP enrollees[b]		
Fever	1,676,646 (6.7)	54
Stomach and abdominal pain	1,123,615 (4.5)	37
Cough	1,086,297 (4.4)	35
Chest pain	931,532 (3.7)	30
Vomiting	832,756 (3.3)	27
Headache	608,218 (2.4)	20
Earache or ear infection	576,345 (2.3)	19
Skin rash	555,034 (2.2)	18
Sore throat	495,267 (2.0)	16
Back symptoms	490,560 (2.0)	16
Shortness of breath	435,228 (1.7)	14
All other reasons	16,113,290 (64.6)	523
Other than Medicaid/SCHIP[c]		
Chest pain	4,619,000 (5.4)	18
Stomach and abdominal pain	4,233,000 (4.9)	16
Fever	2,490,000 (2.9)	10
Back symptoms	2,347,000 (2.7)	9
Headache	2,287,000 (2.7)	9
Shortness of breath	2,118,000 (2.5)	8
Upper extremity laceration	1,790,000 (2.1)	7
Accidents/injury (e.g., fall)	1,738,000 (2.0)	7
Vomiting	1,691,000 (2.0)	7
Cough	1,616,000 (1.9)	6
All other reasons	60,799,000 (70.9)	333

a. Denominator is the noninstitionalized civilian population, and includes the Medicaid/SCHIP population.

b. Denominator is persons covered by Medicaid/SCHIP.

c. Denominator is persons not covered by Medicaid/SCHIP.

National Data, Patients with an Expected Payment Source Other than Medicaid/SCHIP Versus Medicaid Specific Visit Data

When examined in tandem, fever and stomach pain were most common among these three population categories. While noteworthy differences were noted in visit rates for these conditions, those exhibited by fever (among < 15 years old), race, gender, and region are particularly important among Medicaid/SCHIP enrollees (see Tables 3-5, pages 127-129).

Discussion

Examining the reason-for-visits data is critical as an approach to educate users about emergency departments, identify individual risk factors, intensify early detection and control of risk factors, and reduce risk. A major finding of the research reported here is that the leading reasons for visiting EDs is not different for Medicaid/SCHIP patients and the general population. Among Medicaid/SCHIP enrollees, fever, cough, and vomiting visit rates were highest among youth under 15 years of age; stomach pain visit rates are highest among persons aged 25–44 years; and chest pain visit rates are highest among those aged 45–64 years. For the five leading reasons for visits, rates were higher among African Americans and females. Although visit rates were generally higher among Medicaid/SCHIP enrollees compared with the general population, factors that contribute to these findings are multifaceted. Lowe and colleagues recently looked at the association between primary care characteristics and ED use among Medicaid managed care organizations and concluded that patients enrolled in primary care practices with extended evening coverage were 20% less likely to use the ED. The authors found that focusing on system issues (e.g., primary care access, scope of services, etc.) had the propensity to reduce ED use.[13] A government report also recently acknowledged that crowding continues to be a major problem in the EDs and that the primary reason was the inability of hospitals to move patients from EDs to inpatient beds,[14] further attesting to the system issues identified by Lowe and colleagues.[13] In his recent review of ED visits, Bernstein concluded that insurance status, race, and ethnicity are minor determinants of ED use and that health policy goals should focus on accessibility, convenience, and high quality of care in all settings.[15] Irrespective of these factors, efforts should be directed to the subgroups with high visit rates.

This study has multiple implications for health care policies and practice. First, the extent to which the lack of a statewide electronic data system impedes ED performance measures and indicators across multiple states should be studied. This is of particular importance to Medicaid/SCHIP enrollees both in metropolitan and rural areas. According to the estimates generated in the current study, 86% of visits

Table 3.
Rates[a] of Emergency Department Visits for Medicaid/SCHIP Enrollees per 1,000 Persons for Primary Leading Reason for Visit, by Age Group, Race, Sex, and Region, NHAMCS — United States, 2004

	Fever	Stomach and abdominal pain	Cough	Chest pain	Vomiting
Age group (years)					
< 15	99	11	49	3	40
15–24	9	65	16	32	14
25–44	9	84	28	72	22
45–64	12	62	27	96	9
≥ 65	[b]	15	12	28	[b]
Race					
White	51	37	36	27	24
African American	65	44	40	44	40
Sex					
Female	46	49	33	37	21
Male	27	9	16	11	15
Region					
Northeast	47	43	44	38	34
Midwest	48	48	34	39	33
South	78	37	45	31	31
West	29	23	17	18	12

a. Denominator is persons covered by Medicaid/SCHIP.

b. Does not meet reporting requirements.

Table 4.
Rates[a] of Emergency Department Visits for All Payment Enrollees per 1,000 Persons for Primary Leading Reason for Visit, by Age Group, Race, Sex, and Region, NHAMCS — United States, 2004

	Chest pain	Stomach and abdominal pain	Fever	Headache	Back problems
Age group (years)					
< 15	2	9	52	5	1
15–24	13	29	6	13	11
25–44	21	23	3	15	15
45–64	27	16	3	8	11
≥ 65	35	19	7	8	9
Race					
White	17	17	13	8	9
African American	37	31	27	23	16
Sex					
Female	20	25	14	13	10
Male	19	12	15	7	10
Region					
Northeast	18	17	12	9	10
Midwest	19	19	14	10	9
South	21	19	18	12	12
West	17	20	11	8	7

a. Denominator is the noninstitionalized civilian population and includes the Medicaid/SCHIP population.

(20,962,663 visits) were from the metropolitan standard areas. Targeted surveys of subpopulation groups in states lacking electronic ED data should be encouraged because population characteristics might be different from the national and regional data reported in this study. Only 26 states have electronic statewide ED data systems.[16]

Second, although there may be myriad alternative explanations for the underlying results reported in this report, there are numerous conflicting studies on the impact of outpatient services and ED use in the literature. Weber and colleagues recently remarked that the success of efforts to decrease ED use might depend on improving delivery of outpatient care.[6] It should be noted that this study did not provide an indication of how providing health insurance to an individual affects a person's health status. The data analyzed in this study did not contain an empirical measure of the health status of those persons who go to the ED, nor did it assess how an empirical measure of the health status of an individual who is uninsured changes after he/she is provided health insurance.

Third, the finding of higher visit rates for all visit reasons by females is interesting and cannot be explained by the data captured in the surveillance system. Although rates of hospitalizations are higher for females aged 18–44 years because of pregnancy and childbirth,[17] the reasons for visits identified in this study reveal the need for future research to address why women use the ED more than men. Just because women use the ED more does not mean it is inappropriate; the same argument applies to ED use among Medicaid enrollees. There are three broad possibilities:

1) Medicaid/SCHIP enrollees (or women, analogously) are overusing the ED.
2) Non-Medicaid/SCHIP enrollees (or women, analogously) are underusing the ED.
3) Medicaid/SCHIP enrollees (or women) are simply higher risk and sicker, so they are appropriately using the ED more than non-Medicaid individuals.

Fourth, the lower visit rates identified among adults over age 65 may reflect availability of the Medicare payment plan, which may prevent the need to go to the ED for treatment.

Lastly, the reason for markedly different results in visit rates for Medicaid/SCHIP enrollees and the general population could be partly explained by the different age distributions. For example, 50% of Medicaid/SCHIP enrollees are under 15 years old, in comparison to the general population (21%) and patients with an expected payment source other than Medicaid/SCHIP (18%) for this age category. The high visit rates for fever transcends race, gender, and region even when the Medicaid/SCHIP population is compared to the other populations.

Table 5.
Rates[a] of Emergency Department Visits for Other than Medicaid/SCHIP Enrollees per 1,000 Persons for Primary Leading Reason for Visit, by Age Group, Race, Sex, and Region, NHAMCS — United States, 2004

	Chest pain	Stomach and abdominal pain	Fever	Back problems	Headache
Age group (years)					
< 15	2	8	36	1	5
15–24	10	24	6	9	10
25–44	18	19	3	13	13
45–64	24	13	3	10	7
≥ 65	36	19	7	9	7
Race					
White	16	16	9	9	8
African American	35	27	16	15	22
Sex					
Female	18	22	9	9	11
Male	18	11	10	15	7
Region					
Northeast	16	14	8	9	8
Midwest	18	16	11	9	9
South	20	16	11	11	11
West	17	19	8	7	7

a. Denominator is the noninstitionalized civilian population, and excludes the Medicaid/SCHIP population.

This study also has certain limitations. First, because of the NHAMCS design, state-level data are unavailable. Second, an item in the survey asks for "primary expected source of payment" and that is what was used in this research. It is possible that the primary expected source of payment was different from who eventually paid for the visit. Third, a difference exists between the patient's reason for visiting the ED and the final diagnosis. The reason is useful in understanding what caused the patient to come to the ED, but the diagnosis typically reveals what the physician's opinion is regarding the ailment. Fourth, this study did not determine appropriate use or misuse of EDs. Previous research has indicated that Medicaid/SCHIP enrollees were more likely to use EDs as the usual site of care, despite the fact that visits to the ED for non-urgent conditions can be managed by primary care providers.[5] Access to care has been associated with decreased ED usage, regardless of insurance status.[4] However, examining how to keep patients satisfied with their usual source of care, which Sarver and colleagues reported are more likely to contribute to non-urgent ED visits,[18] should be studied. Finally, multivariate regression analysis could have been used to identify what parts of the increased rates is due to Medicaid/SCHIP, as opposed to numerous covariates such as age group, race, region, metropolitan vs. rural, etc. In addition, it would also be interesting to look at the difference between all non-Medicaid/SCHIP patients vs. Medicaid/SCHIP payments and statistically test difference in means. Separate research is looking at these important research methods.

Although NHAMCS-ED provides accurate data regarding the differences in health status, access to care, and health services experienced by multiple population groups, state epidemiologists and program directors should identify and focus on specific indicators amenable to change at their policy or program level (e.g., quality of care, state and local level estimates, strengthening health promotion and disease prevention, and expanding health education opportunities). Additionally, the recent requirement regarding citizenship documentation for Medicaid/SCHIP enrollment which has resulted in enrollment declines in several states should be examined.[19] **NCMJ**

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POLICY FORUM

Long-Term Care: Are We Ready to Meet Expected Needs and Demand?

Introduction
Thomas C. Ricketts III, PhD, MPH; Christine Nielsen, MPH

Issue Brief: Long-Term Care Challenges Ahead for North Carolina: 2010 and Beyond
Gordon H. DeFriese, PhD; Polly Godwin Welsh, RN-C

> ***In North Carolina, and across the nation, people ages 65 and older represent the fastest growing segment in the population...Given this inevitable demographic shift... the state is racing to determine how to best meet their needs.***

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The Challenges of Regulation in Long-Term Care
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Bob Jackson

Introduction

POLICY FORUM

Long-Term Care: Are We Ready to Meet Expected Needs and Demand?

In North Carolina, and across the nation, people ages 65 and older represent the fastest growing segment in the population. Nearly 2.3 million baby boomers (those born between 1946 and 1964) are now reaching retirement age in North Carolina. North Carolinians are also living longer than ever before and more of us are living with chronic disease and disability. Given this inevitable demographic shift, and considering the unique characteristics of the elderly component of our population, the state is racing to determine how to best meet their needs. Research suggests that there will be a growing demand for services and supports in long-term care, transportation, education, health, and nutrition for the elderly. More people will require either community-based or institutionalized care, both which have the potential to place significant financial and emotional burdens on family members as well as put pressure on government budgets.

Currently, the long-term care industry is very complex, highly regulated, and quite fragmented. This situation often makes it difficult for individuals and their family members to determine the best way to meet their current or anticipated long-term care needs. There are major choices to consider when planning for long-term care, including whether or not to be cared for at home or in long-term care facility. Evidence tells us more and more individuals are interested in receiving care in the comforts of their own home as opposed to seeking care at assisted living or long-term care facilities. This preference has led to an “aging in place” industry which encompasses personal care services and home health care provided by direct care workers including nurse aides, home health care aides, and personal care workers who work outside the walls of traditional long-term care facilities. However, due to the added costs of this option or the inability of informal caregivers to effectively function in this way, this is not always an option.

When the needs of individuals can no longer be met by their home or community-based caretakers, individuals may be transitioned into long-term care, such as a skilled nursing or assisted living facility. We have to recognize that there is often stigma surrounding nursing homes and concerns with quality and the level of compassion in the care found in these institutions. The long-term care sector must deal with the public’s demands for greater regulation combined with their often conflicting call for greater choice and freedom, while still offering affordable and desirable options. Fortunately in North Carolina, a combination of state, local, and private organizations have been effective in creating and implementing innovative approaches for the regulation of facilities, the organization and coordination of services, and even in pioneering staff training in long-term care facilities—all with the aim to improve patient safety, quality of care, and overall satisfaction.

In this issue of the *North Carolina Medical Journal* we hear from various individuals involved in the long-term care industry, including nurses, lawyers, policymakers, and other interest groups who describe current and future issues in North Carolina and possible ways to address them. Additionally, we explore how North Carolina is leading the way in training and attracting a qualified long-term care workforce through new and innovative programs. Through this collection of articles, we hope to present a broad range of views and opinions, with the ultimate goal of drawing some much-needed attention to the important issues within the field of long-term care.

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ISSUE BRIEF

Long-Term Care Challenges Ahead for North Carolina: 2010 and Beyond

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Given the minimal attention paid by the news media to long-term care issues in the recent deliberations about national health care reform, one would think that these are problems of relatively small importance to the nation's future health services needs. But the reality is that both federal and state governments spend substantial sums of money each year to provide long-term care to persons (particularly the elderly) with disabilities, and the number of persons needing these services is expected to grow substantially over the coming decades. Estimates are that the number of older people with disabilities will nearly double over the next 20 years. National public sector expenditures for long-term care in 2007 were approximately $150 billion, and these expenditures are expected to increase to about $295 billion by 2030.[1] It is estimated that one in five North Carolinians over the age of 65 will be admitted to a nursing home for some period of time.[2]

In this issue of the *North Carolina Medical Journal,* Mary Anne P. Salmon and Gary M. Nelson make clear the extent to which the need and demand for long-term care services in several categories are likely to increase dramatically in coming decades. Jose Gonzalez also describes the increasing burden of chronic disease and disability which are major contributing factors in these increasing demands for long-term care services.

Public financing of long-term care services is a critical component of this level of care. Although families of individuals needing care while living at home are providing a great volume of these services at a substantial cost to themselves, they could potentially be leaving many critical needs unmet. Estimates as high as 85% indicate that older adults requiring disability-related assistance rely on unpaid care from family members at home.[2] Yet no other part of the health care system in this country is as dependent on public financing as long-term care. As Joshua Weiner at RTI notes in his 2009 testimony to the US Senate Committee on Finance, "In 2008…77% of nursing home residents had their care covered by either Medicare or Medicaid."[3]

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The need for either in-patient or home-based long-term care can arise in a most unpredictable and catastrophic manner. Hence, the urgency of dealing with these situations can affect almost every family. Yet the purchase of long-term care insurance has not been widely adopted as a personal strategy for preparing for the likelihood of such expenditures. Nationally, only 16% of adults over age 65 with an annual income greater than $20,000 have purchased long-term care insurance.[4] In North Carolina the percentage is much lower. Most of those who purchase long-term care insurance are younger, wealthier, and more educated than their parents. Purchase rates of long-term care insurance have eroded in recent years among middle-income people, implying that this type of insurance is not seen as providing a

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service or value commensurate with its cost, although some 70% of those who turn 65 will have long-term care needs as they grow older.[4]

The market for long-term care insurance is one area where public policy might be able to produce the incentives that would encourage more people to buy this coverage, even though many assume that Medicare and Medicaid will cover their need for services when these services are required. North Carolina is likely to join with 33 other states to participate in the Long-Term Care Partnership Program, first initiated by the Robert Wood Johnson Foundation in several states. Under this program, a collaboration will be forged between the North Carolina Division of Medical Assistance (which operates the state's Medicaid program) and the North Carolina Department of Insurance. If this program becomes a reality, citizens (usually middle- and upper-income groups) will be offered an opportunity to buy long-term care insurance that can cover the cost of long-term care up to a maximum level of expenditure, and these personal expenditures will then be used to offset the spend-down requirements for establishing Medicaid asset levels. It is assumed that such arrangements will eventually reduce the demand for public funds and ultimately save Medicaid dollars.

A Bewildering Array of Consumer Choices

When the need for long-term care services arises, there are many choices and options that may be considered. Often there is pressure from hospital discharge planners to move a patient out of acute care facilities into another level of care. Quite often, it is the range and types of options, as well as the personal financial implications of any of these options, that remain unclear, and families and individuals find it nearly impossible to anticipate what will happen were any particular option chosen. The long-term care sector is complex, involving a wide array of both nonprofit and for-profit service providers, and multiple levels of federal and state regulatory agencies surveying every component of care. As indicated by Senator William R. Purcell in this issue of the *Journal*, efforts by public sector decision-makers to address issues related to any component of long-term care will likely encounter forceful representational advocacy from the provider community and often strong public interest advocacy as well.

Public images of formal care options are often negative, with most Americans voicing their fears and apprehensions over admission to a nursing home; but there is considerable confusion over the definition of those facilities or the level of services provided by them. The AARP Public Policy Institute estimates that about 84% of persons over the age of 50 would prefer, all other things being equal, to "age in place," and "never go there."[5] Even 87% of those who have existing disabilities would prefer to live in their own homes. Bill Herzog, Glenn Wilson, and Nan Rideout discuss in their commentary efforts now underway in some North Carolina communities to facilitate the efforts of some to age in place through the establishment of concierge help lines and referral services that link those needing gap-filling services with vetted and approved providers of those services.

As a result of these public perceptions of long-term care, there is a large and growing demand for personal care services and home health care to enable individuals to live in their homes with various types of services and assistance with both personal (i.e., non-medical) and medical care needs. When home and community-based care is no longer able to meet individual needs, there are increasing expectations that skilled nursing care facilities (nursing homes) will offer these services in a manner that enables the resident of these facilities to live much as one would at home in the larger community. Such are the challenges of meeting public expectations associated with long-term care. Public sector decision-makers are beset with a constant set of demands for greater regulation of these facilities and programs, while at the same time having high expectations for increased availability and affordability of such services and facilities.

It is in the context of such public expectations, and the complexities of answering these demands, that this issue of the *North Carolina Medical Journal* seeks to covey some of the positive steps being taken to address these important issues in our state.

Who are the Users of Long-Term Care Services?

While most would think that the majority of long-term care services are provided to elderly persons, the reality is that people of all ages are clients of long-term care providers. Any person with a serious illness, injury, or disability may have a need for long-term care. Nationally, approximately 10 million persons were estimated to need long-term care in 2005. Of this number, about 40% were working-age adults or children. Dual-eligible persons receiving health care paid for by both Medicare and Medicaid include 5.6 million people over the age of 65 and another 3.2 million under the age of 65. Medicaid typically covers two-thirds of nursing home residents and one in five persons under age 65 with chronic disabilities.[6]

Even among those older than 65 years of age, there is considerable variability in the need for long-term care. It is estimated that among those turning 65 today, about 30% will never need long-term care. Yet 20% will require as many as five years of care. As Judith Feder pointed out in her Congressional testimony on health reform's implications for long-term care, "half the people turning age 65 today can be expected to live their lives without spending anything on long-term care; another quarter are expected to spend less than $10,000 (in present discounted value)."[2] At the other end of the spectrum, 6% can expect to face over $100,000 (in present discounted value) in long-term care expenditures.[7]

The Key Components of Long-Term Care

So what are the essential elements of what might be defined as the "long-term care delivery system?" Typologies of such service delivery programs depend on the state in which the services are sought or provided. Some types of long-term care services are often overlooked. The point is that long-term care is *not* "just nursing home care." Beyond in-home, informal family care, formal assistance may be obtained from one or more of the following types of service providers/programs:

- **Skilled nursing facilities (nursing homes)**
  Offering 24-hour professional nursing care for both sub-acute (Medicare covered, short-stay) and longer term chronic care (paid by private insurance, self-paid, or Medicaid). Nursing homes include both for-profit and nonprofit, as well as government-owned facilities. Though these facilities are often thought to provide mainly longer-term residential care, the increasing involvement of these facilities in short-term, sub-acute, and rehabilitative care as hospitals have been forced to discharge patients earlier in their trajectories of care, has meant that the number and frequency of new admissions and discharges of residents of nursing homes have increased. In this issue of the *Journal*, Polly Godwin Welsh, Carol Durham, and Mandy Richards describe some of the efforts North Carolina nursing homes are making through the use of new technologies to increase the skills and team functioning of nursing personnel and efforts to enrich the daily life experiences of their residents.

- **Rehabilitation hospitals or facilities**
  Facilities, often owned by or affiliated with acute care hospitals, whose sole function is to provide post-hospitalization rehabilitation care (which would usually include physical and occupational therapy) on a short-term basis.

- **Transitional care units**
  Facilities often operated by hospitals for the benefit of patients no longer needing acute medical/nursing care, but who may need various forms of rehabilitation or palliative care, especially pain management or symptom control. Hospice care organizations that offer in-patient services are another example of this type and level of care, some of which are hospital-affiliated.

- **Assisted living facilities/adult care homes**
  These facilities are usually free-standing, multi-unit organizations offering full-time residential care for those who may need continuous physical and/or social support, but not 24-hour skilled nursing care. Technically, an assisted living facility is one that serves two or more unrelated adults, provides at least one meal per day, and provides housekeeping and personal care services. Adult care homes are facilities principally providing 24-hour custodial care (including meals, housing, housekeeping, etc.), health monitoring, and some assistance with medication administration.

- **Continuing care retirement communities (CCRCs)**
  Often referred to as "life care communities," these facilities range in size, but are separately licensed to operate assisted living and skilled nursing care components. They often offer entering residents the option of independent living cottages, apartments, and other accommodations. CCRCs have in place procedures and counseling associated with in-house transitions from one level of care to the next. For those in independent living arrangements, a number of amenities are usually offered for dining, recreation, education, and general life enrichment. Residents pay a one-time entry fee, as well as a monthly fee for these comprehensive services. In this issue of the *Journal*, Patricia E. Sprigg provides a commentary on what CCRCs represent as a component of long-term care and the policy issues surrounding the rapid growth of these facilities in our state.

- **Community-based in-home nursing care (home health care)**
  Visiting nurse services, as prescribed by a physician, are offered by a number of private (either for-profit or nonprofit) firms. Nurses may visit on a schedule recommended by a physician to administer care such as giving injections, monitoring vital signs, and providing supervision to home care aides or homemakers. In addition, such companies may also provide inhalation or other assistive services in the patient's home. Some hospice organizations provide their services for clients who choose to live at home at the end of life.

- **Community-based in-home personal care**
  Services provided by both for-profit and nonprofit companies/agencies that are of a non-medical/nursing nature (e.g., laundry, meals, housekeeping, shopping, and transportation). These activities of daily living services are covered by Medicaid so long as at least one such service is deemed by a medical care provider as essential to one's ability to live independently in a home or community setting.

- **Adult daycare facilities**
  This is an option for frail older adults who may require daytime supervision or as a form of respite care for caregiving family members who work or have other responsibilities outside the home. Some of these facilities may provide transportation to a central location. Services usually include some meals and participants may come to such facilities on a daily or less regular basis.

This list represents the major options individuals and their families must consider in selecting a form of long-term care when needed. Often these choices must be made within a short period of time (e.g., near the time of hospital discharge), and in consideration of the available payment options associated with each.

Many who face these decisions often think that the federal Medicare program will cover all or most of the cost of these services when needed. Although most would prefer home-based services if possible, the fact of the matter is that Medicare does not provide funding for long-term custodial care. When families then explore the options for coverage of these costs through the state's Medicaid program, they learn, often for the first time, that there are eligibility requirements, both financial and otherwise, that will require specific steps to be taken to establish eligibility. Low income alone does not constitute a sufficient criterion for establishing Medicaid eligibility.

Howard Gleckman of the Urban Institute has written that many of those who need long-term care services do not readily distinguish between and among these various types and levels of care.[8] The person with severe rheumatoid arthritis who is unable to walk without assistance or home-based assistive devices, or the young person with severe multiple sclerosis simply do not distinguish between services officially labeled as "personal care" and those that may be considered professional "medical or nursing care." For these individuals, either category of care is considered "essential" care.

Where the Gaps Occur: Transitions of Care

Long-term care, in each of its manifestations, exists to fill gaps in service needs that cannot be met by individuals and families on their own. It is often judged to have failed when its beneficiaries face rehospitalization. Vincent Mor and his colleagues report an analysis of data from the federal Medicare program that shows almost one-fourth of Medicare beneficiaries discharged from a hospital to a skilled nursing facility were readmitted within 30 days, costing Medicare some $4.34 billion in 2006.[9] In North Carolina, more than one in six Medicare patients admitted to nursing homes from acute care hospitals are readmitted within 30 days. In this effort to reduce rehospitalizations, the importance of transitional care planning cannot be overestimated. In the period following acute (usually hospital-based) care, communication among patients, families, and their health care professionals is extremely important. Discharge planning from hospitals and other acute care facilities should be a two-way street, involving understandings of expectations of patients and families, as well as realistic communication about what is likely to occur once subsequent care arrangements are put into place.

Dennis W. Streets and Ann C. Eller offer an important commentary in this issue of the *Journal* and describe the challenges faced by long-term care providers in assuring a smooth transition from acute to long-term care as they attempt to make the entire process as patient-centered as possible. Streets and Eller give details of a number of innovative new approaches to these transitional issues now taking place in North Carolina.

One aspect of such transitional care is the necessity for a clear and concise description of the discharge condition and prognosis of the patient so that nursing home or home health service providers can be fully aware of medical and social care issues that will need attention if any long-term care arrangement is to be successful. Among these transitional considerations is the matter of: "Who will pay for long-term care?" Although some coverage under Medicare may be possible for services such as physical therapy, occupational therapy, and certain home-based nursing care services, for the most part Medicare coverage for post-acute skilled nursing care is limited to no more than 100 days of care following at least three days in an acute care hospital, the first 20 days at 100% of charges, and at a daily Medicare approved rate for days 21-100. Medicare will only cover such services when provided in a qualified (certified) skilled nursing facility. Medicare beneficiaries who choose to live at home and need post-hospital care involving an attendant (either nursing personnel or a personal care services provider) on the premises will discover that these services are typically not covered by Medicare and not unless the patient would otherwise be considered an appropriate nursing home admission, for which home care is an acceptable alternative. At that point, the individual must either pay out-of-pocket, depend on long-term care insurance, or consider application for coverage under his/her state's Medicaid program.[10]

It is clear that long-term care need determination is made all the more complex due to the unique characteristics of every individual who arrives at the point where such services are needed. One's physical and cognitive abilities, financial resources, social supports, living arrangements, and access to volunteer unpaid caregivers who may lend assistance are all factors that must figure into the decisions regarding care options. While home-based care is most often valued highly by persons as they are discharged from hospital care, there are important considerations concerning whether there will be adequate professional oversight of the care received in the home environment, including whether or not often subtle changes in one's physical, cognitive, or mental condition will be noticed and appropriate actions taken. Home-based care providers and the professionals who staff skilled nursing facilities must both be aware of the trade-offs between personal preferences and safety, and strive to make long-term residential care options as life-affirming as possible, while meeting the medical/nursing care needs of the individual.

The Regulatory Environment of Long-Term Care

It is often said that the long-term care field is the most regulated sector in the American health care system.

In North Carolina, Jeff Horton and Jesse Goodman are responsible for the periodic surveys of health care facilities for regulatory purposes, and they explain the process and procedures that regulation entails in this issue of the *North Carolina Medical Journal*. Not only are those who administer these programs (at least those offering in-patient, skilled nursing services) licensed by every state, but the facilities themselves are subject to unscheduled inspection visits by multidisciplinary teams that can levy substantial fines and other penalties for failure to comply with either federal or state regulations governing care in (and the condition of) these facilities.

North Carolina health care attorney Ken Burgess has addressed this situation in his commentary in this issue of the *Journal*, in which he focuses on the impact that these regulations have had on the ambitions of those who would seek to make life as a resident in skilled nursing facilities as enjoyable and humane as possible. Nursing homes in this country have faced what Burgess describes as "an ever-increasing set of directives that dictate virtually every aspect of nursing facility life and care," thus limiting efforts to offer residents of these facilities even modest amounts of autonomy and choice in their daily routines. Nursing homes and other long-term care facilities have attempted to deal with these situations by exploring the possibility of what are called "negotiated risk agreements," through which health care facilities and mentally competent residents (or surrogates of incompetent residents) agree to allow for certain degrees of resident choice and less-restrictive activity in exchange for a moderation of the facility's liability.

Though these arrangements are not without controversy, they are illustrative of initiatives designed to offset some of the burdensome regulations that have given long-term care providers their reputations as unconcerned with the nature of residential life. These same issues arise in the care older adults living at home receive as well, especially for persons with dementia and others who are cognitively impaired. Persons at risk of falls, for example, who may have had previous falls, or those who may be taking multiple medications that can impair balance, gait, or musculoskeletal strength, may be restricted in their desired activities of daily living. But patients who wish to continue performing activities beyond their balance or strength capabilities may be asked to accept certain risks of injury through negotiated arrangements with their professional care providers. Such arrangements, whether for persons living in community settings or in residential care, require careful assessment of the degree of risk involved, attempts to minimize risk through proven methods and technology applications, and efforts to assure informed decision-making by the individual and his/her family members. In each of these circumstances, the goal is to balance considerations of safety with the desire for functional independence.[11]

Workforce Issues

Given the expected increases in the need for long-term care services in the decades ahead, there are reasons to be concerned about the adequacy of the supply, and the ability to retain, qualified and dedicated providers of these types of care. There have been continual discussions of the difficulty of attracting younger physicians and nurses into the fields of geriatric medicine and gerontological nursing, and these concerns have led to the creation of new training programs to address these issues. The paid workforce in long-term care involves a number of both licensed and non-licensed categories of personnel, including direct care workers (nurse aides, home health care aides, and home care/personal care workers), registered nurses and licensed practical nurses, licensed social workers, physical and occupational therapists, physician medical directors, and licensed nursing home administrators.

In this issue of the *Journal*, Eleanor S. McConnell, Deborah Lekan, and Kirsten N. Corazzini discuss the efforts now underway to strengthen the caregiving workforce in long-term care, as well as efforts to make long-term care and care of older adults a career destination of choice among those pursuing educational programs in a number of health-related disciplines. North Carolina is gaining attention nationally for its efforts to recruit and retain its direct care workforce of unlicensed personnel. In their commentary, Susan Harmuth and Thomas R. Konrad describe the programs that have been developed over several years to recruit and sustain a high quality direct care workforce serving the long-term care needs of our state. WIN A STEP UP and Better Jobs, Better Care, have each gained national attention as model programs in this area. Elsewhere in this issue of the *Journal* attention is focused on the Fabulous Fifty Program, an initiative of the North Carolina Health Care Facilities Association that recognizes direct care workers each year who have devoted many years of their careers of service in long-term care facilities in our state.

In their recent article in *Health Affairs*, Robyn Stone and Mary Harahan describe several principles that should constitute a new framework for addressing the workforce requirements and shortages in the long-term care field.[12] Among these is their view that traditional supply and demand theories are not applicable within this field. This is the case for several reasons, including: (1) the traditional sources of labor for the long-term care field (i.e., native born female populations between the ages of 25 and 54) are not as readily available as a source of labor for either paid or unpaid employment in this field; (2) negative stereotyping of long-term care environments and workers has had the effect of discouraging many potential applicants for employment; (3) this field has been characterized by low wages and fringe benefits for many years, partly as a result of the dependence on

Medicare and Medicaid as sources for more than 70% of its financing; and (4) a perception that frontline workers in this field are not valued and respected, coupled with a relative lack of career advancement opportunities for those employed in these positions. The programs and initiatives described by Harmuth and Konrad are examples of North Carolina initiatives intended to address these very issues.

The Implications of Recent Health Reform Legislation for Long-Term Care

Even though the deliberations of the US Congress with regard to health reform, and the recent passage of the Patient Protection and Affordable Care Act (HR 3590, signed into law March 23, 2010) focused for the most part on medical care insurance reform, there were several provisions that have significant importance to the field of long-term care.

The first of these is the establishment of a new national voluntary insurance program to purchase "community living assistance services and supports" (CLASS) financed through payroll deduction (with the option to not enroll). Through this new program, those who enroll and pay the requisite premiums will be, after a five-year vesting period, able to access funds to cover the costs of non-medical services and supports necessary to maintain community residence in the event that they experience dependencies in more than one activity of daily living.

Monthly premiums paid by voluntary payroll deductions allow all working adults to enroll in this program unless they opt out. Workers in companies that choose not to participate may enroll through a program to be set up by the Secretary of the US Department of Health and Human Services through a mail-in coupon arrangement. Payments will be contributed to a "Life Independence Account" on behalf of the beneficiary and will be managed by the Department as a new insurance program separate from Medicare and Medicaid. Those below federal poverty levels and full-time students can enroll at nominal premium levels.

Persons enrolled in the CLASS program may receive benefits, after a five-year period, when a functional limitation is expected to last for a continuous period of more than 90 days. The CLASS Act would have no effect on eligibility for Medicaid, Medicare, Social Security retirement, survivors or disability benefits, or Supplemental Security Income benefits. If a beneficiary were to be a resident of a long-term care facility and covered by Medicaid at the time benefits were requested, he/she could retain 5% of the daily or weekly cash benefit amount, with the remainder of the benefit being applied to the facility's cost of providing the beneficiary's care. Similarly, a Medicaid beneficiary residing at home and receiving Medicaid-financed home- and community-based services would be able to retain 50% of the daily allowed benefit (based on level of disability), with the remainder of the allowable benefit applied to the cost of providing these home and community-based services.[13]

Other provisions of the new health reform legislation include: (1) a provision (the Community First Choice Option) allowing states to provide home and community-based services and supports to persons eligible for Medicaid whose income does not exceed 150% of federal poverty guidelines, if they would otherwise need institutional care; (2) a provision allowing states to extend full Medicaid coverage to persons who are receiving home and community-based services; (3) the expansion of state aging and disability resource centers; (4) the expansion of the Nursing Home Compare component of the Centers for Medicare and Medicaid Services website to include information on nursing facility staffing, links to state survey inspection data, and information about complaints and criminal violations; (5) support for national demonstration projects on "culture change" and use of information technology in nursing facilities; and (6) a requirement that direct care workers in skilled nursing facilities receive formal training in the care of persons with dementia and patient abuse prevention.[a]

It will take some time before the full meaning and significance of these provisions for long-term care become clear, but it is evident that long-term care was not an oversight as Congressional committees worked to address a broad spectrum of the nation's health care needs.

In this issue of the *North Carolina Medical Journal* we have assembled a number of commentaries from various stakeholder groups, academic researchers, and public sector decision-makers and regulators who have attempted to describe some of the most important current issues facing this field. As we move forward, it is hoped that these contributions will be of value to those who have the responsibility of formulating public policies to address these issues, and informative to the general public for whom the availability and quality of long-term care services is so very important. These issues are likely to increase in importance to our state as our older adult population grows in coming decades.

Judith Feder, once again, has captured the very essence of the severe problem Americans face with respect to long-term care:[2]

> *The problem with today's long-term care system is not that individuals and families fail to take enough responsibility. Rather, they simply do not have enough to give. The need for extensive long-term care is an unpredictable and catastrophic risk. Typically, as, for example, in health care, we rely on insurance to "spread" such risks—having a large population contribute to a fund that is then*

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a. Silberman PC. NCIOM president and CEO. Personal communication. March 28, 2010.

distributed to the minority for whom catastrophic risk becomes a reality. For long-term care, however, instead of insurance, costs are concentrated on the individuals and families of those who use service, backed only by a public program (Medicaid) that finances care—primarily nursing home care—as a "last resort"—only after they have spent virtually all they have.

These are some of the most important health care challenges of our time, but ones that are often neglected in any attempt to deal with the nation's health care policy in a comprehensive way. However, as echoed by Bob Jackson's commentary in this issue of the *Journal*, now is the time for collaboration and advocacy on behalf of the long-term care industry in North Carolina. **NCMJ**

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Long-Term Services and Supports in North Carolina

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North Carolina will face enormous challenges in the years to come as it prepares to meet the service needs of older adults and people with disabilities. By 2030, about 25% of the state's population will be over age 60, dramatically affecting the resources required to meet the needs of an older population.[1] Along with the projected growth of older North Carolinians, their increasing ethnic and racial diversity, rural living and poverty, the aging of individuals with physical and mental disabilities, and the slowed economy all create major challenges. Yet these challenges also present opportunities to find better, more efficient, and creative ways to meet the growing demands.

North Carolina has long been aware of the growing long-term service challenge. In 1981, the General Assembly established a long-term care policy (NCGS 143B-181.5) to address these issues. While recognizing family and friends as the primary resource for long-term care, the policy acknowledged that "the public interest would best be served by a broad array of long-term care services that support persons who need such services in the home or community whenever practicable." In 1999, the General Assembly asked the Secretary of the Department of Health and Human Services to develop a long-term care system that could provide a continuum of care for older adults, people with disabilities, and their families, and to report its progress. A task force, facilitated by the North Carolina Institute of Medicine (NCIOM), produced *A Long-Term Care Plan for North Carolina*, which was submitted to the General Assembly in January 2001.[2] The report noted that the fragmentation of many funding streams and oversight agencies makes it difficult for consumers to navigate the service system. It recognized the difficulties of moving from one type of service to another, identified inequities in funding and eligibility, and discussed workforce issues. It also examined the shortfalls of available data to monitor quality. The Task Force offered recommendations about entry into the long-term care system, availability and need for long-term care services, workforce, quality of care, and financing.

> ***By 2030, about 25% of the state's population will be over age 60, dramatically affecting the resources required to meet the needs of an older population.***

These recommendations, as well as newer initiatives generated from the grassroots and federally, are guiding change in North Carolina's long-term services and supports delivery system. These changes have been spurred by strong collaboration across the Department of Health and Human Services to maximize funding and plan for future needs.

One major federally-supported impetus for improving access to long-term services and supports is the Community Resource Connections program (CRC). CRCs create a "no wrong door" coordinated system of information and access through local agencies for people seeking long-term services and supports. CRCs aim to minimize confusion, enhance individual choices, and enable informed decision-making. Agencies collaborating in a CRC help consumers understand options, plan for future long-term service needs, and access public and private pay services. Supported through the Centers for Medicare and Medicaid Services (CMS) and the US Administration on Aging (AOA), North Carolina developed two pilot projects (then named Aging and Disability Resource Centers) in Surry and Forsyth counties in 2004 and 2005. With continued grant funding, the program now reaches 47% of the state's population in 28 counties, with plans to develop several more local projects within the next two years and is moving toward statewide coverage within five years. Effective use of information technology is a key component of this initiative. As an example, NCcareLINK was developed to provide a statewide, web-

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based information and referral system for consumers and providers (https://nccarelink.gov/).

In addition to better coordinated information and access, the state is working on initiatives to promote healthier lifestyles, support individuals to better manage their own health care needs, and connect individuals with primary health care providers in order to avoid—when possible—more expensive and restrictive services, including emergency room visits, hospital stays, and facility placements. One such initiative is the Living Healthy Program, funded through AOA grants. Based on the evidence-based Chronic Disease Self-Management Program curriculum developed at Stanford University,[a] Living Healthy participants attend workshops on (1) dealing with frustration, fatigue, pain, and isolation; (2) appropriate use of medications; (3) communicating effectively with friends, family, and health care providers; (4) appropriate exercise; (5) healthy eating; and (6) making informed treatment decisions.

A key platform for introducing many of these critical reforms and maximizing their effect is Community Care of North Carolina (CCNC). With 14 Community Care networks, comprised of community physicians, hospitals, health departments, and departments of social services, these established systems represent a patient-centered medical home for Medicaid recipients, who include people dually eligible for Medicare and Medicaid. North Carolina is one of only two states given permission by CMS to undertake a new Medicare 646 waiver demonstration for care of people with complex medical and social conditions that require a holistic and person-centered approach. The initiative's success will depend largely on collaboration and integration among the variety of initiatives—including the CRC and the Living Healthy Program—that support seamless access to services, smooth transition of care among settings, and maximum consumer choice.

As the General Assembly noted in its long-term care policy, most long-term services and supports are provided informally. A priority recommendation of the NCIOM report was to "invest in family caregiving so that it can be sustained as the primary resource for long-term care, reducing the risk for needing formal, publicly-financed services." Several initiatives are striving to meet this need.

Project CARE ("Caregiver Alternatives to Running on Empty") provides consumer-directed respite to family caregivers of people with dementia. Its primary goals are to increase quality, access, choice, and use of respite and support services to low-income, rural, and minority families caring for a person with dementia at home. An estimated 70% of people with Alzheimer's are cared for at home by unpaid family and friends.[3] Research has shown that family caregivers needing and then receiving respite are more likely to postpone or avoid the care recipient's institutional placement.[4] Funded through federal and state funds, Project CARE has been successfully implemented in 22 counties, serving more than 3,800 families through 113 local provider agencies. There are efforts underway to expand to additional counties and, ultimately, statewide.

The Family Caregiver Support Program, funded under the federal Older Americans Act, began in 2001. It serves family caregivers providing care for an adult age 60 and older or for a person with Alzheimer's Disease or related brain disorder (working with Project CARE when possible). It also provides services to caregivers age 55 and older who are raising a related child age 18 and under or caring for an adult with a disability. It leverages public and private resources to develop a multifaceted support system for caregivers, enabling them to better fulfill the caregiving role. Services include information; individual counseling; support groups; training in health, nutrition, and financial literacy; respite care; and supplemental services (e.g., home modifications, temporary home-delivered meals, and/or transportation) on a limited basis.

Most recently, North Carolina was selected as one of 12 states to develop a Lifespan Respite Program. Funded through a federal grant, it is intended to enhance and expand the quality and availability of respite services for all age groups via consumer and provider education and information, volunteer and provider training, and resource development. The objective is to create a more coordinated system of respite services by improving access and reducing barriers to respite care for people of all ages.

Strong coordination is especially critical as service needs grow and public resources are limited. Emerging service models that support greater collaboration and increased consumer choice will certainly become more important in efforts to help individuals remain in their own homes or even return home. Several consumer-directed care models are being tested and applied by the Division of Aging and Adult Services and the Division of Medical Assistance.

Among the growing array of new models are Money Follows the Person (MFP) and the Program of All-Inclusive Care for the Elderly (PACE). In MFP, individuals who have been in a qualified Medicaid facility for at least three months are eligible to return to a home-based or small group setting. MFP provides additional Medicaid funding and incentives to create systemic changes to make it easier for people to transition home. The PACE program integrates Medicare and Medicaid financing to provide social and medical services in an adult day health center supplemented with other services. For most PACE participants who would otherwise be eligible for nursing home placement, the service package permits them to continue living at home. There are currently two active PACE programs in North Carolina, at Elderhaus, Inc. in Wilmington and Piedmont Health Services, Inc. in Carrboro.

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[a] Information regarding this program is located at http://patienteducation.stanford.edu/programs/cdsmp.html.

Driven in part by the aging baby boomers, the focus and definition of service quality is changing. Culture change toward more person-centered practices is encouraged through the service industries, as well as through the Department of Health and Human Services and federal funding agencies. These changes promote finding a balance between addressing what is important to individuals (as defined by the individuals themselves) while also attending to a person's health and safety. It shifts staff focus from the person's medical treatment or service needs to how these needs can be met in the context of what is important to the individual. Person-centered practices also support workplaces that are attentive to staff needs, recognizing that promoting more satisfied staff will result in more stable staff.

It is critical for the long-term services and supports system to have a well-qualified and stable workforce, as recognized by the NCIOM report. One result of developing consumer-directed programs is to create more options for hiring employees outside of a traditional agency, creating a larger potential workforce. There are also initiatives in the Department of Health and Human Services to develop continuing education, career opportunities, and incentives to promote stability for direct care staff. Two relatively new job categories, "Medication Aide" and "Geriatric Aide," have been established for nurse aides working in nursing homes. Both provide opportunities for nurse aides to increase their knowledge and skill base and to help establish career advancement. WIN A STEP UP is a program implemented through a partnership with the North Carolina Institute on Aging at UNC Chapel Hill that aims to reduce turnover of nurse aides in nursing homes through training, education, and rewards.[b] It upgrades skills, increases career commitment, improves retention of quality workers, and provides rewards and recognition.

The NCIOM recommendations included suggestions that agencies should be provided more incentives for developing quality programs that go above and beyond the minimum standards. North Carolina New Organizational Vision Award (NC NOVA) is a statewide, voluntary special licensure designated for nursing facilities, adult care homes, and home care agencies. It is a "raise-the-bar" workplace culture change program that addresses known causes of direct care staff turnover. Those achieving this designation have met a comprehensive, progressive set of criteria. In addition, the Division of Health Service Regulation has a new star rating system for adult care homes that allows for earning additional points for certain quality improvement programs above the minimum standards.

While acknowledging the challenges of the future demands for long-term services and supports, the Department of Health and Human Services is optimistic about the effect of changes underway. Its vision includes well-informed consumers who have support to plan for their futures; seamless access to coordinated primary health care and supportive services; an investment in families and other informal caregivers; services that are empowering, preventive, and person-centered; and a well-qualified workforce. **NCMJ**

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[b] More information about this program can be found at http://www.aging.unc.edu/research/winastepup/index.html.

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The Need for Paid Long-Term Care in North Carolina: 2010 to 2020 and Beyond

Mary Anne P. Salmon, PhD; Gary M. Nelson, MSW, DSW

There is no one in the fields of medicine, health, or social services who has not heard the dramatic statistics describing the growth of the older population over the next few decades. There is also probably no one who does not appreciate the complexity of the current system of health care and supportive services, and the difficulties associated with translating perceived need for care into services. This commentary provides a snapshot of the growing demand for long-term care services, some challenges in responding to that demand, and a few words on implications for the future.

Growing Need for Long-Term Care

In North Carolina, it is expected that the number of individuals 65 and older will nearly double from a projected 1.1 million in 2010 to nearly 2.2 million by 2029. Over that same timeframe, the number of adults ages 21 to 64 will grow by only 25% (from 5.6 million in 2010 to 7 million in 2029). Unlike the past two decades, the growth of the high-risk population, ages 85 and older, will be slower than that of the "young old" with only a 45% increase. This will rise again from 2040 to 2050.[1,2] Demographic changes, inevitably, have an impact on the need for paid long-term care, but this may be exacerbated or mitigated by trends in disability rates, the availability of informal caregivers, and the intentional and unintentional consequences of public policy.

Table 1 shows the 2008 disability rates for community-dwelling adults in North Carolina.[3] Applying these age-specific rates to the population projections implies a 58% increase in the number of people with disabilities from 1.1 million in 2008 to 1.7 million in 2029, including a 60% increase in those unable to bathe and dress themselves. However, those calculations are based on stable disability rates over the next 20 years. In recent years there appears to be a modest decline in disability prevalence among older North Carolinians and a somewhat larger increase in prevalence among younger populations, but because of changes in measurement it is not possible to make reliable projections of the state trend.[4-8]

There has been a national decline in disability rates for older adults since 1982,[9-13] which has offered some hope of mitigating the impact of the growing older population. Medical and technological improvements have especially reduced the amounts of disability in the areas of vision and cardiovascular damage.[9] Although rising rates of obesity threaten to offset some of these gains, there is also hope that improvements in the treatment of diabetes and other diseases for which obesity is a risk factor will prevent a reversal of the downward trend.[10] The bad news for the public service sector is that the reduction in disability is disproportionately seen among those with higher levels of education and income,[9] which means that the demand for publicly-funded services may not be as strongly mitigated by this trend.

> ***…access to the needed services and resources to meet current demand is falling short, and the gap is only likely to grow larger in the years to come given the constraints of the current economic environment.***

Informal Caregiving

A large majority of care to older adults is provided by informal caregivers, including family members and friends.[11-13] In North Carolina, an estimated 17% of adults are "providing regular care or assistance to someone who has

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Table 1.
Overall and Self-Care Disability Rates by Age Groups for the Civilian, Non-Institutionalized Population: North Carolina, 2008

Age Group	Population	Any Disability[a]		Self-Care Disability[b]	
		Number	Percent	Number	Percent
18 to 34	2,007,932	119,183	5.9	16,809	0.8
35 to 64	3,672,412	528,768	14.4	97,072	2.6
65 to 74	609,705	178,427	29.3	31,897	5.2
75+	477,099	254,567	53.4	72,308	15.2
Total 18+	**6,767,148**	**1,080,945**	**16.0**	**218,086**	**3.2**

Source: US Bureau of the Census. *American Community Survey, Tables B18101 and B18106.* Washington, DC: US Bureau of the Census; 2008.

a. Beginning in 2008, "Any disability" included vision (even with glasses); hearing; cognitive (concentrating, remembering, or making decisions); mobility (walking and climbing stairs); self-care (difficulty dressing or bathing); and independent living (the ability to do errands alone such as going to the doctor's office or shopping).

b. "Self-care disability" refers specifically to difficulty in dressing or bathing oneself.

a long-term illness or disability" to adults of any age, and nearly half of these are caring for people over the age of 75.[14]

In general, families care for their family members who are aging or have disabilities. In fact, even after family members move to facilities, family members continue to provide care.[15] However, three trends that reduce the amount of available hands-on, 24-hour caregiving began with the previous generation of older adults and will likely continue into the next two decades and beyond: (1) the majority of women work outside the home and their incomes are needed, (2) today's older adults have fewer children than previous generations, reducing the number of potential caregivers, and (3) people have been increasingly mobile such that potential and actual caregivers may be far from their care recipients.

Men who need care in later life may fare slightly better than women because trends in divorce and remarriage suggest that they are more likely to reach high-risk ages with spouses and second-family children much younger than themselves, while women are more likely to reach their own high-risk years widowed or divorced.[16] Taken together, these trends suggest that families will continue to be involved over the next two decades, but that shifting a greater percentage of the overall care onto the informal caregiver would be difficult to impossible.

Some Effects of Current Policy

Older adults and adults with disabilities are Medicaid's most expensive enrollees. In state fiscal year (SFY) 2005, they made up only 30% of the Medicaid-enrolled population but nearly 70% of the state's Medicaid expenditures were on their behalf.[11] In SFY 2009, more people received Medicaid-funded in-home care than received Medicaid-funded nursing home care.[17] However, as Table 2 demonstrates, for adults ages 60 and older, expenditures for nursing home care far exceed those for in-home care.

What might account for this concentration of spending on facility care? To answer this question, the North Carolina Department of Health and Human Services commissioned a study that identified 10 sources of bias and made recommendations to address them.[11] Since 2003, the general trend has been an increase in the ratio of in-home to facility spending, but there was a decrease in the most recent fiscal year. It remains to be seen how much impact the efforts to implement some of the Lewin Group recommendations by the State Study Commission on Aging[13] and the several state programs described in the paper by Streets and Eller in this issue of the *Journal* will be able to rebalance in-home and facility spending, especially if there remain service gaps and waiting lists for community services.

Will there be enough beds? North Carolina experienced a 32% increase in beds per 10,000 population between 1990 and 2002.[18] However, whether supply will increase at similar rates in coming decades is largely a policy decision. The North Carolina Division of Health Service Regulation's Certificate of Need program controls the supply of both nursing home and assisted living beds, and they have to steer a careful course to help keep down spending by controlling supply, but allow for growth in the numbers for whom facility care is appropriate. Applicants for certificates must submit data on the need for new beds. However the Division does not currently conduct its own studies projecting needed additional or replacement beds.[a]

In addition to initiatives to rebalance public expenditures, the Department of Health and Human Services is trying to encourage more private responsibility for long-term

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[a] Speroff B. Chief, Nursing Home Licensue and Certification Section, North Carolina Division of Health Service Regulation. Personal communication. January 2010.

Table 2.
Ratio of Home Health and In-Home Service Expenditures to Institutional Expenditures for Medicaid Only and for All Public Programs Including Medicaid, for Consumers Ages 60 and Older: North Carolina, State Fiscal Years 2004–2009

Medicaid Only

State Fiscal Year	Home Health and In-Home Care	Institutional Care	Ratio of Home to Institutional
2003-04	$383,102,157	$949,713,640	$0.40
2004-05	$441,927,605	$1,107,119,083	$0.40
2005-06	$501,369,843	$1,120,503,846	$0.45
2006-07	$490,545,614	$1,100,781,714	$0.45
2007-08	$526,341,219	$1,121,191,999	$0.47
2008-09	$534,224,704	$1,232,933,278	$0.43

All Public Funding Including Medicaid

State Fiscal Year	Home Health and In-Home Care	Institutional Care	Ratio of Home to Institutional
2003-04	$423,314,275	$1,093,341,342	$0.39
2004-05	$484,832,899	$1,245,053,835	$0.39
2005-06	$544,670,981	$1,233,810,553	$0.44
2006-07	$534,305,747	$1,227,459,117	$0.44
2007-08	$572,122,508	$1,297,833,362	$0.44
2008-09	$582,411,268	$1,427,343,948	$0.41

Source: "State Totals by Agency" and "Table III-B Report" for SFY 2004 to 2009. NC Division of Aging and Adult Services website. http://www.dhhs.state.nc.us/aging/expenddata.htm. Accessed March 5, 2010.

care. Neither Medicare nor traditional private insurance will pay for long-term care—except for some post-acute, rehabilitative services—and the number of North Carolinians who have long-term care insurance is small. Less than 2% of long-term care in North Carolina is currently paid for by long-term care insurance.[b] To change this picture the Department of Health and Human Services is developing a Long-Term Care Partnership Program. If adapted, North Carolina would join 33 other states that encourage the purchase of long-term care insurance by sheltering a portion of their assets of the insured if insurance is expended and the insured person must rely on Medicaid.

The public response to the growing demand for long-term care services has historically been to restrict services based on financial need. Only those services offered under the Home and Community Care Block Grant operate on a sliding contribution basis. Current federal reform initiatives and pending federal health care legislation speak to broadening access to long-term care services to the growing population of individuals and families in need, irrespective of income. Such a move would benefit the majority of older North Carolinians who are unable to pay for private services, do not have long-term care insurance, and have too much money to qualify for services under Medicaid unless they enter a facility and spend down their resources.

Because of North Carolina's structure of county autonomy, a consumer's choice of and access to in-home care are somewhat different in each of the state's 100 counties. As this model of government is unlikely to change, it will be a challenge to create the policies and develop the necessary infrastructure to help assure counties across the state will be prepared to address the demand in the next 20 years. There are already shortages of some services in some counties.

An estimated 14,000 older North Carolinians are on waiting or enquiry lists for home and community care—especially home-delivered meals and in-home aide services[19] and these lists vary widely across counties. This number does not include younger adults with disabilities who, nationwide, make up about 40% of the long-term care population.[20,21]

The CAP-DA Medicaid waiver program that provides in-home services to people who are functionally eligible for nursing home placement is now available in all 100 counties, but counties have a limited number of slots that they can fill, regardless of the need. Statewide, 88% of slots are

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[b] Obiol C. Deputy commissioner, SHIIP, North Carolina Department of Insurance. Personal communication. January 2010.

filled but because slots are assigned to specific counties, some counties have lengthy waiting lists while others have vacancies.[11,13] Personal care services are also available through Medicaid for people who are not in the CAP-DA program, but because of the high cost of this program, policymakers are debating serious cuts to this service.[22,23]

For those who need personal care and/or supervision and are very poor (those who qualify for Supplementary Security Income), State and County Special Assistance (SA) finances assisted living or living in a family care home. There are currently 23,351 active SA cases in adult care and mental health supervised living.[c] There is also an SA in-home program for those with similar needs. Like CAP-DA, this is allocated through a number of slots allotted to a particular county, and there are currently nine counties that have not requested any slots. For this relatively new program, there is not a problem with waiting lists. There are 2,099 active clients for 2,578 allocated slots and the Division of Aging and Adult Services has the flexibility to reassign unused slots to different counties quickly to meet unanticipated new need.[c]

Conclusions

The demand for long-term care services in North Carolina, as in other states, is affected by an aging populace, changing disability rates, the changing role and availability of family caregivers, and the changing expectations of the older and disabled individuals themselves. Against these developments, the general finding is that access to the needed services and resources to meet current demand is falling short, and the gap is only likely to grow larger in the years to come given the constraints of the current economic environment.

What are the implications for policymakers and consumers? First, if the preferences of the growing numbers of individuals in need are to be met, inefficiencies in the current system of health and long-term care will have to be identified and eliminated to free up resources for options that consumers value and will support and pay for. It is not likely that any significant new resources will come available. Thus, a realignment of current long-term care spending is essential.

For this to happen, more transparency will be needed in what is now a very opaque system. We must highlight the choices, results, and trade-offs in the current system, including the inequities resulting from county autonomy, so the public, policymakers, and providers alike can weigh in on the system they want to create for the growing number of older and disabled adults.

Absent a system-wide assessment and coordinated adjustment of our highly interconnected network of services and outcomes, individual advocacy groups will continue to push their particular agendas to the exclusion of a much needed shared agenda and governance process that identifies what we are willing to support and pay for. Absent such a system-wide assessment and governance structure and process, trends may push the current system to collapse from its own weight, complexity, and costs. **NCMJ**

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The Challenges of Regulation in Long-Term Care

Jeff Horton; Jesse Goodman

Regulatory oversight of long-term care services has evolved over the past 20 years to include a matrix of activities focused on the safety and well-being of those served by an array of long-term care providers. Basic oversight involves regular survey visits of providers and investigation of complaints, both of which are carried out by the state agency responsible for the licensing of the various long-term care providers. In North Carolina that responsibility resides with the Division of Health Service Regulation (DHSR) in the Department of Health and Human Services.

The survey process for residential providers is very similar in that surveys are conducted annually, are focused on compliance with rules and regulations, and, to a large extent, determine whether the care systems that providers have in place are meeting the health and safety needs of the residents they serve. The three types of long-term care providers that fall under DHSR's oversight authority include skilled nursing homes, adult care homes—including assisted living facilities and family care homes—and residential facilities for people who are mentally ill, developmental disabled, and/or substance abusers. Each of the oversight programs are discussed in more detail below.

Skilled Nursing Homes

The oversight of 423 of the 436 nursing homes in North Carolina is governed by federal regulations. Under these regulations, nursing homes that are certified to receive Medicare or Medicaid reimbursement must be surveyed annually and complaints, depending on the severity, must be investigated within certain timeframes that are determined by the severity or the complaint allegation. If noncompliance is identified in either process, the state must notify the provider and if noncompliance is at such a level to put residents at risk of harm—or if harm occurs—the state may recommend monetary penalties as well as other actions to the federal Centers for Medicare and Medicaid Services which has the authority to impose penalties and/or termination from the Medicare and Medicaid program. States are required to follow-up after the survey to assure that the facility has corrected its deficient practices. A portion of every penalty imposed is returned to the state for use in enhancing resident health and safety.

Required nursing home staffing includes a medical director, a licensed administrator, dietary staff, licensed nurses, nurse aides, and other staff as necessary to meet the needs of the resident population. Providers are required to obtain criminal background checks on all unlicensed direct care employees and must also check the Nurse Aide I and Health Care Personnel Registries to determine if an applicant for employment is either currently under investigation for allegations of abuse, neglect, or misappropriation of resident property, or has a substantiated finding for the same on either of the registries. If an applicant has a substantiated finding the provider is barred from employing the applicant.

> ***As new ideas are being developed and tested, the challenge to the regulatory community is to maintain an open and flexible process that allows for changes that will result in better living environments and services to residents.***

Adult Care Homes

The monitoring of adult care homes is a shared responsibility between DHSR and each county's department of social services. Like the nursing home oversight program, adult care homes are required to be surveyed annually by DHSR. Additionally, counties are required to

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complete monitoring visits of all adult care homes in their respective counties at least quarterly. Counties are also required to investigate complaints or refer them to DHSR for investigation. If a home is found to have violated rules, DHSR has several options for how to address these deficient practices. A plan of correction is always required. This plan illustrates how the home will correct its problems and must include a timeframe for completion of these steps. If serious harm has occurred or if the risk is high that harm will occur, the home may be cited for an "A type" violation, which usually results in a recommendation for monetary penalties and may include other actions such as suspension of admissions or provisional license, or, in more extreme cases, revocation of a home's license.

All recommendations for monetary penalties must be sent through DHSR's Penalty Review Committee, which has the responsibility of recommending specific penalty amounts. DHSR has the responsibility of assessing the penalty and is not bound by the Committee's recommendation. The North Carolina Constitution requires that penalty monies collected be forwarded to the public education system.

As adult care homes are considered a social model provider, where the residents' needs are primarily in the areas of activities of daily living and not medical or nursing needs, the staffing requirements do not include licensed nurses or medical directors. The adult care homes are required to have a certified administrator, personnel care aides that have between 40 and 80 hours of training, medication technicians who have successfully passed the state medication technician exam, and dietary and housekeeping staff. Adult care homes also have required staff-to-resident ratios. Providers are required to obtain criminal background checks on all unlicensed direct care employees and must also check the Health Care Personnel Registry to determine if an applicant for employment is either currently under investigation for allegations of abuse, neglect, or misappropriation of resident property, or has a substantiated finding for the same on the Registry. If an applicant has a substantiated finding the provider is barred form employing the applicant.

Mental Health, Developmental Disabilities, and Substance Abuse Residential Facilities

This category of long-term care covers a broad spectrum of providers who serve an even broader spectrum of clients. However the oversight of these providers is carried out in a relatively consistent manner. All providers in this category are required to be inspected annually. Complaints are received through DHSR's consolidated Complaints Intake Unit where they are triaged and forwarded to the Mental Health Licensure Section for investigation. Like adult care homes, when violations occur, plans of corrections are required by the provider and, based on the seriousness of the violations, may result in monetary penalties being assessed against the providers. If, as a result of a required follow-up survey, it is determined that the provider has failed to correct their violation, DHSR has the option to assess daily monetary penalties of up to $1,000 per day for each day the provider has remained out of compliance from the initial citation. Licensure actions such as suspension of admissions up to revocation of a provider's license may be imposed if it is determined that the provider is experiencing difficulty in meeting their current resident needs or if residents are in danger.

Basic staffing requirements are consistent across providers with specialized training required for the specific type of residential setting licensed. The competency of each staff member to perform the required functions must be determined prior to performing the various required care duties. Providers are required to obtain criminal background checks on all unlicensed direct care employees and must also check the Health Care Personnel Registry to determine if an applicant for employment is either currently under investigation for allegations of abuse, neglect, or misappropriation of resident property or has a substantiated finding for the same on the Registry. If an applicant has a substantiated finding the provider is barred from employing the applicant.

Future Regulatory Challenges

As North Carolina and the nation begin to see the impact of the first ripples of the "graying of America" we must be prepared to address the challenges this impact will present. Current and future consumers of long-term care are demanding changes in the system to move care settings away from institutional models to more home-like environments. In addition, providers of care are seeking new and more effective ways of meeting their clients' needs. As new ideas are being developed and tested, the challenge to the regulatory community is to maintain an open and flexible process that allows for changes that will result in better living environments and services to residents. As the state's primary regulatory agency for oversight of long-term care services, the Division of Health Service Regulation must maintain a balance that does not hinder the development of new and exciting ways of providing care as well as the development of more home-like and "green" facilities for our long-term care resident populations. We must ensure our regulations are consistently reviewed with changes implemented when needed to encourage these positive changes while at the same time assuring that health and safety standards are firmly in place.

Other challenges facing the regulatory system center on the impending growth of the long-term care system as a result of the aging of America and how agencies will meet the demand for more oversight with little or no new resources. New ways of doing business are currently under discussion, including the introduction of "Just Culture" models into long-term care systems (which are the adoption of approaches to foster active learning wherein the staff of a organization is encouraged to openly discuss errors without the fear of reprisal) along with modified survey processes that reward providers with proven track records of providing excellent care with shorter streamlined surveys. Other changes include:

- focusing more oversight resources on providers whose track records show continuing problems
- encouraging self assessments where providers identify deficient practices or systems
- taking immediate corrective action to correct any issues that arise
- maintaining compliance and documenting these actions without fear of regulatory cites or penalties for these corrected past noncompliance
- more aggressive enforcement of continued noncompliance when providers fail to correct identified problems within the timeframes established by DHSR
- allowing more use of directed staff training in lieu of penalties and fines to correct past problems and improve the overall care to residents.

The challenges facing the regulatory system will require new ways of doing business. Providers, advocates, and state regulatory agencies must work together to assure that our citizens in need of long-term care services receive the highest quality services possible. This can only be accomplished through a balanced approach where providers of excellent care are rewarded, providers who have continuous problems are more aggressively regulated, and where new and innovative approaches to care are encouraged and supported. **NCMJ**

Public Policy and Long-Term Care

Senator William R. Purcell, MD

When most of us arrived in Raleigh as members of the North Carolina General Assembly, our knowledge of issues related to long-term care was minimal, informed mainly by our own personal experiences and observations gleaned from interactions with family members and friends who were admitted to nursing homes or who had made arrangements for various types of home-based services as these needs arose. Having spent my professional career as a physician in the practice of pediatrics, I had limited encounters with long-term care issues and was not involved as a physician in nursing home care.

Now, nearly 13 years later, I know and appreciate the complexity of issues relating to long-term care as never before. As the co-chair of the Subcommittee on Health and Human Services Appropriations, I have devoted many hours to these issues. They are likely to become even more complex as we see increasing numbers of persons at advanced ages, some with multiple chronic and disabling conditions, requiring various levels of care. Moreover, the service delivery sector offering these services is now far more complex, with each component of long-term care having its own special role to play, and each having its own legislative and regulatory agenda. Long-term care is now one of the components of health care policy requiring the focused attention of legislative policymakers, as well as representing one of the largest segments of the state's financial resources devoted to health care services.

Examples of the Most Complicated and Pressing Issues in Long-Term Care

Over the past couple of years, the General Assembly in North Carolina, as well as the North Carolina Department of Health and Human Services, have been concerned with the huge cost of providing personal care services and community support services, separate from home health services, to those individuals who are dependent on the care of others for one or more activities of daily living, but who live in the community in their own homes or other non-institutional settings. Many of these services are, for those who receive them, essential to their ability to sustain a daily pattern of living without the necessity of institutional care (i.e., adult care, assisted living, or nursing home). These services are expensive, even though those who provide them are not health care professionals in most cases, and though the services often are provided only a few hours per week. There is a need to make certain that the services provided are indeed essential, provided by competent persons on a regular and dependable basis, and are offered at a fee that is commensurate with acceptable costs. There have been assertions that the state has over-paid for many of these services and these issues will occupy considerable additional time and attention in the coming sessions of the General Assembly. The annual outlay of public funds for these services is so large that the overall budget allocation for these services is in need of constant monitoring and the target of proposals for substantial cuts. The General Assembly is likely to spend many additional hours in a continuing review of this program and the benefits it offers to our citizens who have requested these services.

Long-term care is now one of the components of health care policy requiring the focused attention of legislative policymakers, as well as representing one of the largest segments of the state's financial resources devoted to health care services.

We are continually faced with issues related to "guardianship" in decisions about the most appropriate and

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affordable choices for individuals and families in long-term care. In this arena, there remain many areas of confusion and our laws and regulations in this regard are in need of continuing review. One of the themes heard over and over again in legislative deliberations about these issues is the intent to make certain that decisions about the most appropriate level and type of care provided to those in need are made by professionals with the skills, knowledge, and experience to make these decisions, and not have such decisions dictated by lawyers or the courts. Working out a set of laws and regulations that takes us where we ought to go with regard to these matters of great importance to families in our state is a task likely to occupy legislative attention in the future.

Long-term care facilities (adult care homes, assisted living facilities, and nursing homes) have all maintained that the rate at which the state's Medicaid program reimburses for services in these facilities is too low, thus restricting the ability of these facilities to modernize their facilities or expand to meet increasingly demanding expectations of the public they serve. Coupled with this is the problem of low wages and benefits for direct care workers in these facilities (e.g., nurse aides and other non-licensed staff). We believe that these issues warrant our continued attention and concern, but the overall expenditure for long-term care services financed by Medicaid has risen to the point that major increases in these reimbursement rates present a considerable budgetary challenge for all of us.

Making matters worse is the plight of our state's mental health care system, which has embraced the idea of transferring more of the burden of care for the state's population who suffer from mental or emotional illness to community-based settings. Because many of those who may have formerly been cared for in a state mental hospital are now being transferred to other levels of care, the state's long-term care industry is now faced with carrying a substantial part of this burden as well. One of the issues of continuing concern is the set of problems that relate to resident mix in these facilities, forcing them to offer services to persons who have very different needs and reasons for admission to these facilities.

These matters are exceedingly complex and have significant implications for the financial solvency of our state's Medicaid budget. North Carolina's Medicaid program is expected to be $250 million above budget for this year. One can expect this to be a major concern as we move into future discussions of our state's fiscal situation and our health and social services responsibilities.

Related to the issue of reimbursement rates for service providers of long-term care services is the equally complex matter of Certificate of Need (CON) laws in our state which mandate that proposals for the expansion of expensive health care facilities demonstrate a need and a reasonable plan for building any new facilities providing either inpatient or outpatient care. Though there are criticisms of CON from those who have struggled to demonstrate a need in a particular area and been denied the opportunity to build such facilities or offer a particular service, these laws have made it possible to carry out reasonable health care planning statewide in a way that helps prevent excessive capacity building and assures that quality service will be available where the needs can be documented. We expect a continuing examination and re-examination of the impact of CON laws, particularly as they relate to long-term care and hospital construction/expansion.

The Major Emphases in Public Policy for Long-Term Care

From a public policy perspective, there are major dilemmas affecting how we should go about crafting long-term care policy. For example, should emphasis be placed on home- and community-based services, or on improving options for in-patient skilled nursing care and other residential services for our aged and disabled? One would hope that a relatively seamless web of such services and programs could be possible that would allow for smooth transitions from one level of care to another as individual needs change. Moreover, there are legislative proposals to give continuing care retirement communities (CCRCs) the ability to offer services to persons who do not reside in these communities, presumably to persons who have signaled their intention to move to such facilities and are on the priority list of those who will be future residents of CCRCs. But these services (e.g., assisted living, meals, ambulatory care, primary care, or services like physical therapy) may be made available outside a facility to persons who request them in their larger surrounding communities. These transitions taking place in this field suggest an even greater degree of complexity, and therefore the need for an even more complex web of both regulatory and financing options than we have at the moment.

In our state, and in the nation as a whole, the demographic transitions we are seeing, particularly in terms of the increasing numbers of senior citizens who will need long-term care, suggest a growing importance of these issues. It also suggests a concern for how the precise needs for such services can be measured and then met through the most appropriate, affordable programs of benefit to those who need them. We are fortunate in North Carolina to have a vibrant and extensive network of long-term care service providers and strong and competent advocates for these stakeholders who work with members of the General Assembly to anticipate the shifting needs of North Carolinians and propose new initiatives to meet these needs over time. **NCMJ**

Assuring the Adequacy of Staffing of Long-Term Care, Strengthening the Caregiving Workforce, and Making Long-Term Care a Career Destination of Choice:

From Mission Impossible to Mission Critical?

Eleanor S. McConnell, PhD, RN, GCNS, BC; Deborah Lekan, RNC, MSN; Kirsten N. Corazzini, PhD

Nationally, over 3 million certified nursing assistants and licensed nurses work in long-term care (LTC). Of these 3 million providers, about 2.5 million are certified nursing assistants (CNAs) and the remaining 500,000 licensed nurses are evenly divided between licensed practical nurses (LPNs) and registered nurses (RNs).[1] With the aging of our population, experts estimate that the demand for this workforce will double in the coming decades, requiring up to 5 million direct care workers, 868,000 RNs, and 231,000 LPNs nationally.[2] In 2007, an estimated 109,900 full-time equivalent direct care nursing positions at nursing facilities across the United States were vacant; approximately two-thirds of the vacancies were for CNAs and one-third for licensed nurses. National turnover rates among CNAs, LPNs, and RNs remain high, most recently estimated at 66%, 50%, and 41% respectively.[3] The situation in North Carolina is even grimmer: annual turnover rates for nursing staff are conservatively estimated at 86%,[3] with CNA turnover most recently estimated at over 100%.[4]

Supply of and demand for advanced practice nurses (APNs) practicing in LTC (board-certified nurse practitioners and clinical nurse specialists) is not currently tracked systematically, but studies demonstrate their value in managing chronic and acute illnesses in nursing homes, as well as in helping staff integrate quality improvement approaches into routine care.[5,6] The growing evidence of APN effectiveness in LTC at both the patient and organizational level has led to calls to include APNs in nursing home staffing standards.[7] In addition to providing primary care to LTC residents, APNs have shown positive impacts when providing acute or transitional care to older adults, serving in an educational role to residents, families, and staff, and providing consultation to staff or organizations on patient care and systems level issues.[8]

> *The sheer size of the gap between what we have and what we need to ensure adequate nurse staffing in long-term care is staggering.*

The sheer size of the gap between what we have and what we need to ensure adequate nurse staffing in LTC is staggering. Given the high turnover and growing need for a higher skill set among the LTC nursing workforce, simply enticing larger numbers of personnel to enter the field will not suffice to ensure adequate numbers of competent LTC nursing staff in the coming decades. Three key challenges in the LTC work environment need urgent attention before incentive programs to address the current shortfall in personnel will have any lasting effect:

> (1) Recognizing that a diverse nursing staff mix is required, with educational preparation and competency commensurate with the increasingly complex case mix and organizational challenges of LTC.
>
> (2) Enhancing the work environment of LTC to address the extremely high turnover rate. Improvements in pay, supervisory approaches, career advancement opportunities, and development of learning organization approaches that improve quality of care

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are each evidence-based approaches that should be implemented to lower staff turnover.

(3) Integrating LTC into the mainstream of academic work so that scientific advances in the fields of gerontology and geriatrics can be rapidly integrated into LTC practice and so that LTC challenges are routinely addressed by educational and research programs. Such integration would also increase the potential for accelerating translation of care innovations that arise in LTC settings, such as approaches to restraint reduction, rehabilitation, and person-centered care.

The work of LTC, done properly, is time-consuming and must take into account an increasingly complex array of clinical and social factors. Older adults, the primary recipients of LTC, become more individualized as they age; the disability that drives LTC needs is typically accompanied by multiple comorbid chronic diseases and a complex set of social circumstances that also require attention if acceptable quality of life for disabled older adults is to be maintained. The nursing staff who currently work in LTC face considerable challenges in the work environment that add to the substantial clinical challenges inherent in LTC work, including chronic staff shortages,[3] limited access to needed expertise to deal with clinical and social complexities, unrealistic work assignments, low pay, little respect, and few opportunities for career advancement.[9-11] The shift in case mix in LTC toward greater acuity of illness to accommodate declining hospital lengths of stay has been well-documented,[12] and has exacerbated the factors that contribute to turnover. As acuity of resident care has risen in nursing homes, RN hours per resident day have declined by 25% to an average of 19 minutes per day,[13] while nursing assistive personnel levels have remained relatively stable.[14] In many nursing homes the director of nursing may be the only RN on staff.[15] Such staffing trends result in consistently fewer opportunities for staff to access professional nursing expertise to learn how to provide quality care to the growing numbers of older adults in need of increasingly complex care, and undoubtedly compromises the quality of supervision available to staff. The decline in the level of RN staffing is particularly troubling in light of the mounting evidence that RN staffing levels influence care quality.[16]

Even as the case mix in LTC has become more complex clinically, contemporary thinking about long-term care quality emphasizes resident-centric and family-centric approaches in direct contrast to traditional notions of profession-centric approaches to care.[17] Few would challenge the value of moving toward resident-centered approaches; however, the process of changing to a more resident-centric approach requires that staff have access to a much more sophisticated leadership climate than has typically been available to them.[18,19] Although those who have dedicated their professional lives to the important work of LTC may characterize the work as challenging yet highly rewarding, the circumstances just described, coupled with the resource-constrained nature of LTC financing, and the many potential roles available for nurses in other care sectors makes LTC a perfect set-up for continued workforce shortages.

What Incentives Would Attract People to LTC?

The research on staff satisfaction and turnover in LTC increasingly points to the circular relationship between care quality and turnover. Put simply, good nursing staff do not want to work where they cannot carry out their responsibilities effectively and humanely. In order to systematically address nursing staff turnover, there is no escape from confronting the issue that LTC is currently woefully understaffed, with an impoverished skill mix. The problem will only get worse as scientific advances in medicine and geriatrics mean that people can live with increasingly complex chronic diseases. Therefore, the first incentive needed to bring needed nursing personnel into the field of LTC is to recognize the complexity and demand of LTC work by hiring adequate numbers of diverse staff who are paid competitive wages. A recent systematic review summarizing studies conducted by the Centers for Medicare and Medicaid Services (CMS) and others to quantify staffing thresholds associated with minimum care quality outcomes recommends the following: (1) "total minimum direct care staffing levels of 4.1 hours of care per resident day, which should be subject to change to account for differences in resident case mix or comorbidity measures," as is already required by nursing home law; (2) direct care RN staffing levels of 0.75 hours of care per resident day, not including administrative RNs, which should also reflect differences or changes in resident case mix characteristics, and (3) 24-hour RN staffing.[13] Adequacy of staffing levels in long-term care requires attention to both sufficient numbers of staff and their level of preparation. Licensure status matters, but increasingly, adequate educational preparation and demonstrated ability to function in the complex world of geriatrics and long-term care will be required. Not only is RN care critical to quality outcomes such as preventing pressure sores,[20] urinary tract infections,[20] hospitalization,[21] mortality,[22-23] and promoting more rapid discharge home for post-acute patients,[24] but also to reducing the likelihood of expensive litigation.[25] Adding APNs with geriatric competencies would further enrich the care environment by injecting additional combined nursing and medical expertise and enhancing communication between medical and nursing personnel.

In addition to ensuring adequate staffing levels, North Carolina must ensure that those who work in LTC do not suffer serious economic disadvantage compared to workers in other sectors of health care, by mandating LTC payment levels that allow direct care nursing staff to be adequately compensated. Recent salary surveys suggest that RNs in

LTC make approximately $10,000 less per year than in acute care.[26] Although much has been made of the dedication of LTC nurses and their willingness to sacrifice better wages to engage in satisfying work, serious attempts to attract nurses to LTC cannot continue to ignore serious economic disincentives.

A Second, Critical Incentive

The expansion of a meaningful career ladder for staff working in LTC is a significant incentive that should simultaneously address organizational climate factors that impede the staff's ability to implement evidence-based practices. Promising achievements toward this goal have been made through the North Carolina New Organizational Visions Award (NC NOVA) which provides a special licensure status for LTC agencies that provide safe and balanced workloads for staff and that have an organized approach to training and career advancement. Likewise, the innovative WIN A STEP UP program, where CNAs take 30 hours of clinically-oriented continuing education with a modest raise in pay upon successful completion, is another excellent example. Importantly, when integrated with a supervisor training program, this program had greater impact on outcomes of pressure sores and turnover among nurse aides.[4] We cannot overemphasize the importance of coupling pay with training and organizational-level interventions. As noted by one LTC researcher, although frontline workers in LTC, when questioned about what keeps them on the job, almost invariably point to the importance of their ability to care for aging patients, that is not the same as saying adequate pay is not important.[11] Increasingly, the evidence points to wage increases as being necessary but not sufficient to produce increases in job satisfaction.

To be sustainable, attention to career pathways must go beyond the level of nursing assistants to include licensed nurses, as they struggle to obtain the needed skills required to be effective in LTC. The evidence is clear that nursing assistant turnover is tied to the quality of supervision they receive.[11,27,28] With the majority of supervisors in LTC prepared as LPNs, there is clearly a need to prepare LPNs with supervisory skills. But, as we have observed when teaching delegation/supervision skills to undergraduate nursing students at Duke—systematic preparation for supervisory roles is critical.[29] Organizations such as the Paraprofessional Health Institute have developed useful toolkits for training in supervision—the challenge now is how to best integrate these into basic nursing curricula so that all who graduate have the capacity to be effective as supervisors of frontline staff.

Many LTC employers already recognize the value of recognizing nursing staff who are passionate about care of the elderly and who are committed to working in LTC settings. Employer-supported scholarships for advancing education and adoption of career ladders are initiatives that have been shown to improve retention and provide opportunity for increased wages,[30] but a diversified set of approaches will be required to obtain the needed workforce. The workforce needed in LTC today must be better educated about the complexities of geriatric care, geriatric syndromes, comorbid conditions, and the interrelationships of biologic, psychosocial, and spiritual domains. Supervisors and clinicians will need to be experts at managing the multiculturalism that increasingly pervades all levels of the organization. Staff need to be more diverse and must be capable of interacting effectively with diverse coworkers as well as diverse patients. Investing in CNAs, who often are from racial or ethnic minority groups, to help advance their education to professional RN and advanced practice roles is a logical approach to addressing both recruitment into the licensed nurse segment of the LTC nursing workforce and aligns with the goal of developing a meaningful career ladder.

Fortunately, an array of educational interventions have demonstrated success in addressing the knowledge deficits that may exist among LTC nursing staff as the clinical case mix and supervisory challenges increase.[6,31-35] These include both workplace-based continuing education approaches conducted in partnership with universities, as well as the development of advanced practice nursing expertise through more traditional graduate level education.

LTC and Health Professional Schools

There is an urgent need to strengthen partnerships between LTC and health professions schools to foster adequate preparation of graduates for practice in the LTC setting and to foster accelerated implementation of new knowledge into LTC. Again, North Carolina has made some promising initial starts, but the breadth and depth of these partnerships needs to expand beyond individual university, school, or faculty efforts, to mobilize efforts that reach across LTC settings and programs. One particularly compelling model has been developed in Oregon, where nursing educators have come together to develop a seamless approach to integrate the ADN (associate degree in nursing) and BSN (bachelor of science in nursing) education to address the broader nursing shortage. Key to this model is coordination among academic centers on admission processes, curriculum development and integration, and matriculation across the education programs. A similar strategy is currently being pilot tested in North Carolina through the Foundation for Nursing Excellence. Combining innovations to streamline access to university preparation for nurses with transitions into practice initiatives that are also underway to improve nurse retention, and shifting their focus to LTC settings could have an incredibly strong impact on nursing practice in LTC. Encouraging high performing LTC nurses to enter innovative academic programs, such as the doctor of nursing practice program, with its emphasis on translation, transformation, and quality could also accelerate the pace of transformational change in LTC.

Training alone will not suffice to eliminate the large shortfall of LTC workers. LTC organizations, nursing organizations, and educational institutions will need to partner as never before to develop, test, and facilitate implementation of the knowledge that is required to keep an appropriately skilled workforce in LTC in a cost-effective manner. No one organization has yet shown they have the full set of knowledge needed to address LTC workforce needs on the scale that is needed, but many of the universities and schools in North Carolina have led effective LTC innovations, suggesting that the key ingredients needed for productive academic-practice partnerships exist that could lead to sustainable improvements in the LTC work environment. For example, Duke University's Center of Excellence in Geriatric Nursing Education[35] and the Duke Aging Center provide two examples of innovations led by the private sector; the UNC system schools have also demonstrated the capacity to innovate in LTC, through inter-school initiatives such as the UNC Institute on Aging, and through school-specific innovations such as UNC Chapel Hill School of Nursing's simulation learning innovations[36,] and work by the UNC Greensboro School of Nursing[37] to improve access to geriatrics at the bachelor's level. Finally, the innovative work of the Foundation for Nursing Excellence points to the potential for linking these diverse groups. New national health care reform legislation contains several provisions that could be used to finance the reforms described above. The proposed CMS innovation center and new funding for nurse-managed clinics could provide funding to examine the effects of enhanced APN staffing. Increased federal funding for geriatrics education, including a much anticipated realignment of graduate medical education funds to support advanced practice nursing education is also on the horizon.[39] Although a mix of federal, state, industry, and philanthropic funding will likely be required to support the realignments needed to address the root causes of chronic LTC workforce shortages, North Carolina has a strong history of securing all three types of funding to address LTC problems.

The shortfall of nursing staff needed to care for North Carolinians in need of LTC is massive. Half-hearted efforts to stimulate and form needed partnerships will not be sufficient to create the needed incentives and structures that will ensure an adequate LTC nursing workforce. However, North Carolina is better positioned than most states to mobilize the evidence base to address nursing workforce shortages in LTC, as it is home to a critical mass of talented scholars with a demonstrated capacity to collaborate with innovative LTC workplaces and leaders. Will this be the decade where we finally find a way to join forces to move this problem from its status as "mission impossible" to "mission critical?" **NCMJ**

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Strengthening the Direct Care Workforce in North Carolina

Susan Harmuth; Thomas R. Konrad, PhD

Developing the capacity and quality of the direct care workforce continues to be a serious issue for states, including North Carolina. There are many well-trained, committed, caring, and competent direct care workers in North Carolina providing care every day to persons in need of long-term care services at home or in residential- or facility-based settings. This fact, however, does not negate the reality that high turnover and vacancy rates continue to be a major concern for states. With the aging of the population and advances in medical care that help people live longer lives, demand for well-trained, quality direct care workers will grow rapidly. This is illustrated by the fact that two of the three major categories of direct care workers currently tracked by the US Bureau of Labor Statistics are ranked as the second and third fastest growing occupations in the country between 2006-2016.[1] North Carolina is projected to need 43,340 additional direct care workers between 2006 and 2016, a 43% increase.[2]

North Carolina has had an ongoing focus on the direct care workforce since the late 1990s. Through numerous collaborative efforts with a variety of stakeholders, several major initiatives and other smaller scale projects have been implemented. This forward momentum has occurred in spite of two significant downturns in the economy during this period. Early efforts positioned North Carolina to successfully compete for federal and private foundation grants focused on the direct care workforce. Civil monetary penalty funds have also been used to help support nursing home targeted efforts. Initiatives implemented were intended to address recruitment and retention, improve direct care jobs and the workplace culture, improve the quality of care provided, and develop an ongoing data collection and analysis capacity to examine workforce trends and assess the effect of various initiatives.

Having a continuing focus, combined with considerable consistency in the make up of key partners in the work, has enabled North Carolina to integrate, wherever possible, new workforce efforts with other training and quality improvement efforts being undertaken by the state, provider associations, or other stakeholders.

While not every group listed has participated in all the major initiatives discussed in this commentary, key partners have included the North Carolina Health Care Facilities Association; North Carolina Long-Term Care Facilities Association; North Carolina Assisted Living Association; Association for Home and Hospice Care of North Carolina; numerous divisions/offices within the North Carolina Department of Health and Human Services (NCDHHS); Direct Care Workers Association of North Carolina; Friends of Residents in Long-Term Care; the Carolinas Center for Medical Excellence; UNC Institute on Aging; the Gerontological Nursing Specialty Program at Duke University; North Carolina Board of Nursing; the North Carolina Community College System; and the North Carolina Foundation for Advanced Health Programs, Inc.

> ***...high turnover and vacancy rates continue to be a major concern for states. With the aging of the population and advances in medical care that help people live longer lives, demand for well-trained, quality direct care workers will grow rapidly.***

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Some of the major accomplishments over the past decade have been the creation of two advanced job category listings on the state's Nurse Aide Registry. These job categories were developed to provide meaningful career path options for nurse aides on the Registry while also responding to advanced training and skill needs identified by long-term care employers. The two job categories include a medication aide and a geriatric nurse aide. To be listed as either a medication aide or geriatric nurse aide, nurse aides must successfully complete additional training and a competency test. Data analysis efforts have also been instituted to track medication error rates as well as determining the extent to which these new job categories provide a career path for workers in terms of increased pay. A third new career path option, a home care nurse aide specialty, is currently under development, funded by a grant to the North Carolina Foundation for Advanced Health Programs from the North Carolina Health and Wellness Trust Fund. The home care nurse aide specialty will focus on the unique service delivery issues experienced by nurse aides working in home care settings where on-site supervision is not routinely available. Listing for this new job category will also require successful completion of training and competency requirements. Once implemented, trend data pertaining to nurse aides completing this additional training and wage data related to this job category will also be tracked.

North Carolina has earned national recognition for two innovative programs viewed as potential models for other states, stemming from projects implemented through the national Better Jobs Better Care research and demonstration grant initiative funded by the Robert Wood Johnson Foundation and The Atlantic Philanthropies. North Carolina's research grant project built upon the existing WIN A STEP UP program for nurse aides working in nursing facilities. WIN A STEP UP emerged from a partnership between the North Carolina Institute on Aging at the University of North Carolina at Chapel Hill and NCDHHS, and was initially supported by the Kate B. Reynolds Charitable Trust in 2000. The program aims to enhance care for North Carolinians living in nursing homes by addressing the costly problem of nurse aide turnover which interrupts the caregiver-resident relationship and exacerbates staffing shortages.

WIN A STEP UP is based on three principles: (1) *education*, which is essential for quality service by building competence, self-esteem, and teamwork in the workforce; (2) *compensation*, where concern about direct care workers is reflected in nurse aides' paychecks and benefits; and (3) *commitment*, ensuring that all parties who receive program benefits formally agree to contribute and be held accountable for their performance. WIN A STEP UP currently provides two days of intensive coaching supervision training for frontline nurse supervisors and provides 30 hours of training for direct care workers, monetary payments, and recognition. Direct care workers agree to attend classes and keep working at the facility for a specified period of time after they finish the classes. Their employer agrees to commit staff time to completing the program and distributes a retention bonus or wage increase to participants who successfully complete the curriculum. For the last several years, the program has supported continuing education of nursing assistants and their supervisors in nursing homes and strengthened facilities' capacity to reinforce and accelerate organizational culture change by embedding certified coaching supervision trainers within participating homes.

WIN A STEP UP has reached over 1,000 direct care workers and their supervisors in nearly one-quarter of North Carolina nursing homes and has gained national recognition because it has the proven capacity to improve skills, increase career commitment, and provide recognition to its participants.[3] In 2004, the US Department of Health and Human Services identified WIN A STEP UP as one of three programs nationwide proven to be effective in reducing nurse aide turnover. In 2007, WIN A STEP UP was selected as one of two national finalists for the Rosalynn Carter Caregiving Award. Program design has evolved by developing and applying evidence through applied research, and rigorously conducted evaluations have linked WIN A STEP UP to improvements in nursing care, reductions in aide turnover, and decreases in pressure sores among residents in participating facilities.[4-7]

The second innovative project recognized nationally is the North Carolina New Organizational Vision Award (NC NOVA), developed through the Better Jobs Better Care demonstration grant to the North Carolina Foundation for Advanced Health Programs (NCFAHP). NC NOVA is a first in the national special licensure program for nursing homes, adult care homes, and home care agencies and is intended to improve direct care jobs, build effective workplace teams, boost staff morale across the organization, reduce turnover, and improve quality care and consumer satisfaction. Qualifying organizations are awarded a special license by the state's Division of Health Service Regulation. To date, nine organizations have achieved this prestigious designation. Although still early in the data analysis process, in 2008 annual average turnover rates for NC NOVA adult care home and nursing home designees were between 61%-89% lower than the aggregate statewide rates for these settings.[a] Average annual turnover data for NC NOVA home care agency designees were 12% lower than average statewide data home care agencies overall. It is also worth noting that the three state-operated neuromedical treatment centers are working to implement NC NOVA criteria with the

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[a] Moxley J. Office of Long-Term Services and Supports, North Carolina Department of Health and Human Services. Personal communication. November 2009.

ultimate goal of attaining NC NOVA designation since these settings can also benefit from the workplace culture change expectations included in the NC NOVA special licensure designation program.

NC NOVA's partner team developed the program with several core principles in mind including linking state policy to practice through special licensure, being voluntary and incentive based, being a comprehensive "raise the bar" program, having a determination process separate from the state's regulatory process through use of an independent review organization, and having the special license issued by the state which provides creditability for employers, workers, consumers, and the general public. North Carolina has received national attention not only for NC NOVA but also for the partner team's highly effective and collaborative approach to the program's development.[8] In light of NC NOVA successes, the Robert Wood Johnson Foundation provided additional funding to the NCFAHP after NC NOVA was implemented to create a guide for other states that may be interested in developing a similar program.

Currently, NC NOVA partners are working to further strengthen NC NOVA by working to put in place the structures to provide a Medicaid-funded enhanced performance payment for NC NOVA designees at some point in the future, put structures in place to ensure long-term integrity and consistency of the independent review process, and develop structure and technical supports for organizations interested in working toward NC NOVA designation. These efforts are being funded through a grant from The Atlantic Philanthropies to the NCFAHP.

North Carolina has been successful in the face of numerous challenges over the last decade for several reasons. First, the state has kept together a broad coalition of stakeholders who have recognized that the direct care workforce shares many common strengths and challenges despite differences across a variety of work settings. Secondly, North Carolina's stakeholder coalition has been persistent, flexible, and pragmatic in the acquisition and deployment of limited public and private resources for workforce development. Finally, North Carolina has made extensive use of data and evidence, systematically monitoring programs, evaluating program performance, and using that evidence to continuously improve effectiveness and increase efficiency. Finally, it is clear that North Carolina's programs strengthening the direct care workforce are part of a dynamic process of ongoing culture change activities and quality improvement collaboratives that are coming to be an accepted part of the landscape in the long-term care sector throughout the state.

Although important steps have been taken, these efforts must be sustained and built upon. North Carolina will need approximately 43,000 additional direct care workers by 2016. The title of the national direct care workforce initiative, known as Better Jobs Better Care, most aptly describes the core focus for all future work if we are to attract and retain the significant number of additional workers that will be needed in the coming decade to provide quality care to consumers and families in need of paid long-term care services. **NCMJ**

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Identifying Challenges and Opportunities for the Long-Term Care Medical Practitioner

Jose Gonzalez, MD, CMD

I am a "SNFist" or a "SNFologist." That is to say that I devote my full-time medical practice to taking care of residents and patients in long-term care (LTC) facilities. Firsthand knowledge and daily interactions with patients in various settings and different facilities has allowed me to gain insight into some of the challenges and opportunities of caring for residents in LTC facilities such as skilled nursing facilities (SNFs).

Currently, most of the residents I care for in skilled nursing facilities comprise two larger groups. The first is described as "post acute care." As hospital stays have become shorter in recent years, the SNF has become an important and useful intermediary step in the transfer of residents from inpatient hospital care towards returning to their home setting. Common examples of this group include residents who suffered traumatic injuries, significant surgical interventions, elective orthopedic procedures, or debility and deconditioning, where patients are unable to safely perform their activities of daily living (ADLs) within the limitations or circumstances of their domiciliary arrangement. The second group of residents in most skilled nursing facilities is what most people commonly associate with a nursing home resident. These are residents that reside long-term in a facility for daily assistance and management of their medical problems and ADLs. Returning home is not a practical or safe alternative for these patients. Circumstances that usually preclude a transition to a SNF include the availability of social support, frailty, and chronicity of medical problems.

One big challenge in meeting the needs of these two groups is the constraints of the physical facilities themselves; many were set up, designed, and built in the distant past. Residents and families in the post acute care setting, who are working towards returning home, usually prefer to live in private rooms, which are not readily available. Some buildings have a specific area devoted to rehab patients; others do not. Sometimes patients in a facility for a short-term stay have to share space and areas with residents with entirely different needs. There is currently a national trend developing to convert and change the physical set up of some facilities to a 'residential/community' structure. In this arrangement, instead of all residents sharing a pool of interdisciplinary teams (e.g., patient care, nursing, dietary, laundry), residents reside in smaller subgroups within the facility, usually called neighborhoods, and are cared for by a smaller, more familiar core care team that share the duties of the interdisciplinary team with a smaller group of residents. The difficulties of retrofitting older facilities and building new facilities to accommodate this patient structure are major challenges in moving to this neighborhood concept.

> ***In contrast with a more interventional disease driven model, caring for a resident in a long-term care facility is frequently more about disease management and how these processes affect the resident's quality of life.***

Transitions in care are a big issue within long-term care. Residents may initially come from their homes, an inpatient hospital setting, or from another facility. Obtaining accurate information on current medications, recent medication changes, indication for antibiotic treatments, duration of treatments, and dates for follow-up appointments with community providers can often be challenging. Residents can be sent to the emergency department and/or admitted to hospitals from the SNF for evaluation of new significant acute issues or decompensation of chronic medical problems. In the past, most patients were cared for by a primary care

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physician in the community who saw them in an outpatient setting and then in the hospital, and, if needed, in skilled nursing facilities. Some physicians even made home visits. Current changes in delivery of health care, driven by multiple constraints including time, expenses, and productivity have further fragmented the health care delivery system, and it is now more common to have a community primary care provider who does not follow patients in the hospital, where they are cared for by a hospitalist, and then transitioned back to the community or to a skilled nursing facility. In the case of transferring a patient to a skilled nursing facility, the patient is usually cared for by an attending who may or may not be in the primary care physicians' group. Instead they may be another community attending not previously associated with the patient. We now have a group of providers that care for patients exclusively in some LTC facilities. These shifts in responsibility create challenges in coordination of care of residents, and in meeting expectations from patients, families, and other health care providers.

Many local communities struggle with finding physicians and providers to care for residents in their facilities. There is an increasing shortage and need of primary care physicians, especially in the field of geriatrics. Many facilities have medical directors and attendings that are no longer taking new patients in facilities or choosing not to continue to care for residents in LTC facilities. New medical students are choosing non-primary care medical specialties, and it has been hard to attract students to choose careers in primary care. Physician extenders (nurse practitioners and physicians assistants) help fill the void and are playing a larger role in caring for residents in LTC, collaborating with and under the supervision of a physician. State and federal regulations for clinical care mandate a minimum number of visits for new and established residents. Currently new admissions to a skilled nursing facility must be seen every 30 days for the first 90 days, and after this period every 60 days. The initial admission visit must be made by their attending physician, and subsequent visits may be alternated with an extender.

The American Medical Directors Association (AMDA), the leading group of medical directors and attending physicians in LTC facilities, has a strong mentoring program for younger physicians who may be interested in a career in long-term care. AMDA also offers a curriculum for the certified medical director (CMD), and recently published results that a facility with a CMD demonstrated up to 15% improvement in quality measures.[1]

Caring for residents in skilled nursing facilities is often different than caring for residents in the community or outpatient setting. Discussion and review of goals of care between the patient and family and the interdisciplinary team are crucial. In order to provide person-centered care, one must understand the physical, medical, personal, and even spiritual needs and expectations of a patient. In contrast with a more interventional disease driven model, caring for a resident in a long-term care facility is frequently more about disease management and how these processes affect the resident's quality of life. It is important to review and discuss expectations in order to facilitate and accommodate the patients and their families' needs. In the state of North Carolina we are fortunate to have the Medical Orders Scope of Treatment (MOST) tool.[2] This document is complementary to advanced directives, and expands upon the traditional "do-not-resuscitate" form. It differs in that it is a portable "medical order." The form, in addition to addressing resuscitation orders, expands on issues such as the level of medical interventions, antibiotics, intravenous fluids, and nutritional support allowable. Local and coordinated community utilization of the MOST tool between facilities, emergency medical services, hospital, and emergency rooms is important in implementing this tool successfully. The admission process to a SNF is a good opportunity to discuss and review goals of care with a resident and their families when applicable.

The demographics of the Baby Boom generation predestine us to a significant growth in LTC services in all locations. Aging advocates have successfully lobbied Congress to fund a series of demonstration projects that focus on fostering a more patient-focused (and cost-effective) system of LTC care. This concept was incorporated into the Medicare Modernization Act (Section 646 of the Medicare Modernization Act, also known as the Medicare Health Care Quality Demonstration Program).

In North Carolina, the Division of Medical Assistance (Medicaid) saw the same problems as those recognized in Section 646. The Division, working with the 14 existing Community Care networks, established a new nonprofit—NC Community Care, Inc. This entity applied for and won a grant to implement a two-pronged program to improve "quality of care and services delivered to Medicare beneficiaries through system redesign that fosters best practices..."[3] One arm focuses on community care, the other on LTC settings. In the demonstration, there will be 26 intervention counties in the state, with the target population being dual eligible (those eligible for both Medicaid and Medicare coverage) and Medicare-only patients.

Avoiding unnecessary transfers and the needs for pharmacotherapy management are two of the main issues in which LTC facilities may be affected by interventions. By coordinating patient care between facilities, attendings, and medical directors, the 646 Demonstration will treat patients in place, instead of, or prior to, sending them to the emergency room. Managing this population with multiple chronic illnesses may help in improving health care outcomes. With the utilization of pharmacy consultants, monitoring for drug interactions and pharmacotherapy optimization and medication reconciliation (the process of reviewing medications and changes) during the various transfer process of the residents may also result in improvement in health care outcomes.

Long-term care facilities are becoming a crucial component in the delivery of health care and management of chronic health problems. Challenges include recruiting health care providers to manage and care for residents to meet their personal care needs and coordinating the flow of information between inpatient services, community consultants, and specialists, as well as community providers. Opportunities exist to improve on systems to deliver health care to these residents that are consistent with their goals of care. **NCMJ**

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The North Carolina Chapter of the American College of Physicians congratulates the winners of its 2010 Associate Poster Competition. The competition was held March 5, 2010 during the NC/ACP's Annual Scientific Session at the Washington Duke Inn in Durham.

Best Overall: Laurel Kilpatrick, MD (Wake Forest University)

Best Clinical Vignette: Brittany Bohinc, MD (Southeast Area Health Education Center)

Second Place Clinical Vignette: Steven Heatherly, MD, PhD (Wake Forest University)

Third Place Clinical Vignette: Melanie McMinn, MD (Carolinas Medical Center)

Best Clinical Research: Laurel Kilpatrick, MD (Wake Forest University)

Best Basic Research: Surovi Hazarika, MD (Brody School of Medicine at East Carolina University)

Best Student (tie)**:** Brian Petullo, MS (University of North Carolina at Chapel Hill) and Alex Warren, MS (Brody School of Medicine at East Carolina University)

Congratulations, winners!

The next meeting of the Chapter will be January 28-29, 2011. For more information, contact Nancy Lowe, CMP at (919) 833-3836 or nlowe (at) ncmedsoc.org.

"Rum Raisin, Monkey Crunch, and Mocha Frappucino Cherry with Gummy Bears on Top:"

Striving for Personal Autonomy and Choice in a Regulated Long-Term Care Environment

Ken Burgess, JD

The title of this commentary comes from a metaphor often used to describe the current generation of baby boomers who are now entering, and will continue to enter in unprecedented numbers, America's and North Carolina's long-term care facilities. The hugely profitable Ben and Jerry's ice cream brand reputedly owes its success to a wildly creative willingness to give consumers whatever they want and to leap, not crawl, beyond the chocolate, vanilla, and strawberry consumer choices of the past. The metaphor has been applied to describe America's aging population as a generation used to getting what they want and entering old age expecting that to continue. Put simply, we baby boomers are used to having choices *and* the freedom to exercise those choices—and we like both very much.

The generation of aging North Carolinians who are heading into the state's long-term care facilities (and community-based alternative settings as well) generally has been exposed to more educational opportunities, earned more money, bought and sold more homes, changed jobs more frequently, married and divorced more often, and has been presented with more options in all phases of life than any prior generation. Demographers tell us that two out of every three Americans, and thus North Carolinians, over the age of 65 will spend some time in a long-term care facility. So, we should assume they'll arrive at the doors of the state's long-term care facilities armed with this experience of choice and fully expecting, and likely demanding, that this will continue.

Add to the mix the reality that long-term care and, in particular, skilled nursing facilities, are the most heavily regulated sector of the American health care industry and you've got a formula for trouble. During my nearly 26 years as a long-term care attorney, I've visited nursing homes in virtually every state in the country. But one visit, several years ago in California, really made an impact on me. I was chatting with an elderly gentleman and innocently asked "So, how do you like it here?" "It's a'right," he said, "except they tell me when to eat, what to eat, how to eat, and how much to eat. I'm not a baby."

This kindly old gentleman was living the reality of a system of prescriptive long-term care regulation that has developed in this country since the passage and full implementation of the Omnibus Reconciliation Act of 1987 (OBRA), also called The Nursing Home Reform Act. Laudable in its goals, and certainly with many improvements in quality of care and quality of life to its credit, this well-intentioned statute and its implementing regulations, seven separate sets in all, have morphed into the most restrictive and punitive set of federal regulations in all of American health care. Among its many other features, the law prescribed an array of alternative sanctions, called "remedies" by federal regulators, which include daily civil money fines ranging from $50 up to $10,000 per day for each day of an alleged violation of one of the 187 separate requirements to which skilled nursing facilities are held. The result has been that even a single instance of a well-intentioned staff member making an inadvertent error can cost a facility hundreds of thousands of dollars.

Both environmental and programmatic components of long-term care have developed with more focus on safety than on individual autonomy and choice.

No other sector of the health care industry has such a system. For the vast majority of health care providers, available sanctions for alleged violations of applicable regulations are limited to a required "plan of correction," short-term denials of payment for care provided, loss of licensure (relatively rare), loss of Medicare or Medicaid

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certification (i.e., the ability to participate in those programs), or loss of accreditation by a third-party accrediting body (also rare). There is no corollary to the nursing facility sanction system in any other part of the health care industry.

The negative impact of this system of sanctions has been multiplied by federal regulators' consistent expansion of the federal OBRA regulations via a set of "interpretive guidelines" made available to state health surveyors, who apply these regulations for federal officials under contract. This has expanded the outcome-oriented OBRA regulations well beyond their original language to an ever-increasing set of directives that dictate virtually every aspect of nursing facility life and care. Rather than defining a required outcome for residents, the published regulatory interpretations not only dictate the result which must be achieved, but how it must be achieved.

The common theme in many of these regulations and the expansive "interpretive guidelines" designed to explain them is the notion that providers must ensure the safety of residents at all times and at all costs. That's a notion with which most people would agree—in a vacuum. But when we insist on safety at all costs in long-term care to the exclusion of individual resident autonomy and choice, that's a very high price to pay.[1] By making this value judgment a precept of long-term care law, we severely limit and often fully extinguish the rights of seniors to make their own informed choices in favor of some third party's view of what is best for them.

One noted expert on quality in long-term care captured the problem when he said, "what we want is autonomy for ourselves and safety for those we love."[2] It's quite clear, at least to me, that federal policymakers and regulators of the nursing facility industry have consistently weighted safety over autonomy for many years. In the past few years, federal regulators have at least given lip service to balancing resident safety with individual choice and autonomy. Yet the regulations themselves, their interpretation by regulators, and the deficiency citations which emanate from them reveal a regulatory system still heavily weighted towards safety over resident choice.

One tool which could help rebalance these potentially competing tensions is known as a "negotiated risk agreement." Negotiated risk agreements are written agreements between facilities and competent residents, or surrogates of incompetent residents, which are designed to balance the inherent tension between federal or state regulations, the resulting facility policies designed to comport with those regulations, and resident choice. The concept is simple. The debate surrounding these contracts is not.

In 2002, the Assisted Living Federation of America published *Negotiated Risk Agreements in Assisted Living Communities*, a manual designed to promote discussion of the topic and to suggest appropriate uses of negotiated risk agreements, highlight their limitations, and suggest some protections against possible abuses of the tool.[3]

In response, a number of national consumer advocates lambasted the concept as a ruse by providers simply seeking waivers of liability from substandard resident care and called for their outright ban. They also argued that no contract is needed to guarantee residents freedom of choice because that right is already protected under existing laws, and that adequate care planning is the tool for effectuating those rights.[4] Those arguments, however, missed the point that care planning and the exercise of resident rights found in existing laws both exist within the context of regulated institutional environments where providers are expected, first and foremost, to ensure the health and safety of residents. The very fact that negotiated risk agreements did arise as a method of promoting resident choice attests to the reality that care planning will not, in every case, adequately resolve the conflict between government regulations or interpretations, facility rules and policies, and a resident's specific choices.

A negotiated risk agreement is simply a contract between a long-term care provider and a resident, or the legal surrogate of an incompetent resident, which memorializes the parties' discussions and agreements regarding the resident's preferences and how they will be accommodated by the provider. These contracts were born from a desire to maximize resident autonomy, independence, and choice in the micro-regulated environment characteristic of institutionalized long-term care.

The issue of whether increased regulation has benefited residents and improved the long-term care industry is beyond debate—clearly it has. But those improvements arguably have come at a high price for residents. Many of the regulatory changes designed to make long-term care facilities safe for residents have also resulted in the institutional feel of facilities, including the use of hospital beds, the absence of locked doors, and so forth. Both environmental and programmatic components of long-term care have developed with more focus on safety than on individual autonomy and choice. And those developments have necessarily stressed the avoidance of harm and the reduction of risk over the promotion of choice by residents.

Negotiated risk agreements were first developed in the 1990s by assisted living providers trying to rebalance the inherent tension between resident safety and choice away from an over-emphasis on safety. These contracts were originally conceived as the end product of a process in which an assisted living community and a resident negotiate over a resident preference to engage in or avoid certain activities or behaviors which the community normally would not allow because they involve unacceptable risk to the safety or health of the resident, and to then negotiate some resolution of that tension between the community and the resident. These agreements arose as a matter of practice first and were only later incorporated into law by several states through their licensure regulations for assisted living communities.[5]

By the end of 2006, 14 states and the District of Columbia expressly authorized negotiated risk agreements (sometimes called managed or shared risk agreements) in their assisted living licensure laws.[6] No states currently prohibit their use. To date, the use of negotiated risk agreements has been confined largely to the assisted living setting. However, that may be more a function of history than substance. When these agreements were first used, there was a presumption that because assisted living communities were less regulated than nursing facilities, there was more room for creativity and thus for tools like negotiated risk agreements. In the decade or so since these contracts were first used, however, that has changed. Although the assisted living industry still lacks a national quality of care statute akin to OBRA for nursing homes, licensing laws in most states now closely mirror corresponding laws for nursing facilities, particularly regarding care planning, admission and discharge, staffing levels (though not types of staff), assessments, and other substantive care requirements. Although states generally do not allow the admission of residents into assisted living communities who need 24-hour nursing care, other regulatory attributes of the two service sectors seem more alike than different. Given this convergence of regulatory environments, it is certainly arguable that, to the extent negotiated risk agreements can be appropriately used in assisted living communities, they can also be used appropriately in nursing facilities. Put another way, why should nursing facility residents be denied the same access as assisted living residents to tools that promote individual choice and autonomy?

While there is no standard form or content for a negotiated risk agreement, even in the 15 states that expressly authorize their use, most legal and policy experts familiar with these documents agree they should include several key elements:

- An expression of the resident's expressed preferences or choices.
- An explanation of the conflict between the resident's choices and the provider's normal policies.
- A discussion with the resident of the potential risks of that behavior to the resident or others in the facility, memorialized in the agreement.
- An exploration of alternatives to the expressed preferences of the resident which may be acceptable to both resident and provider.
- An agreement between the resident and the provider governing future behavior of the resident and the provider on the issue or issues under discussion.
- An acknowledgement, either express or inherent, that the resident understands the risks he or she is taking and wants to take them nonetheless.

It is the last element, sometimes inappropriately called a "liability waiver," that has created intense debate and raised the ire of some consumer advocates. They view it as an attempt by providers to avoid legal liability for inadequate care or supervision and, in that simplistic argument, overlook the fact that the larger purpose of negotiated risk agreements is to restore, as much as possible in the highly regulated environment of long-term care, a resident's rights to exercise the same freedom of choice he or she would exercise if living independently in the community.

To be sure, negotiated risk agreements can be abused. But they also create benefits for residents frustrated by the loss of freedom of choice caused by the absolute requirement that residents be safe first and foremost. When these agreements are used judiciously and properly, both the resident and provider benefit. Many industry observers who have studied this issue agree that by operationalizing and standardizing a process for identification of conflicts between individual choice and a regulator's or provider's desire for resident safety, discussion of those conflicts and exploration of creative ways to resolve them, and ultimately reaching agreement on a resolution, negotiated risk agreements can foster choice, help avoid miscommunication and misunderstanding in the care process, and avoid serious disputes later between providers and residents or family members. They also focus attention on issues where care planning has not satisfactorily resolved a conflict between resident choice and facility policy or regulatory expectations.

A number of significant issues must be considered when using negotiated risk agreements, and those states that regulate them have offered little guidance on these issues. Included among them are the range of resident choices that can be covered by a negotiated risk agreement; when the extraordinary step of negotiating risk in a formal agreement should be used to accommodate resident preferences in addition to the normal care planning process; when residents with diminished mental capacity should be allowed to express their preferences via a negotiated risk agreement executed by a designated health care agent or guardian; and, ultimately, whether these agreements are enforceable. To date, there are no reported judicial decisions specifically involving negotiated risk agreements. How courts will view them is unclear, including whether a competent resident injured solely as the result of a choice expressed in a properly executed negotiated risk agreement may nonetheless successfully sue the provider. So, many questions remain unanswered about these documents.

However, proponents of negotiated risk agreements do agree on several important points, many of which dispel some of the traditional objections to negotiated risk agreements. First, it is the law in every state that no private contract can change or avoid state or federal law. So, providers cannot "negotiate" away their responsibility to provide care and services consistent with state or federal law and the applicable standard of care in their community, or their liability for negligent care. Arguments by opponents of these contracts that this is the primary goal of providers misunderstand basic contracts and negligence law.

Second, any agreement with a resident who lacks the legal mental capacity to execute a contract will be unenforceable. So, the suggestion that providers will benefit by asking incompetent or questionably competent residents to enter such agreements as a shield to future liability is misinformed.

Third, providers should view these agreements as an extraordinary measure that may benefit both provider and resident in cases where the normal care planning process has not resolved the conflict between the provider's normal policies and a resident's expressed preferences. They are not, however, a method of avoiding regulatory responsibility or legal liability for substandard care, inadequate staffing, the retention of residents who do not meet admission or retention policies, or a host of other practices that would be impermissible or illegal under state or federal law, reimbursement policies, or facility policies.

Fourth, any process designed to resolve conflicts with residents over their personal choices should include safeguards to ensure that residents are competent to make such decisions, that residents are not coerced or threatened with discharge if they fail to enter an agreement with the provider, that the spirit of the negotiation is one of give and take, and that a sincere desire exists to compromise the tensions sometimes inherent in individual choice and facility responsibility for the resident's safety. Simple steps like developing a facility policy on the use of negotiation and negotiated risk agreements, including a resident's family member, an ombudsman or other third party representative in the negotiation, and/or recording the negotiation session, for example, can help allay concerns that the process will be one-sided or unfair to residents.

Despite harsh criticism of negotiated risk agreements by some consumer advocacy organizations, their use is growing and the concept seems to be gaining official recognition in the law and among government regulatory and policy authorities, at least in the assisted living setting. A November 2000 report by the US Department of Health and Human Services referred to these contracts as "the formal mechanism for achieving" resident independence and autonomy.[7]

In February 2006, the US Department of Health and Human Services issued a report entitled *A Study of Negotiated Risk Agreements in Assisted Living.*[6] That report was significant because it was the first comprehensive study by the federal government of negotiated risk agreements. Moreover, while the report acknowledged some controversy surrounding the use of these agreements, it also concluded that "negotiated risk agreements can be a useful tool to help residents and providers achieve a balance between desires for autonomy and concerns about safety." The report also highlighted some of the inconsistencies in the use of these contracts and suggested the need for additional guidance and training on their use. Unfortunately, this potentially important tool has not found its way into the skilled nursing facility regulatory environment.

Much of the published literature on this topic is more of a war of words and accusations than an informed public discourse on how to promote resident autonomy in long-term care institutional settings. Residents, regulators, and providers will be better served by cooperating to develop guidance on the proper use and limitations of negotiated risk agreements and other tools designed to promote resident autonomy, acknowledging the risks of these tools, and ensuring the presence of adequate safeguards in their development and use.

Finally, these agreements need to be incorporated into statutes and/or regulations governing long term-care facilities. The current safety-over-autonomy mindset of long-term care regulators is deeply embedded in and stems almost entirely from existing regulations governing the skilled nursing facility industry. And those regulations are here to stay. Given that, the competing notion of resident choice and autonomy, properly balanced with safety, must also be given official acknowledgement in those same regulations to claim its rightful place in the regulatory scheme. Put differently, it matters not what providers or their customers, the residents, agree upon if regulators can essentially overrule those agreements under the guise of regulatory enforcement.

So, for the record, I do like chocolate, vanilla, and strawberry ice cream. But, if it's all the same to you, I just want to the right to choose monkey crunch if I want it. **NCMJ**

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Innovations in North Carolina Skilled Nursing Care:

New Uses of Technology and Approaches to the Routines of Care

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Polly Godwin Welsh, RN-C; Carol Durham, RN, EdD, ANEF; Mandy Richards, RN, MSN, CCCN

Many changes are underway in the structure and operations of skilled nursing care facilities in North Carolina. Not only are facilities across our state making changes in their physical structures through renovation and new construction, but many changes are taking place in the role they play in the larger spectrum of health care services in the communities they serve. For example, as a result of the trend toward more rapid discharge from hospitals following acute care episodes, many skilled nursing care facilities have expanded their post-acute care and rehabilitation services. At the same time, modern medicine's ability to manage chronic disease and increase life expectancy have greatly impacted the need for skilled nursing services, as well as the need for expertise in the care of residents who reflect the increasing prevalence of certain forms of dementia.

As these facilities have grappled with these changes in the need and demand for their services, there has been an increased interest and investment in various forms of technology that can make the care provided in these facilities both technically more effective and at the same time more likely to assure a high quality of residential life for those who reside in skilled facilities regardless of the duration of their stay.

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In this commentary, we will describe two such uses of technology that are seeing increased use in nursing homes in North Carolina. The first of these is a new approach to nursing staff in-service training; the second is a new, multifaceted technology for enhancing the life experiences of older adults now living in nursing homes.

The Patient Care Simulator Project

Patient care simulators (PCSs) have become ubiquitous in American health care educational settings. These electronic and computerized mannequins have been used to train teams of EMS first-responder care personnel and medical and nursing students. Hospitals in several North Carolina communities have purchased simulators and established patient care simulation laboratories for the in-service education of multispecialty clinical teams. These simulators have also been used in conjunction with the North Carolina Area Health Education Centers (AHEC) program to train nursing personnel from multiple skilled nursing facilities who journey to regional AHEC training sites for these sessions.

Nursing homes in the state have found the centralized or regionalized structure of these training sessions somewhat difficult to incorporate into their normal patterns of staff development because of the necessity for the learner to leave the workplace for an extended period of one or more full days in order to take advantage of such training. Due to

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this scheduling difficulty, another model for the extension of this type of training within the long-term care field was called for: a facility-based approach to advanced team training in skilled nursing facilities

To meet this need, the private, nonprofit educational and research foundation, *FutureCare of North Carolina*, sponsored by the North Carolina Health Care Facilities Association, designed a new program. This program enables an itinerant nurse educator to travel with a patient care simulator to individual nursing homes for three to five days, during which a high proportion of all nursing personnel on every shift (nurse aides, licensed practical nurses, and registered nurses) would interact with the PCS mannequin and work through one or more clinical modules of care. Through a generous grant from The Duke Endowment, this program was launched in the spring of 2009 and will eventually reach as many as 40 nursing homes in North Carolina.

Using a familiar respiratory problem scenario in the geriatric setting, staff interact, use assessment skills, communicate, and intervene to respond and collaborate within the interdisciplinary team. During the training, the focus for nursing aides is on confidence building and their place within a care team while development of leadership skills and awareness is targeted toward nurses. Positive behavioral changes and attitudes that create self-efficacy are goals for the nursing team.

Initial reaction to the instructional modules being used has been extremely positive, with multiple expressions of appreciation for what this experience has meant to nursing staff interactions in each participating facility. These facilities have each seen positive results from the use of this technology, and the logistical complexity of placing this technology in any particular facility appears to have been offset by the overwhelmingly positive response once it has been implemented.

It's Never 2 Late (IN2L)

North Carolina skilled nursing facilities are well aware of the challenges of making long-term care a life-affirming and comforting experience for those who are dependent on the assistance of others for both medical/nursing care and for the accomplishment of normal activities of daily living. Facility staff, residents, and families know the intense need for personal fulfillment, enjoyment, sense of purpose, and connection to the people and interests they love. The search never ends for ways to combat loneliness, longing for the way life was before a long-term care admission, the boredom of physical limitation, and the innate wish to feel useful.

One of the most exciting applications of information technology in long-term care is a software development called "It's Never 2 Late," pioneered by a company of the same name located in Centennial, Colorado. Presented to the White House Conference on Aging, this exciting hardware and software system is based on an easy-to-use touch screen computer combined with a simple interface that offers a wide variety of customizable content appropriate to the interests and capacities of long-term care facility residents. The IN2L system includes continually updated content for cognitive/brain fitness, education, virtual travel and experiential enjoyment, spirituality, music, games, and other content. The software makes it possible for nursing home residents, even those with significant physical and/or cognitive limitations, to engage in activities for fun and learning and to enjoy many of these in conjunction with friends and family members of multiple generations. Emphasis is on individualized and tailored content exposure, but it also allows for group interaction when desirable. These sorts of systems are now employed in some 25 nursing homes in North Carolina and many more have expressed interest in acquiring such technologies as IN2L.

The philosophical perspective of North Carolina skilled nursing care facilities that has embraced these technologies is one that gives emphasis to values such as engagement, enrichment, and energy enhancement. There is a strong value emphasis in the contemporary field of long-term care that stresses the enablement of long-term care residents rather than an emphasis on relative degrees of (dis)ablement. The underlying values are ones stressing capacity, interests, and attitudes, and the use of modern technologies for facilitating these important personal and social goals.

It is exciting to see the many ways that moderately expensive technologies, both for staff training and for enriching the lives of nursing home residents have become possible over such a short period of time. This part of the larger health care delivery system is ready and poised to take advantage of these technologies and to see them as yet another facet of the effort being made to make the experience of this level of care both professionally competent and personally satisfying to staff, residents, and their families. **NCMJ**

Continuing Care Retirement Communities in North Carolina

Patricia E. Sprigg

Over the next 25 years, the number of seniors in North Carolina will double. North Carolina ranks third among the states for in-migration of retirees, and the majority of these retirees are seeking an active, independent lifestyle with support services they will need.[1] While it is true that an overwhelming majority of older adults live in a community without the benefit of any formal services or support, it is also known that over one-third of the 65 and older population will have at least one disability and will experience functional loss increase with age, requiring them to seek assistance at some point.[2]

Continuing care retirement communities (CCRCs) offer a long-term care option that incorporates various levels of health care and related services in addition to providing independent housing, usually offered in one location. For the most part, they are designed for older people who are still independent, in reasonably good health, and can afford to pay an entry fee and a monthly service fee in return for a place to live and access to various levels of care for the duration of their lives. The amount of entry fee and monthly fee paid is usually reflective of the contract type, size of housing unit, refund policy, and inclusiveness of services (particularly health care).

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In 1989, North Carolina enacted a statute (General Statute Article 64 Section 58) that defines continuing care as "furnishing to an individual other than an individual related by blood, marriage, or adoption to the person furnishing the care, of lodging together with nursing services, medical services, or other health related services, under an agreement effective for the life of the individual or for a period longer than one year." Not all states regulate or monitor CCRCs, and there is no federal legislation regulating CCRCs.[3] However, North Carolina does, and the regulatory body that oversees this long-term care option is the North Carolina Department of Insurance.

While some may believe that CCRCs are a fairly recent phenomenon, the reality is that many CCRCs across the country have been in existence for decades, with a handful in existence for over 100 years.[4] In 2009, Kathryn Brod, senior vice president and director of research for Ziegler Capital Markets, and Harvey Singer, principal NIC-REDMARK economist, presented the "National CCRC Listing and Profile Findings."[4] In their presentation, they explained that approximately 1,860 entities across the country fell within the general definition of CCRC, 82% of these were not-for-profit, and approximately 37% to 44% were single site. The majority have some type of faith-based origin or affiliation and some are aligned with colleges and universities. The alignments do not necessarily indicate some form of financial support. Approximately 25% of all CCRCs are not affiliated with a faith group or any sponsoring organization such as a university.

North Carolina is home to 57 CCRCs that fall under the state's definition. The oldest CCRC in North Carolina opened in 1913 and eight more were in operation by the 1960s. Eleven opened in the 1970s, 22 in the 1980s, 10 in the 1990s and, at the time of this writing, five additional CCRCs were developed since 2000. In North Carolina 85% are not-for-profit, with the majority operating as single site operations.

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The original continuing care communities grew out of a need to provide a modest but secure retirement living option for aged ministers, missionaries, and/or single or widowed women. The idea behind the original concept was to pool all the assets of individuals when they entered the community and augment them with charitable funds. While the practice of individuals turning over all assets has stopped, this common misperception still exists. However, the concept of pooling resources is still the underpinning philosophy of many, but not all, CCRCs, in that it presents an insurance-like risk-sharing option by tailoring services to individual residents, placing them in a coordinated care system, keeping them as independent as possible, providing support as needed, and spreading the cost over the entire community. The model maximizes the use of individual resources and minimizes their reliance on government entitlements, particularly Medicaid. For many CCRCs, the contract stipulates that residents who unexpectedly run out of funds are protected by the assurance that no one would be asked to leave because of financial hardship. For many individuals, the components of "aging friendly" housing, coordinated health care, and financial security provides peace of mind while they continue to enjoy an active and quality lifestyle.

Most CCRCs in North Carolina tend to have all three levels of care, or at least independent living with some type of nursing provided directly on their campus. Independent living is the level where most individuals enter a CCRC. Very few communities have only independent living units. Those communities that do not have an onsite health care center are defined as a CCRC if they have a formal arrangement with an outside health care facility to provide services for their contract holders. The other two levels of service traditionally offered by CCRCs are assisted living and skilled nursing. Assisted living provides support for bathing, dressing, taking medication, and other daily activities, but not 24-hour nursing care. The next level, skilled nursing, is the highest level of care that most CCRCs offer. It provides 24-hour nursing care for those with significant chronic illnesses, needing rehabilitation services, or recovering from a hospital stay.

Comparing CCRCs can be quite complex. Through the years, the types and pricing of CCRCs, as defined by their contracts, has evolved. The earliest type of CCRC to be developed is known as a Type A contract, referred to as the All-Inclusive. In this particular arrangement, an individual or couple pays a one-time entry fee, must be capable of independent living, and, after taking occupancy, pays a monthly fee. These combined fees cover housing, all residential and health care services, and unlimited days in assisted living or skilled nursing. In general, no additional fees are required as needs for services increase, including a move from an independent to a care facility.

The Type B contract, referred to as the Modified Plan, also requires a one-time entry fee and an ongoing monthly fee. Like the All-Inclusive, the monthly fee includes housing, all residential and health related services, and guaranteed access to nursing care. However, the overall cost of assisted living or skilled nursing is shared between the organization and the individual. CCRCs of this type usually offer a certain amount of "free days" in nursing care and offer a per diem discounted rate. Modified contracts vary tremendously as far as the financial responsibility and the amount of services that are covered by the basic monthly fee. This type of contract has seen the most growth over the last 10 years and offers a shared risk option for both the organization as well as the individual. In these first two types, it is expected that applicants are able to pass a health screen.

The third type, known as Type C, or the Fee for Service Plan, also includes a one-time entry fee. The monthly fee includes housing, some residential services, and guaranteed access but requires individuals to pay full market per diem rates if health care facilities are needed. In North Carolina, Type A, B, and C contracts are all present.

In the mid 1990s, the field introduced the Type D, or the Rental Plan. These are communities in which the individual or couple does not pay an up front entry fee, and the monthly fee is strictly based on a basic set of services. All additional services require an added fee. It is a type of *a la carte* contract. Access to health-related facilities varies greatly, and the contract does not have to be annually reinstated. In none of these contract options does the individual purchase real estate.

The last emerging type of CCRCs that the field is seeing is known as the Type E, or the Ownership or Equity Type contract. Equity contracts involve an actual real estate purchase with the transfer of ownership of the unit. In this particular arrangement, as opposed to a contract that provides housing and services, the independent living unit is purchased on a cooperative ownership basis. Usually a very modest package of services is attached to a monthly fee, and all additional services are purchased at market rate as needed. Health-related arrangements vary significantly.

Just as the contract type and services vary considerably, so do the financial arrangements. Most CCRCs require some type of financial screen to ensure that the prospective resident is able not only to meet the entry fee but also the anticipated monthly fee and other fees that might apply. Not only do contract types affect the amount of entry fee, but also the size of the unit. Independent accommodations can range anywhere from efficiency/studio apartments all the way to free standing homes/villas. Another determining factor is the type of refund that is offered. Typically, the higher percentage of refund that is offered to an individual, the higher amount of entry fee paid. Refund policies range from no refund, reflecting 18% of the CCRCs in North Carolina, to those that offer full refund. Communities may choose to offer several options as far as refundability. According to calculations based on the Department of Insurance reference guide, 65% of North Carolina communities offer more than one option.[5] Entry and monthly fees also vary based on the type of unit and the amount of services offered. Therefore, in North Carolina when one looks at the entry fees that are currently being charged by communities, the range varies anywhere from zero to over $890,000.[5] Communities that include current and future health care as part of the monthly fee obviously have significantly higher monthly fees than those CCRCs whose health care offerings are the sole responsibility of the individual. Some CCRCs are based on actuarial principals, meaning that the entry fee is amortized over the life of each individual, rather than taking it in as expendable income. Therefore, one can readily see the comparison of CCRCs from a consumer standpoint is not a simple matter and goes way beyond just comparing square footage, amount of entry fee, and the stated monthly fee. It is a significant financial investment, and when evaluating the options, one should be aware of the numerous legal and financial aspects as well as the organization's or owner's past business record and experience in providing this type of service.

In the state of North Carolina, the Department of Insurance requires that every CCRC provide the consumer with a disclosure statement at the time or prior to any transfer of money and prior to entering into a continuing care contract. This document goes into detail about the corporate structure, board of directors, services and fees, major policies including types of refund and how deposits are secured, audited financials, five-year projections, status of reserves, and an actual copy of the residence and service agreement. Careful review and understanding of this document is one of the most important steps in analysis, and yet it is a step that is often overlooked by many consumers. Copies of all current CCRC disclosure statements are available for viewing of the office at the North Carolina Department of Insurance or at their website, http://www.ncdoi.com. Because of the complexity of pricing structures and the long-term commitment, consumers are encouraged to seek professional advice from attorneys or accountants prior to signing any contract for continuing care.

In 1985, the Continuing Care Accreditation Commission (CCAC) launched the first voluntary accreditation process for CCRCs. This was in response to the growing consumer concern over the need for standards to be adopted by organizations to help inform decisions and make appropriate comparisons. CCAC was acquired by the Commission on Accreditation of Rehabilitation Facilities (CARF) in 2003. It remains the country's only accrediting body for CCRCs and other aging service networks.

Continuing care is not an option that appeals to everyone, and for some it is beyond their financial reach. However for those who are planning for the future and seeking out the various long-term care options, CCRCs can be very attractive and more affordable than previously thought. **NCMJ**

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Aging Independently:
A Chapel Hill Perspective

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One of the most important choices seniors face as they retire is where and how they are going to spend their retirement years. Some will choose to age in the home that they have lived in most of their life. Many who can afford it will choose to join a continuing care retirement community (CCRC) that offers a full range of housing choices, onsite health services and facilities, and a life-care contract. Others will choose one of the varieties of alternatives that are developing nationwide, including congregate living, co-housing, shared housing, senior retirement communities, and multilevel communities. Or they may simply downsize to a smaller home or condominium that they believe is more "senior friendly."

For many seniors, the desire to maintain the lifestyle and independence that they have enjoyed for years is of crucial importance. Most have worked hard in their early years to attain home ownership, and that has been fundamental to their sense of independence and control over their own lives. Among North Carolina householders aged 65 and over, 81.7% own their own home (with or without mortgages).[1] Many, though, realize that living independently will become increasingly difficult as they age, and this realization has motivated the search for support systems.

For many seniors, the desire to maintain the lifestyle and independence that they have enjoyed for years is of crucial importance.

Three different types of support systems have developed across the country to meet the special needs of seniors who choose to live independently in their own homes: (1) the "Beacon Hill" or village model; (2) naturally occurring retirement communities; and, more recently, (3) university-based retirement communities. The Beacon Hill models (discussed at more length in the sidebar of this article) generally center around a small professional staff assisted by volunteers in order to provide assessment of member needs, careful referral to vetted providers ranging from housekeeping to specialized home health care services, continual monitoring and quality control of services provided, and vitally important social networking and volunteer opportunities to help seniors living independently avoid social isolation. Naturally occurring retirement communities tend to be volunteer-oriented programs that focus on neighbor-to-neighbor support building from informal networking at the start to provision of extensive volunteer services to seniors as they age. University-based retirement communities are of two varieties: (1) those that are essentially CCRCs that include health services and life-care contracts, and (2) those that are structured more like the Beacon Hill model, but with links to a specific university or college. A recent article by AARP specifies four criteria for a comprehensive university-based retirement community: "A location that is accessible to the school (within one mile of the university, preferably), formalized programming incorporating the school and community, a full program of continuing care from independent to assisted living, and a documented financial relationship between the university and the senior housing provider."[2]

All three of these approaches include several important challenges that must be addressed in order to make a positive contribution to their members and the community at large:

- to carefully assess the needs of members upon enrollment to assure that they can live safely in their own homes;
- to assure that the program complements, but does not compete with, existing services in the community;
- to be unbiased in selection and continual review of service providers;

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- to safeguard the privacy of member information, yet ensure its timely availability to providers;
- to integrate and collaborate with existing neighborhood social networks and support systems;
- to incorporate systems and procedures to continually monitor the health and safety of members; and
- to collaborate with available community resources to build a counseling and referral "safety net" for those members who are caught in the downward spiral of failing health and decreasing resources, and for applicants whose health needs or resources are beyond the point that they could be safely and successfully supported by the program.

An Approach in Chapel Hill

During the past four months the authors have worked on designing a program they believe responds to the unique needs and resources in the Chapel Hill, North Carolina area. This community, one of the most resource rich communities in North Carolina, will experience a significant increase in the number of seniors aged 65 and over in the coming decades. This is due to local, natural demographic changes, as well as a disproportionate in-migration of seniors who continue to choose the Chapel Hill area as their "ideal" retirement community. According to a profile prepared by North Carolina Department of Health and Human Services, the number of North Carolinians aged 65 and over will increase from 969,048 in the year 2000 to 2,194,126 in 2029—a 126% increase.[1] The population increase in persons age 65 and over in Orange County, where Chapel Hill is located, is projected to be between 150%-200%.[3] North Carolina as a whole, according to the US Census Bureau, was ranked fourth nationally in population growth between April 2000 and July 2003, behind only California, Texas, and Florida.[3] The impact of this growth and these numbers on existing facilities, such as CCRCs and other retirement-oriented neighborhoods, as well as on existing resources and services will be impressive.

The purpose of the Chapel Hill project will be to provide guidance and support to senior citizens and others who choose to stay at home as they face the complex array of health, personal, social, and home services that will become increasingly necessary as they age. This will be a nonprofit organization financed by annual subscription fees, contributions, and grant support. The organization, its staff, and volunteers will have no interest, financial or otherwise, in a member selecting a service nor will any of the above solicit or accept any payment or other benefits from any provider group as a result of a referral.

The organization will work to achieve the following goals with financing from contributions and grant support, along with minimum staff and extensive volunteer effort:

- Improve socialization and use of community educational and recreational resources by building awareness of opportunities and assisting in access, communication, and transportation issues.
- Enable subscribers to access high quality and cost-effective resources and services necessary to improve and maintain their home living environment.
- Encourage subscribers to make a continued contribution to the community by incorporating their knowledge, skills, and experience in community and organizational volunteer networks.
- Maximize aging citizens' sense of independence and control over their own lives by providing up to date knowledge of available resources and professional consultation in financial, health, and life planning decisions.
- Provide a "safety net" of professional guidance and care management for seniors as they are affected by illness and injury and find themselves attempting to cope with the complex consequences and choices that follow.
- Improve continuity of care and support services for subscribers by developing active communication and coordination with other existing public, nonprofit, and private organizations that serve senior citizens and the disabled within the community.
- Provide a systematic way for subscribers to provide feedback about the effectiveness of services and how the organization can more effectively meet their needs and improve over time in order to improve the continual effectiveness, relevance, and subscriber satisfaction with organizational services.

Exploration of Community Interests

During February of 2010, a series of small focus groups was held involving potential enrollees, health and social work professionals, and community leaders in order to more clearly identify the nature and extent of need and probable interest in such a program. The results, particularly the substantive comments and suggestions, reinforced community interest in the program and helped focus on specific action priorities. Among these priorities are: close coordination with existing services and neighborhood efforts; transportation; translation services; improved hospital discharge planning; building close ties with primary health care providers and coordination; provision of a social support network; and "multi-generational involvement" in volunteer efforts and recruiting.

Program Focus

The program will be built upon a base of the following four essential functions: social networking, assessment of needs and interests, referral to qualified providers, and monitoring and follow-up of referrals.

Social Networking

The demographic nature of the Chapel Hill area, with neighborhood clusters spread out geographically within and

Beacon Hill Village

Beacon Hill Village (BHV), created in Boston in 2002, was established to enable senior residents to continue living independently in the community. This nonprofit, member-directed program offers a wide range of services through a “one phone call” concierge service. The program aims to address any member need through referral to a vast resource base of screened service providers, a core professional staff, and specially trained volunteers.

Members are encouraged to call for any reason, and BHV offers a wide range of services and social activities such as household repair, personalized transportation, in-home health care, and organized trips to the theater or to educational lectures. In its eight years of operation, BHV has grown to almost 500 members, ages 50 to 98, with current annual dues of $600 per individual and $890 per family. It also offers a Member Plus Option to subsidize lower income members, and its budget is supplemented by private donations and grants.

The success of BHV has tapped a surge of interest nationally, establishing a model which to date has spawned the creation of villages in 50 other communities across the United States. In January 2010, these villages, with the sponsorship of BHV and NCB Capital Impact, formed the Village to Village (VTV) Network (http://vtvnetwork.clubexpress.com). This developing network aims to provide shared resources on village business operations, strategic planning, coordinated web services for the Network, websites for individual villages, and technical assistance in the formation of new villages.

outside the center of town (much like many North Carolina towns), will require a “village network” consisting of a collaboration between neighborhoods, each with its own volunteer base and door to door communication links with local residents. This network will be core to assuring social connectedness among members, locally-oriented volunteer assistance with transportation, daily check-in with the frail elderly, improved participation in community social and educational activities, and, of key importance, maintaining program-wide integration of services within the community as a whole. As in other such networks across the country, these efforts will be augmented by a website that provides secure access by members to information on program services, activities, community resources, and discussion groups.

Assessment of Needs and Interests

Subscriber service needs will be identified by an initial subscription questionnaire and interview. Individual and household needs will be carefully tracked and revised as subscribers use the organization’s service and through follow-up phone calls, periodic surveys, and other information gained in routine contact by organizational staff and volunteers.

Referral to Qualified Providers

Organizational staff and volunteers will provide subscribers with specific recommendations and supporting information on approved providers that meet specific needs, as indicated during assessment and upon direct request. This service will be comprehensive in scope with particular emphasis on health care, social contacts and events, home maintenance, tasks of daily living, and transportation. All providers recommended by the organization will be initially screened and vetted for quality, security, and pricing practices.

Monitoring and Follow-up of Referrals

The organization will negotiate advantageous terms where possible and continually monitor the performance of provider organizations in meeting subscriber needs and in regard to any changes in staffing patterns, costs, and security measures. It will also follow-up with subscribers to solicit their opinion of the services provided and to identify any future needs for service or support.

Special Relevance to Provision of Health Services

The complexity of health services, combined with the increasing needs of the elderly and their decreasing cognitive abilities and confidence, make access and efficient utilization of medical care particularly difficult and the value of a program such as this promising. Among the services routinely provided by similar programs across the country are continual monitoring of member health status and needs, providing transportation and companions to medical visits, assuring compliance in following instructions and medications, communication with younger family members in needs assessment and care planning, coordination of discharge procedures and instructions, and a variety of health education and support groups.

Conclusions

Aside from the incentive of seeing other similar programs develop and succeed across the country, this effort is in line with a recommendation in the *2007-2011 Aging Services Plan* developed by the North Carolina Division of Aging and Adult Services that reinforces an earlier recommendation to encourage “North Carolina’s communities toward becoming more senior-friendly as well as livable for all people through collaboration among citizens, agencies, organizations, and programs, in both the public and private arenas.”[4,5] As in other communities in North Carolina, there are three general levels of need within the Chapel Hill community: those who have the financial resources and income to choose to enroll in one of the local CCRCs or live independently; those in a large middle-income group—some who could afford the CCRC option, some not; and a significant number who live at or near the poverty level. Although the initial focus of the Chapel Hill program will be on the middle- and upper-income groups who choose to live independently, explorations have already begun and will receive continuing priority to improve the safety net for members and a referral resource for those who fall in the lower-income categories. The national Program of All-Inclusive Care for the Elderly (PACE) offers one alternative in this regard and its effectiveness is already being demonstrated in a nearby county.[6]

Given the dramatic growth in those over age 65 expected in North Carolina over the next decades and the precedent of village programs, naturally occurring retirement communities, and university-based retirement communities across the country, it is very likely that physicians and other health workers will see similar developments in their own communities. We would urge health care professionals and others with interests in the needs of the elderly to get involved as these programs develop and work to ensure that they focus on improving awareness, coordination among existing programs, and efficient use of existing health resources. One senior physician in our first focus group provided an insight that has guided much of our planning by pointing out that two strong motivators among the elderly are the striving to be independent and in control of their own lives and the desire not to be a burden on their children or society. Another participant added a third common motivation, that of the need to "continue to be of some use, to continue to making a contribution of some kind." We believe that these basic drives fuel the interests among seniors in living as independently as possible and that will make community efforts such as the one we are attempting to build in the Chapel Hill area successful over time. **NCMJ**

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Improving Quality of Long-Term Care:
It is Time for Collaboration

Bob Jackson

Long-term care is a critical and necessary part of the health care continuum. Whether in a facility, in the community, or at home, how our society designs and delivers quality, accessible, and affordable long-term care for our oldest and sickest citizens is a huge challenge for families and policymakers. Many of us have experienced the task of determining the right level of care for our loved ones and then searching for high quality, affordable options to meet those needs.

Historically, there has been conflict over what quality means and how to achieve it. And let's face it, many of us have heard about or experienced a quality issue in residential and home care situations. In some cases the complaints are overblown or not factual. But clearly, in other cases, the abuse or negligence is proven, and the public confidence in our long-term care system is shaken.

Over the years, a strong influential corps of state agency and non-governmental advocates has developed in North Carolina and they are working on behalf of family members and the general public to improve the quality of care in our communities. At the same time, the facilities and community care industries have strengthened their own cadre of advocates to address quality issues. Both sides have worked hard to impact policies, legislation, and public perception by encouraging legislation; providing input in the rule-making process; serving on task forces, commissions, and work groups; and mounting public awareness campaigns.

Advocacy manifests itself differently across a variety of groups. Organizations like AARP, the Senior Tarheel Legislature, the Governor's Advisory on Aging, the North Carolina Coalition on Aging, and Friends of Residents in Long-Term Care represent individuals, families, and the broad community by pushing for stronger consumer protections, more transparency, safer living and care environments, standards and requirements for training of care workers, and more funding from federal, state, and local entities. Staff and volunteers with these organizations frequently work together to craft priorities and campaigns designed to impact legislation and regulations and to educate the public with a wide range of informative booklets and guides.

On the provider side, organizations like the North Carolina Health Care Facilities Association, the North Carolina Association of Long-Term Care Facilities, the North Carolina Association of Non-Profit Homes for the Aging, the North Carolina Assisted Living Association, the Association for Home and Hospice Care of North Carolina, the North Carolina Adult Day Services Association, and the North Carolina Association on Aging work with their members to represent various aspects of long-term care services, quality, and funding including many of the same issues consumer groups support although sometimes with a different point of view.

> ***The provider industry is committed to delivering high quality services and needs the money to hire adequate staff to maintain efficient and effective care. The public is adamant about wanting safe, adequately staffed, and compassionate long-term care—but at an affordable cost. That is the rub.***

In addition to these consumer and industry groups, an important and not to be underestimated aspect of long-

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term care service is the number of volunteer roles that help individuals, families, and organizations in communities. Such volunteer involvement is not only beneficial to the persons needing long-term care, but it helps keep the community connected to the need for those services. Roles of volunteers include being caregivers for family members or friends; acting as patient advocates with the Ombudsman program through the nursing home and adult care home community advisory committees organized by each Area Agency on Aging; or delivering services such as home delivered meals, volunteer transportation, friendly visitation, and telephone reassurance.

AARP research has found that most people want to stay in their own settings and have as much a say in their own care as possible. Here in North Carolina, a strong priority of the Division of Aging and Adult Services, AARP, and many other aging organizations is the practice of "aging in place" and "senior friendly communities."[1] These terms mean providing support systems and programs designed to help people live successfully in their homes and communities safely and securely. To help do this, an important and relatively recent phenomenon is the development of neighborhood support groups, sometimes called "care teams." In response to this preference, neighborhoods and, indeed, whole communities are creating formal and informal coordinated service programs and teams of volunteers designed to help individuals stay in their homes safely and successfully (e.g., Falconbridge Village in Durham, Beacon Hill in Boston, and Capital Hill Village in the District of Columbia). And in some cases, intentional co-housing communities are being established with the expressed expectation that neighbors help each other with daily chores and various care needs (such as Elderspirit in Abingdon, VA).

As for having a role in one's own care, person-centered services focus on individual values and needs in determining and providing long-term care (such as taking into consideration meal and bathing preferences and particular physical or mental impairments). The goal of person-centered care is to improve the quality of care at every level of health, safety, and liability resulting in more satisfied residents and clients. As person-centered care expands across North Carolina, consumer advocates, the industry, and state regulators can work closely to craft programs and services encouraged by the Centers for Medicare and Medicaid Services (CMS) in their scope of work for quality improvement organizations under contract to CMS.

The bottom line is that we all care about the patient/resident and want the best care possible. The challenge is how to provide remedies that all sides can accept and that are affordable to families as well as federal, state, and local governments. The provider industry is committed to delivering high quality services and needs the money to hire adequate staff to maintain efficient and effective care. The public is adamant about wanting safe, adequately staffed, and compassionate long-term care—but at an affordable cost. That is the rub.

And so advocates on both sides have argued for various provisions that try to balance quality and cost; and legislators are caught, often times, in the crossfire between service delivery advocates and tightening budget constraints. There have been many years of debates on the levels of appropriate and adequate funding per month per patient/resident and the impact on adequate staffing, wages, training, and benefits for the workforce. Also, there have been many cries for transparency about complaints, performance, spending for facilities, and calls for consumer information comparing one facility or provider to another. Additionally, there is the ongoing debate pitting those supporting institutional care versus those favoring home- and community-based care.

As our demographics clearly demonstrate, the numbers of people needing various levels of long-term care are growing and families, communities, and the state are being pushed to new financial realities. A critical aspect of the ongoing debates related to quality is the old "chicken or the egg" issue of who should get priority in funding. Most of the consumer and provider advocates recognize the need for, and regularly ask for, more money from the legislature to deliver better services. The provider groups tend to argue that quality can be improved by increasing the per person/per month reimbursements and reducing the regulatory oversight and requirements that cost them administrative time and money. Patient and consumer advocates support increasing the funding streams but argue that additional funding should be reflected in higher staff-to-patient ratios and reflect better salaries, training, and benefits. How is quality best motivated? Common wisdom might suggest the answer is a combination of all the above.

In the past few years there have been a number of examples where different advocacy groups worked in tandem to shape policies. For example, in the 2009 legislative session, consumer advocates supported provider initiated legislation (HB 436—Fairness in the Certificate of Need Determinations) that would allow nursing homes, adult care homes, and intermediate care facilities for the mentally retarded to renovate or expand the homes, in limited circumstances, without a certificate of need. An example of why we need to work together immediately is the looming debate regarding Medicaid funding for optional services such as physical and speech therapy, dental care, hospice care, and orthotic and prosthetic devices. Adequate funding for these services is critical for providers to deliver quality services and maintain a stable workforce and is equally essential to the health and well-being of older and disabled North Carolinians who need these services.

Another huge opportunity for collaboration exists in supporting the needs of caregivers. In North Carolina, we have over one million caregivers providing some level of care to older and disabled adults. According to national caregiving studies, approximately three-fourths of caregivers have worked while caregiving. A MetLife study recently found that the national economy and the American family pay a steep price when employees don't have the support they need to care for older and disabled loved ones either at their home or in a facility. The study concluded that family caregivers cost American businesses up to $34 billion a year in lost productivity due to replacement and training costs, missed days of work, workday interruptions, and unpaid leave.[2] Families need community support systems to help with caregiving challenges. They need work/life balance options including guaranteed sick leave with pay, more people covered by the Family and Medical Leave Act, and the right to request flexible work schedules without fear of retaliation.[1]

To address these issues and the ever growing demographic and economic reality affecting families, employers, and the state, we must figure out ways to work together and keep collaborations moving forward. The current budget challenges facing North Carolina demand that providers, advocates, consumers, and their families, as well as regulatory and administrative agencies concerned with long-term care in our state work in partnership to support and strengthen our long-term care system. Certainly, consumer and industry advocacy groups meet regularly, but rarely together. We may not always agree, but it is important to keep communication channels open. It is time to sit down at the same table, share concerns, set priorities, and use our collective strength to meet the demands of those who need long-term care and the families, agencies, and providers affected by that care. **NCMJ**

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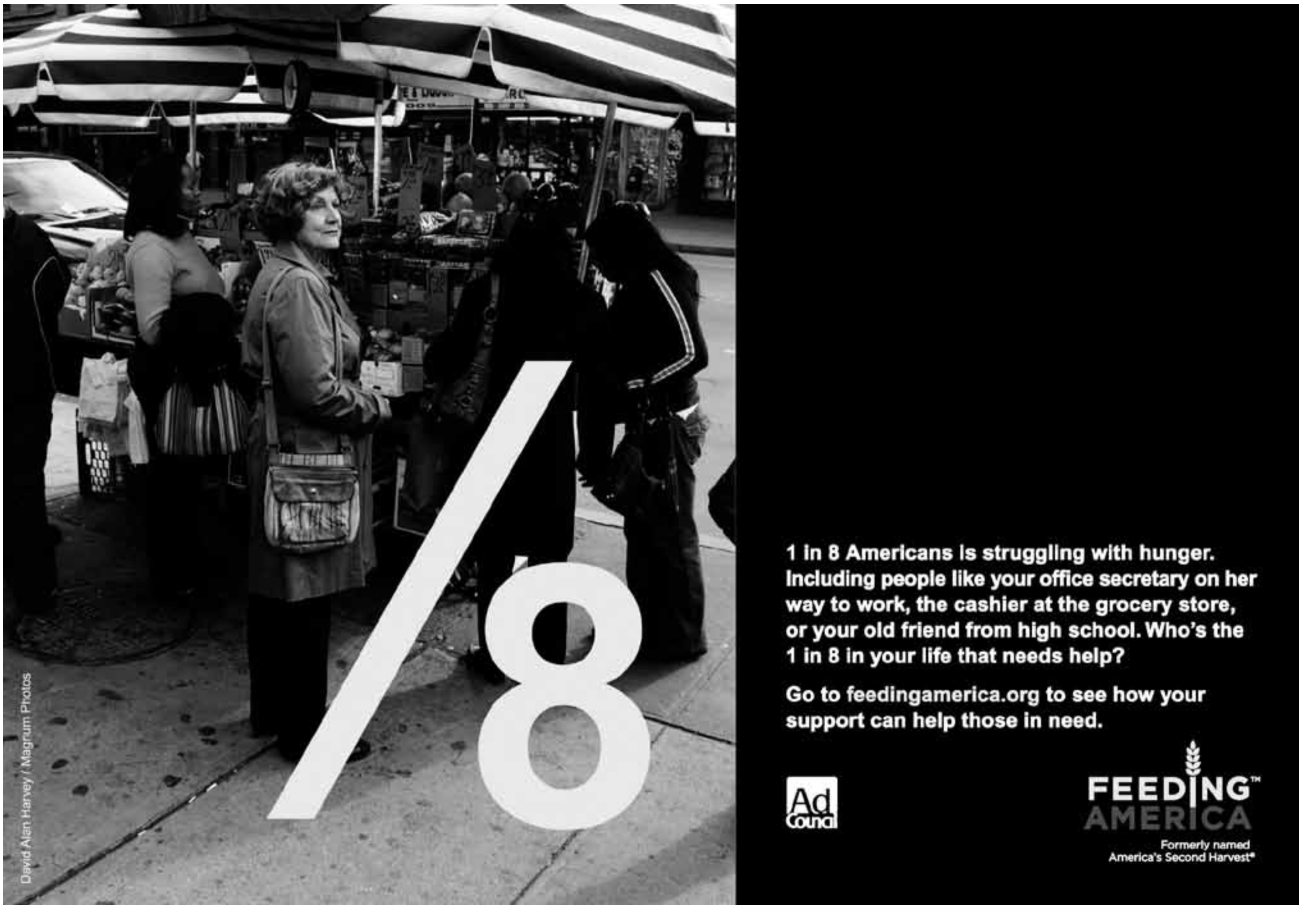

PHILANTHROPY
PROFILE

Taking In-Service Learning Technologies into Nursing Homes:

The Duke Endowment Supports Patient Care Simulator Training in North Carolina Skilled Nursing Facilities

Gordon H. DeFriese, PhD; Polly Godwin Welsh, RN-C

Long-term care facilities depend on several levels of nursing personnel to accomplish their goals of providing the highest levels of medical and nursing care to residents, while at the same time making certain that the life experiences of these residents are of the highest possible level of quality. In addition to registered nurses (RNs), many of the nursing care providers in these facilities are licensed practical nurses (LPNs) and nursing assistants (NAs or CNAs). Several North Carolina nursing homes are beginning to hire nurse practitioners to augment their overall medical-nursing care and to provide a more highly specialized level of care for residents under their care.

Residents of most North Carolina nursing homes are often older and require caregivers with gerontological skills. The specialized needs of older adult patients are a major concern for nursing care providers in these facilities, where residents r equire 24-hour skilled nursing care.

Given the preponderance of persons with serious physical or cognitive impairments, the acuity of nursing observational skills is critical to the assurance of both patient safety and quality of care in these facilities. The complexity of the nursing skills required, and the frequency with which new and more effective ways to manage common health conditions in such populations are developed, necessitates that these facilities find ways to offer in-service or extramural skill enhancement training. However, because of limited staff in most long-term care facilities, it is difficult for these facilities to arrange for lengthy absences of any substantial number of nursing care staff in order to take advantage of training offered at extramural sites (e.g., AHEC facilities or at one of the nursing schools in our state). It would be most useful to have some reliable means of offering sound instructional programs in clinical nursing relevant to long-term care that could be offered on-site for all levels of nursing personnel, thus eliminating the need for extended absences from normal responsibilities in these facilities.

The FutureCare of North Carolina Project: An Itinerant Model Simulator-Based Training Program

FutureCare of North Carolina, a new educational and research foundation created to advance the level and quality of care in North Carolina's skilled nursing facilities, is addressing this need in partnership with the University of North Carolina (UNC) School of Nursing. With support from The Duke Endowment, FutureCare of North Carolina launched a two-year demonstration project through which the most advanced simulation technologies in health science education (the METI Emergency Care Simulator, or ECS) is used in an itinerant and modularized training program for nursing personnel that can be implemented at skilled nursing facilities throughout the state. Using curricula developed by the UNC School of Nursing, this instructional technology is being transported to nursing care facilities for short, four-five day visits, thus enabling all nursing personnel working on different shifts at each facility to gain both information and direct experience in the fundamental observational and interventional skills essential to the provision of high quality care for typical patients served in these facilities. The program:

- Offers the directors of nursing (DONs) in North Carolina skilled nursing facilities the opportunity to schedule the placement of the METI patient simulator, the ad hoc scheduling of facility nursing personnel for instruction and simulated patient care practice, and relevant curricula for its use.
- Transports the METI patient care simulator (PCS) to the nursing facility.
- Allows for the implementation of multiple modules of instructional material at each site using curricula already developed by the UNC School of Nursing and software provided by the METI developer.

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- Enables DONs at each facility to use the results of instructional modules, including end-of-course examinations, to institute follow-up educational programs on-site after the METI PCS has been moved to another facility.
- Makes it possible to address statewide standards of care in long-term care in a manner never before possible in North Carolina's skilled nursing facilities.
- Provides nursing personnel at every level the experience of learning the basic and advanced skills most relevant to serving the state's growing population of persons requiring this level of care.

Overall Reactions to Simulator Use in These Facilities

A director of nursing (DON) at a participating facility remarked: "The spark generated among our staff for this particular educational program was unusual. It is hard to get this type of reaction through any other type of educational format." Another offered the comment that, "This program made our CNAs actually feel like they were part of a team." A third commented that the reaction to the simulator experience was "unexpected" and that "conversation about this experience went on for a couple of days afterward." Finally, one DON reported that "We had a code last week, and at that moment, everyone (including CNAs) knew exactly what to do. Without this experience, it might have been a different situation."

One of the DONs reported that she had observed more frequent reporting by nurse aides of drops in blood pressure or problems with positioning of residents after exposure to the simulation exercise. Another added "nurses are clearer in the instructions and information they give to nurse aides and focus on patient-specific symptoms and needs. Power dynamics are being disassembled." Additionally, a DON offered that "My nurses are now realizing that they are 'educators' and that with some encouragement and on-the-job training, CNAs under their supervision can helpfully contribute to overall nursing care."

Mandy Richards, RN, a FutureCare of North Carolina nurse educator who travels with the mannequin and its associated equipment, explained during some of her debriefing sessions how CNAs can be more "assertive." One of the DONs reported that her CNAs who experienced these educational sessions approached their supervisory nurses more frequently and were more assertive when reporting observed changes in patient status.

Initial experience with the first of these facilities participating in the project have offered us the opportunity to learn a great deal about how to introduce and set up the simulator for use with nursing teams in long-term care facilities. Prior visits to each facility to arrange for the smooth implementation of the technology on-site have proven to be very useful.

Initial reactions to the instructional modules have been extremely positive, with multiple expressions of appreciation for what this experience has meant to nurse staff interactions in each participating facility. These facilities have each seen positive results from the use of this technology and the logistical complexity of placing this technology in any particular facility seems to have been offset by the overwhelming positive response once it has been implemented.

North Carolina nursing homes are the first in the nation to have access to this type of instructional technology, and the results are likely to have considerable benefit for both residents of these facilities and their nursing personnel. **NCMJ**

Spotlight on the Safety Net

A Community Collaboration
Kimberly Alexander-Bratcher, MPH

Just For Us

Do you remember when doctors made house calls? That is what the Just For Us program provides some aging residents of public and senior living housing complexes in Durham, North Carolina. The program began as a community collaboration between the Community Health Division of the Department of Community and Family Medicine and the School of Nursing at Duke University Health System, Lincoln Community Health Center, Durham County Department of Social Services, Durham County Health Department, The Durham Center (the Durham county mental health agency), Durham Council on Senior Citizens, and the Durham Housing Authority. After time was spent researching and communicating with the residents, the Just For Us program was launched in 2001 to help Durham's older adults maintain their health and improve their quality of life and support them as they age in place.

The Just For Us program provides medical care for participants in their own homes. One physician assistant, one nurse practitioner, and a supervising physician provide comprehensive primary medical care. The remainder of the interdisciplinary team consists of a social worker/case manager, community health worker, registered dietician, and occupational therapist. Patients may also receive behavioral health and other specialty services in their homes by partners of the program.

The program has provided consistent, appropriate care in a nurturing and supportive environment that has shifted costs to pharmaceuticals, home health care, and other preventive services rather than crisis management. The program is centered on identifying and meeting patient needs in context. Most patients in the Just For Us program have more than five chronic medical conditions. Prior to participation in the program, these patients often missed clinic appointments with their primary care provider, routinely visited emergency rooms, or were hospitalized and then sent home without connection to services. Those occurrences have dropped as a result of the program. Just for Us patients are engaged in their care, have high satisfaction rates, and are less socially isolated.

Gladys Crank, a 66-year-old stroke survivor who also has asthma, has been in the program for four years. After her stroke, she received care in a skilled nursing facility. When she was able to transition to her home, she was informed about the Just For Us program. She is grateful to have one main provider who knows about her life and cares about her. When she calls Just for Us her provider is "always right there." According to Ms. Crank, "the program is more convenient and works well for all the patients, especially those who can't drive and don't have transportation."

The Just For Us program is an asset to both the patients and providers. Dr. Robin Ali, the supervising physician and pharmacist for the program, notes that the best part of her job is establishing a trusting relationship with the patients. She has an intimate knowledge of patients in their home environment and regularly meets family members and caregivers. When providers are in the patients' homes, the patients are very honest and open and the patient and provider develop long-term relationships. Based on that trusting relationship, Dr. Ali can help families with specialty referrals. They problem solve together and then watch the patient improve from the lifestyle changes. Just For Us providers can be the eyes and ears for the clinic primary care provider in the patient's home and also serve as a resource for other specialists. For example, Dr. Ali was involved in a situation with a patient who had low potassium levels that baffled the clinic provider despite multiple tests and examinations. The Just For Us provider was able to determine that the patient had been taking a medication for its laxative properties but the medication also had potassium-lowering effects. The problem was resolved due mainly to the trusting relationship and in-home context of the visit.

The Just For Us program has been featured in national publications for its unique care delivery model and outcome success. It serves as a national model and is being replicated with community modifications in various locations. The program alleviates access to care barriers by providing patient-centered care in the patients' homes. The partners have worked to focus on maintaining health, using public reimbursement, and sharing electronic health records to coordinate and facilitate the team-based approach.

Through community collaboration and patient empowerment, the Just For Us program is providing the right care at the right time in the right place.

JaNa Royal, PA-C, physician assistant; and Robin Ali, MD, PharmD, supervising physician and pharmacist; both of the Just For Us program in the Division of Community Health, Department of Community and Family Medicine, Duke University Medical Center; Michele Lyn, assistant professor and division chief, Division of Community Health, Department of Community and Family Medicine, Duke University Medical Center; and Susan Yaggy, MPA, president and chief executive officer, North Carolina Foundation for Advanced Health Programs, contributed to this article.

Running the Numbers

A Periodic Feature to Inform North Carolina Health Care Professionals about Current Topics in Health Statistics

From the State Center for Health Statistics, North Carolina Department of Health and Human Services
http://www.schs.state.nc.us/SCHS

Long-Term Care and the Role of Informal Family Caregivers in North Carolina

As the US population ages the demand for long-term care will continue to grow. About 9 million Americans ages 65 and older currently require long-term care and by 2020 the number is expected to increase to about 12 million.[1] The majority of individuals who require long-term care need assistance primarily with activities of daily living, such as bathing, dressing, and using the bathroom, as opposed to skilled, professional care. Because Medicare and Medicaid do not pay for unskilled care, the burden of providing such care often falls on family members or friends, the majority of whom receive no monetary compensation for their services. The value of unpaid care provided annually in the US is estimated at $306 billion.[2]

If given the choice between moving into a nursing home or assisted living facility or being cared for at home by friends or family members, most disabled older adults would prefer the latter. Despite the important role that informal caregivers provide to their family members and to society as a whole, data on the number and demographic characteristics of those providing such care are limited. A 2004 survey conducted by the National Alliance for Caregiving and AARP reported that 21% of adults nationally were informal caregivers.[3]

The only data on informal caregiving that are specific to North Carolina are collected through the North Carolina Behavioral Risk Factor Surveillance System (NC BRFSS). Operated by the State Center for Health Statistics, NC BRFSS is an ongoing survey of a representative sample of all North Carolina adults ages 18 and older. NC BRFSS employs a random-digit-dialed telephone survey of North Carolina households, covering the noninstitutionalized adult population. NC BRFSS has added some questions to its questionnaire on caregiving provided for adults with long-term illnesses or disabilities. Data from the 2008 survey, which is the most recent year available, provides information on the characteristics of informal caregivers in North Carolina and the individuals receiving their care.

Table 1 shows the number and percentage of NC BRFSS respondents who answered "yes" to the following question: "People may provide regular care or assistance to an older adult who has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend?" The survey shows that 19.4% of all North Carolina adults served as caregivers in 2008. There were differences in the percentage of adults serving as caregivers according to selected demographic characteristics. Nearly 22% of female adults are caregivers as compared to 16.8% percent of males. Adults in the age group 55-64 were more likely to report being caregivers (25.5%), while those ages 25-34 were least likely (13.9%). Almost 24% of African Americans and 25.6% of Native Americans reported being caregivers, compared to 19.9% of whites. People with a high school education or some college were also more likely to serve as caregivers. There was not an appreciable difference in the percentage of caregivers by income level, although individuals in the lowest (< $15,000) and highest ($\geq$ $75,000) annual income levels tended to be less likely to be caregivers. Individuals who reported they had a disability were more likely to be caregivers than those who had no disability.

Although the estimated percentage of individuals who provide care to older adults in North Carolina is slightly lower than that reported in a national survey from 2004 (19% versus 21%, respectively), the

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Table 1.
Percent of North Carolina Adults Providing Regular Care or Assistance to an Older Adult with a Long-Term Illness or Disability

	Total Number of Respondents	Number Providing Regular Care	Percent[a]	95% CI[b]
Total	**15,318**	**3,126**	**19.4**	**18.5, 20.4**
Gender				
Male	5,794	1,008	16.8	15.4, 18.3
Female	9,524	2,118	21.9	20.6, 23.1
Age (years)				
18-24	463	84	19.5	15.0, 24.9
25-34	1,456	224	13.9	11.9, 16.2
35-44	2,357	383	15.2	13.5, 17.0
45-54	2,979	706	23.3	21.3, 25.4
55-64	3,298	826	25.5	23.6, 27.5
65-74	2,677	564	21.6	19.7, 23.6
75+	1,988	318	18.9	16.7, 21.4
Race				
White	11,955	2,464	19.9	18.9, 21.0
African American	2,262	513	23.9	21.2, 26.9
Native American	311	69	25.6	19.1, 33.6
Other	634	61	6.8	4.7, 9.7
Education				
< High School	2,153	345	14.0	12.1, 16.2
High School	4,471	925	21.2	19.1, 23.4
Some College	4,013	913	21.9	20.0, 23.8
College Graduate	4,647	939	18.1	16.7, 19.6
Household Income				
< $15,000	1,719	325	16.8	14.4, 19.5
$15,000-$24,999	2,450	555	21.3	18.7, 24.1
$25,000-$34,999	1,621	349	21.6	18.5, 25.1
$35,000-$49,999	2,140	460	20.8	18.5, 23.4
$50,000-$74,999	2,203	467	19.5	17.3, 21.9
$75,000+	3,165	590	16.9	15.1, 18.8
Disability Status				
Disability	5,737	1,226	22.5	20.8, 24.2
No Disability	9,481	1,876	18.0	16.9, 19.2

a. The percentages shown are weighted percentages designed to reflect the entire population of North Carolina adults ages 18 and above.

b. 95% CI = 95% Confidence Interval.

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general demographic profile of family caregivers in North Carolina is similar overall to that of the US — family caregivers are more likely to be female, middle age (35-64), and have chronic medical conditions or disabilities themselves.[3,4]

The financial burden on families of providing skilled, long-term care is often extreme. A single year's stay in a nursing facility averages close to $80,000 per year, and this can quickly overwhelm a family's budget. Unpaid family members are often left to provide much of the care themselves, while trying to balance these duties with work, family, and other responsibilities. Though difficult, this is an option that many families choose when deciding on the type of care to provide for an older adult family member.

Given the high cost of nursing home care and the preferences of many older adults to be cared for by family members, family caregivers can fill a unique and important niche in long-term care in the US. As the data from the NC BRFSS suggest, such responsibilities often fall on female family members — many of whom already have regular jobs outside the home — or those who report having disabilities themselves. Given the trend of increasing numbers of females entering the workforce and the rising disability rates among younger people from conditions such as obesity and diabetes, the availability of in-home family caregivers will likely decrease in the years ahead, while the need for such care will continue to grow.

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Contributed by Robert E. Meyer, PhD, MPH, State Center for Health Statistics, North Carolina Division of Public Health.

A Tribute to North Carolina's *Fabulous* Direct Care Workers in Long-Term Care

The North Carolina Health Care Facilities Association, once each year, recognizes the excellence and dedication of 50 of its most valuable direct care workers, 10 from each of the five regions of the state, as "Nurse Aides of the Year!" These "Fabulous Fifty" are the center of attention at regional dinner events, and one from each region are selected to be honored statewide at a special awards banquet as part of the Association's Annual Meeting. Here are some of their stories, giving all of us reason to be proud of so dedicated a staff of caring individuals who "make a difference" in the lives of our residents and their families.

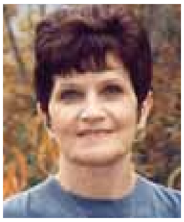
Here are some of the things said about this year's Top Five Nurse Aides of the Year:

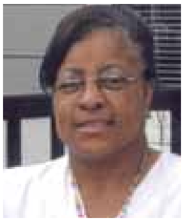
Claudette Davis has worked in long term care for over 22 years. She is a devoted and compassionate Nursing Assistant at Britthaven of Harnett. "Claudette asks her new residents about their lives and activities prior to coming to the facility. From this she gains a better understanding of them and identifies things that they enjoy. She involves the family members in all aspects of care planning and talks to them about their loved ones so they are able to build a trusting relationship. Claudette takes new nursing assistant students under her wing and mentors them. She always tells them how it should be done correctly!"

Miriam Mathabane endured many challenges before becoming a Nursing Assistant at the Lutheran Home of Winston-Salem in 1997. She grew up in the last days of apartheid in South Africa when townships became battlefields and liberation came before education. In 1992, with the help of her brother and sister-in-law, she came to America to pursue her career in the medical field. "She is the consummate team player, and can always be counted on to perform to a high standard even in chaotic situations. Miriam's willingness to help others and her true compassion for the residents in her care are assets that are truly admired by others. She provides care in a gentle and loving manner. She is always smiling and singing while she is performing her duties."

Paige Terry is a Nursing Assistant at Litchford Falls Healthcare in Raleigh. "As a young woman, she volunteered in nursing homes in her community. She loved to ask them questions about their lives and families, fix their hair, and paint their nails. These experiences eventually encouraged her to become an NA. Paige receives praise from every corner of Litchford Falls: family members love her because of her attention to detail; staff love her because they know her follow-through is exceptional; and residents sing her praises because she takes the time to meet their individual needs and listen to them."

Sherry Thomas has worked in long-term care for over 38 years! She has been with Mountain View Manor Nursing Center in Bryson City for the past 18 years. Sherry has worked as a Nursing Assistant for 10 years at the facility and is currently the Transportation/Rehabilitation Aide. "Sherry has always kept track of residents' special occasions. She will purchase a rose for a husband to give to his wife on their anniversary, or a box of candy for a wife to give to her husband on his birthday. She truly loves her residents and their families!"





Pearlie Shine has been a Nursing Assistant at Jesse Helms Nursing Center in Monroe for 19 years. "Families are comforted to know that Pearlie is on duty because they know their loved ones will receive wonderful care. She is a good leader and teacher. She acts as a preceptor with new CNA's. She demonstrates how to treat the residents as individuals and provide them with 'person centered' care and the respect that they deserve. She truly feels that this work is her mission."

With gratitude and admiration, we congratulate our 2010 Nurse Aide of the Year Winners! These are the dedicated providers of care on whom we all depend.

Readers' Forum

To the editor:

We do need to reform the delivery of health care in the USA. It costs too much. But no one is talking about the real reasons why it costs so much. It's not politically correct to do so. The reason health care is so expensive isn't because of insurance companies or doctor fees or hospital fees.

It's because we as a nation don't take care of ourselves. If we eliminated obesity, the national cost of health care would drop dramatically...back problems, hip and knee problems, diabetes, hypertension... the list goes on and on. It's because we as a nation don't take responsibility for our problems. We expect a test and a pill every time we sneeze...and we get it, whether we need it or not. The polypharmacy that I see in patients coming in for surgery is appalling. If patients got the same message from all physicians and the media and the government that their health is largely their responsibility, maybe we'd see some changes in the way we live. As it is we as a nation seem to try to justify obesity and drug abuse as not really "our fault." No wonder we seek a pill instead of eating healthy and exercising.

It's because we spend billions of dollars on end of life care when patients have no real chance of a decent quality of life. Those of us in the health care professions understand that there are worse things than death...all our patients need is to be educated. One of the things that was proposed in the recent health care legislation was paying primary care docs to discuss end of life issues with their patients. The Republicans shot it down as some kind of "death squad." If every patient knew they were expected to address these issues with their families and physicians, and to have a living will and medical power of attorney in the event that they were unable to make decisions for themselves, maybe we wouldn't spend billions keeping people alive who don't even know who they are or recognize their families.

It's because we as a nation sue our physicians and hospitals and medical suppliers every time there is a bad outcome. We need to have reasonable medical litigation reform. It can be done with panels of physicians who volunteer to serve in the interest of good medicine and reasonable patient expectations.

In my view, there is really nothing in the current legislation that will really decrease the cost of health care except by rationing health care. Certainly the cost of administering insurance and government programs is a place where money could be saved, but it's a drop in the bucket compared to the real causes of excessive health care costs.

I think we as physicians have been a big part of the problem. It's easier to write a prescription or order a test than it is to *insist* that our patients start taking care of themselves and face end of life issues *before* a tragedy occurs. We hide behind malpractice litigation, using "defensive medicine" as an excuse for not practicing cost-effective medicine.

If health care legislation addressed these issues and physicians embraced them, we could get costs under control.

Sincerely,
Kent Robertson, MD
Hickory, NC

Readers' Forum

To the editor:

North Carolina is unhealthy. Some of our health status indicators are as bad as, or worse than those found in third world countries. What we need in North Carolina is not a better health care system but rather a better system for health.

People need easy access to screening for common diseases and the risk factors for these common diseases. These include health issues like obesity, diabetes, hypertension, pregnancy, some cancers, and dental decay. Those who are diagnosed with these diseases or conditions should then receive quick, efficient, and effective triage to appropriate care providers who are accessible and affordable. Hopefully most of these disease issues will be handled by primary care providers (family medicine, pediatrics, internal medicine, obstetricians/gynecologists, and dentists).

Public health departments can provide the community assessment and triage function across the state while private physicians and rural or community health centers provide the primary and secondary care services. Hospitals should provide tertiary care services with staffs of specialists who are well-equipped to provide the technologically dependent procedures often required by these ill patients.

Our public health departments are present in all 100 counties of North Carolina. Their primary mission is, and must remain, focused on the prevention of communicable diseases (dealing with outbreaks/epidemics, etc.); their secondary function should be focused on other population-based preventive efforts such as screening for these common diseases.

North Carolina needs healthy people to build a strong economy and infrastructure. Our state has the best health care available in the world. It is time to stop making excuses for not also having the best health among our people. Let's get busy building a system for health.

John H. Morrow, MD, MPH
Health Director
Pitt County

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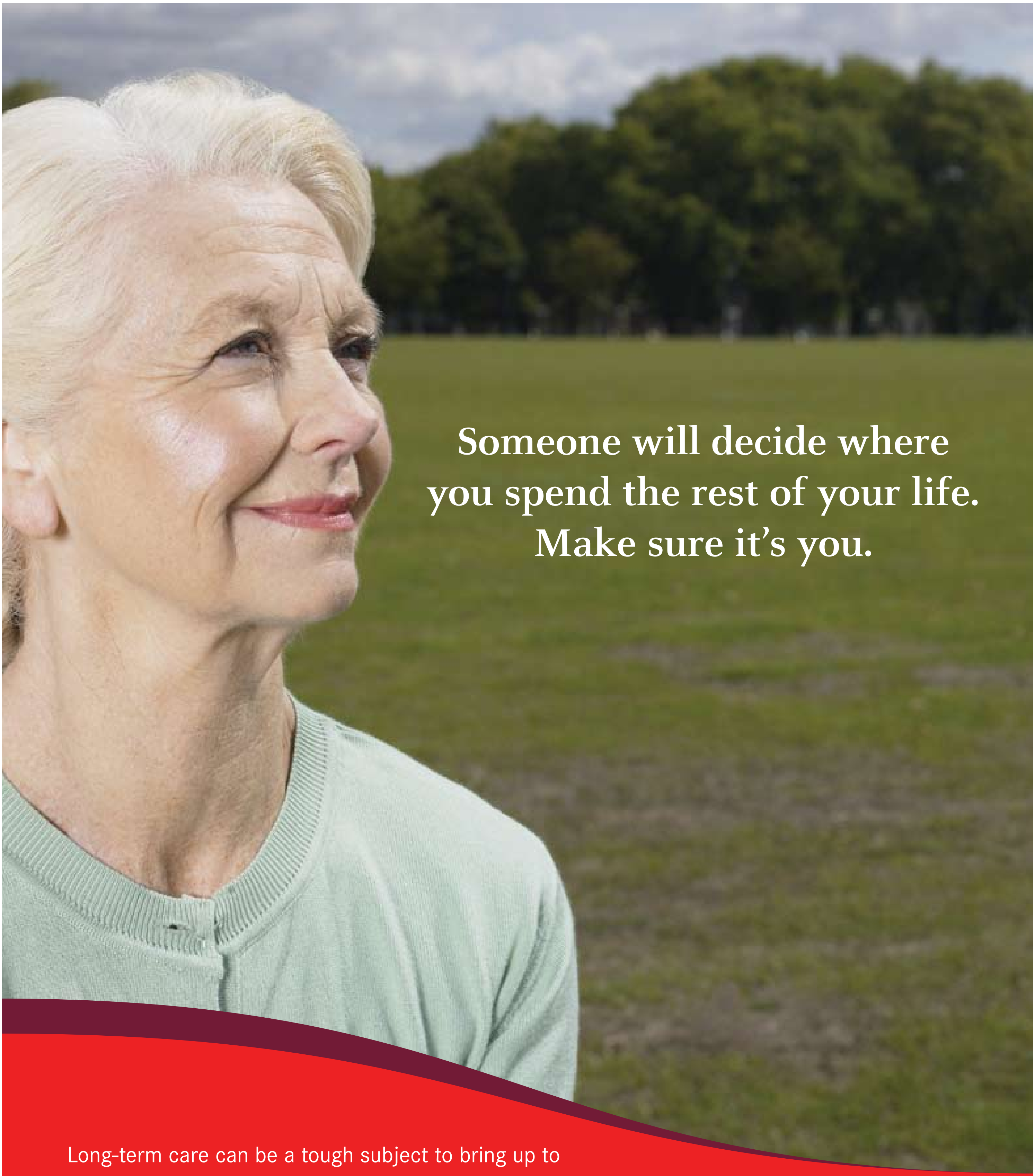

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