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# Health Care Reform and Family Caregivers

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## **Health Care Reform and Family Caregivers**

By

Edward F. Ansello, Ph.D.

Health care reform is in the air. Governor Kaine's Executive Order 31 last year launched an intensive examination of the status of health care in the Commonwealth that resulted in the recent publication of *Roadmap for Virginia's Health: Report of the Governor's Health Reform Commission* (available through [www.governor.virginia.gov/](http://www.governor.virginia.gov/)). The Commission producing the report is a stellar collection of knowledgeable veterans of the system who have prioritized issues and needs, recommended actions, and sought and incorporated comments from citizens and providers. Also this fall, AARP, the Virginia Center on Aging, and others are partnering in conducting *Health Care Reform Town Hall Meetings* in Virginia Beach, Roanoke, and Charlottesville to identify critical paths to improving health care.

Both the Commission report and the Town Meetings highlight, among other things, the primary need to "enhance" the health care workforce, from personal care assistants and home aides to nurses, physicians, and other medical practitioners. On the one hand, personal care assistants, certified nurse aides, home health aides, and other "Direct Support Professionals" (the Commission's term) tend to be underpaid, underappreciated, and undertrained, resulting in (no surprise here) constant workforce turnover. On the other hand, the number of nurses and physicians in Virginia is insufficient to the need and is projected to worsen; the term "nursing shortage" is used to cover a variety of culprits, from the aging and retirement of the current corps of nurses to the decrease in the number of nursing faculty available or willing to teach would-be nursing students; and "physician shortage" is the result of, among other things, failure to retain here medical students, residents, and fellows who complete their training in Virginia. Potential remedies include scholarships, training, loans, pilot programs, marketing campaigns, and more.

It is important to note that the Commission's focus was generic, that is, health care overall, and that the issues of shortages are even more dramatic when applied to older Virginians. For example, shortages of geriatric nurses and geriatricians are pronounced. In Virginia, as in the whole country, the number of physicians with Certificates of Added Qualifications in geriatrics (the rough equivalent of "board certified") is actually declining. Inadequate federal reimbursement for health care through Medicare and Medicaid has only recently been addressed through increases in payments for office visits that recognize that geriatric care is more complicated than previously acknowledged; but staggering amounts of required paperwork still drive many practitioners to conclude that they cannot make a living serving elders. Both the Commission and the Town Meetings address improving accessibility and affordability of health care; this implies, of course, that there are practitioners to access in the first place.

Long-term care is, primarily, an older adult issue. There are notable exceptions, as we have noted with the successful aging of increasing numbers of individuals who are

growing older with lifelong disabilities. Both the Commission and the Town Hall Meetings address long-term care. The Commission's recommendations for improving long-term care are thoughtful and numerous. They include expanding consumer-directed options with Medicaid services; increasing Auxiliary Grants for assisted living; expanding *No Wrong Door*, the Virginia Department for the Aging's single point of entry system; and increasing support and funding for family caregivers. This latter issue comes close to the heart of the matter.

“Long-term care” often translates to continuing or adjusting a relationship of long standing; it is providing assistance to a spouse, partner, child or parent when that person becomes incapacitated. We are usually reluctant to let go a relationship and will go to great lengths to keep someone we care about at home, in the community. While buying more long-term care insurance may be an important step in the long-term care process, and while creative initiatives such as Governor Kaine's new public-private partnership are attempting to increase the number of Virginians with long-term care insurance, the most important issue in long-term care seems to be focusing more on family caregivers. This is where the action is. Family caregiving is the common practice across income, racial, ethnic, and geographic lines.

Researchers have found that, for every older adult occupying a nursing home bed, there are three or four others with similar conditions still living in the community because of sustaining family care. We and other investigators have found that, with lifelong, developmental disabilities, for every older adult with such disabilities who is receiving services (or is wait-listed to receive services) from disabilities-, aging-, or health-related agencies, there are on average two or three receiving none. Again, the reason is sustained family caregiving. The inescapable conclusion is that family caregivers are the foundation of any long-term care system.

When we first proposed in the General Assembly what became the Virginia Caregivers Grant Program, we called it the Caregivers Investment Bill in order to recognize that investing in family caregivers is as prudent as investing in a business; providing support or tax incentives is as potentially fruitful as encouraging business zones. We testified that for every one million dollars invested in helping caregivers, through \$500 grants, to continue their care to family members with two or more impairments in Activities of Daily Living, the Commonwealth saves more than this amount if fewer than 10% of the assisted caregivers are able to defer or postpone the care recipient's use of a Medicaid nursing home bed by less than four months. And yet the Virginia Caregivers Grant Program, active since 2000, has been moribund for several years and languished with minimal funding otherwise.

Family caregivers need the **Three Rs: Recognition, Reinforcement, and a reliable Resource** of assistance. They need for the Commonwealth to recognize that they are the bedrock of long-term care; they need to be trained and strengthened in their knowledge of available community resources, in their ability to manage medications they oversee for loved ones, in their understanding of nutrition, heavy lifting, how to maintain their own well-being, and more; and they need reliable resources to call upon when they wish to

find out more, so that they can keep on doing what they want to be doing, namely, keeping loved ones in the community; such resources might be a steady source of financial assistance, like the VCGP, or of helpful information, like SeniorNavigator or No Wrong Door, or of knowledgeable health care practitioners.

These observations, admittedly, just scratch the surface. Health care reform requires an array of initiatives. But minimizing investment in family caregivers would short circuit any serious effort to improve the health status and care of older Virginians. The Commission's report is thoughtful. It and related proposals address prevention and consumer actions, bureaucratic initiatives, estimated costs of improvements, workforce shortages, expansion of existing programs, and more. Reform is in the air. Let's hope we act on it.