Do We Need a Surgeon General's Report on Home and Community Based Services? A Personal and Policy Journey

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During my career, my attention became focused on elder community care policy after reading a Commonwealth Fund-supported report of the Commission on Chronic Illness (1956) *Care of the Long-Term Patient*. The report described the problems of coordination and integration of services for the patient with multiple needs, which required simultaneous solutions. It argued for some type of community-based central organization to oversee and plan for the needs of long-term patients. (Note the focus on the long term patient, not the long-term care system.)

The Community Welfare Council of Schenectady, where I held my first professional job, issued a report in 1964 detailing the chronic illness needs in Schenectady County, New York. I wrote that report with technical assistance from the State Charities Aid Association of New York and the New York State Department of Health. This report was written in the time before the establishment of Medicare. It was a time when Visiting Nurse Association nurses returned to their offices at 4 p.m. each day, filled out their records and sharpened their hypodermic needles with a needle sharpener (similar to the one used for pencils). The report listed a number of radical recommendations such as: (a) acute care hospitals should establish stroke rehabilitation programs, (b) married couples residing in the gender-segregated county nursing home should be able to visit each other, (c) nursing homes should have at least one registered nurse available to oversee care, (d) a community-wide home-care program should be created, (e) Blue Cross/Blue Shield should reimburse for in-home care, and (f) a new homemaker program should be established. That report is almost 40 years old.

I was a student at the Heller School, Brandeis University, from 1965 to 1968, where Robert Morris chaired my dissertation *Obstacles to Community Planning for the Elderly* (Callahan, 1968). From 1969 to 1972, I was director of the Massachusetts Medicaid Program. Morris wanted to do a study of elders on Old Age Assistance and asked for my help in getting access to records and people. These were the years when the Harvard Community Health Plan (HCHP), a prepaid staff model group practice, had been established. Medicaid actually had a contract with HCHP for 1,200 Aid to Families With Dependent Children recipients in the Mission Hill area of Boston. Morris produced a report calling for the creation of a prepaid organization (like HCHP) to provide social services to elders, for which he had found a great need. Services would include homemaking, chores, transportation, meals, legal services, etc. It would be called the Personal Care Organization (PCO). We moved ahead, received one of the early 1115 waivers, and created a PCO in Worcester, Massachusetts. Two others were established in Wisconsin. All this happened about 30 years ago.

From 1973 to 1977, I managed a long-term care hospital and school for physically handicapped children. My first task there was to move 48 children back into the community as part of the reform of special education. Our staff was only successful with about half of the group because of the lack of home-
and community-based services (HCBS). Therefore policymakers need to think beyond older persons when considering HCBS.

Massachusetts had the first statewide public home-care system operated by a department of aging in the United States. I was Secretary of Elder Affairs in 1977 when statewide coverage of the home-care network was completed. It was a system conceptually designed by a task force that was supported by former Secretary of Elder Affairs Jack Left and led by Louis Lowy of Boston University. The task force had access to empirical data generated by Laurence Branch in his longitudinal study of the health and social service needs of people age 65 and older in Massachusetts (Branch, 1977). The underlying concepts of the home care model were to: (a) destigmatize the receipt of services previously provided by the welfare department; (b) achieve local and/or consumer input; (c) reduce government red tape; (d) focus on case management; and (e) serve as a repository for funds from many sources. The result was the establishment of 27 locally based nonprofit case management agencies with funding from the state, municipalities, and private sources. The home-care network was a small step toward the vision of the 1956 Commission on Chronic Illness report.

In 1979, I moved to the Heller School to work on disability and long-term care. Federal support for the PCO idea was vanishing, but Stuart Altman and Stan Wallack were working on a number of projects with the Health Care Financing Administration (HCFA) and soon the PCO idea and needs of the Medicare program merged to create the concept of the Social Health Maintenance Organization (SHMO). Four SHMOs were established in the first round of demonstration funding in the early 80s. Now the SHMO, conceived 20 years ago, has an ongoing designation in Medicare. During this same period, I was involved in the process evaluation of the National Long-Term Care Demonstration (better known as “channeling”), which demonstrated the strengths and weaknesses of a case management approach to HCBS.

In the last 10 years, I have worked on Robert Wood Johnson Foundation projects with my colleague Susan Lanspery: (a) Life Care at Home; (b) Supportive Services Program in Senior Housing (SSPSH); (c) Naturally Occurring Retirement Communities (NORCs); and (d) affordable assisted living. Both Susan and I believe, along with some other observers, that the SSPSH program influenced the Department of Housing and Urban Development to expand its policy and financial support of service coordinators in senior housing.

From the perspective of this long background, I suggest that a surgeon general’s report is needed for in-home and community-based services. There are three developments that inspired me to call for such a report. First, is the example of the surgeon general’s report on mental health. There have been many surgeon general’s reports over the years. One author cites 50 (Hegner, 2000). Perhaps the most famous are those on tobacco, but there have been others dealing with preventive health care, children, nutrition, and oral health. This year the surgeon general’s report on mental health (U.S. Department of Health and Human Services, 2000) was released and has done a service for mental health consumers, providers, and funders by gathering and evaluating the scientific evidence underlying our understanding of mental health.

The mental health report took a public health focus that included not only issues of diagnosis, treatment, and etiology, but also epidemiological surveillance, health promotion, prevention, and evaluation. A recent book Public Health and Aging edited by Tom Hickey, Marjorie Speers, and Thomas Prohaska has recommended a similar public health approach for services to older persons (Hickey, Speers, & Prohaska, 1997).

A public health approach may disclose new options or revive former strategies for serving elders. For example, in the book by Hickey and colleagues, Kutza (1997) argues for a return to a neighborhood approach, to bring services closer to older people who usually do not stray very far from their homes. I have a particular interest in naturally occurring retirement communities—essentially neighborhoods with a dense population of elders—and have argued that density makes a difference. Density will offer economies of scale, opportunities for elder participation, and the potential for physical and housing planning. In another chapter, in the Hickey and colleagues book, Andersen and Pourat present an integrated public health-aging paradigm (Andersen & Pourat, 1997). Its elements are a focus on older people, concern with chronic disease, secondary and tertiary prevention, a community orientation, and population-based interventions. This model could guide the development of a surgeon general’s report.

The surgeon general’s report on mental health identified and suggested resolution to fundamental issues that have plagued mental health and/or illness over the years: (a) the artificial separation of mind and body; (b) the deeply embedded problem of stigma; and (c) questions about the validity of the scientific base of mental health and/or illness research. HCBS agencies have their own set of fundamental issues policymakers need to identify and resolve. My list includes: (a) medical versus social models; (b) professional versus consumer direction; (c) risk versus autonomy; and (d) home versus institution. Versus may be the wrong term; maybe some combination of both/and would fit better.

A surgeon general’s report on HCBS must address how to reduce ethnic and racial disparities of access and quality. Marian Gornick, of the Georgetown Public Policy Institute, who had a 20-year policy career at the HCFA, has recently published a book on vulnerable populations and why disparities exist within Medicare (Gornick, 2000). Works like this add to the evidence base of HCBS.

Although the substance of the mental health report is impressive, the process used to produce it, I believe, strengthens its results and guarantees its im-
plementation. There was broad representation from the scientific, practice, and research communities, from various agencies on the national, state, and local levels—public and private. Most important, the process included consumers of mental health and family members of mental health consumers. Both of these groups have articulate organizations to put forth their messages.

A surgeon general’s report on HCBS should adopt a similar process and strive to be inclusive of all the interests. Policymakers need to identify parallels in the aging field for the National Alliance for the Mentally Ill, the Mental Patients Liberation Front, Empower, and the mental health recovery movement. This level of consumer interest and expertise must be included, along with gender, ethnic, and racial minority groups. Membership organizations like AARP, the National Committee to Preserve Medicare and Social Security, and the National Council of Senior Citizens will be important for both ideas and implementation.

Certainly, families and caregivers are essential partners in HCBS. There is probably no one reading this who has not directly or indirectly been affected by caregiving needs or responsibilities. Employers and directors of employee assistance plans can contribute to this process. And the service users themselves would have to be heard from—from their bedside if necessary. Putting together the right people and the right process would be a first step in a surgeon general’s HCBS report.

Second, members of the gerontological community know the goals and values of home- and community-based care. These goals are to be where an older person’s preference lies, where autonomy is exercised, and where dignity is supported. This does not mean the cheapest solution. It does not depend on a simple cost benefit analysis. It is a value commitment. It is a societal choice up front that sets the constraints on the analytic tasks required to identify and design the HCBS system or systems older persons require.

This is a position I have held for a long time. Testifying on the issue of alternatives to institutional care before a Senate Special Committee on Aging hearing in 1977, I noted that some analysts were arguing that the cost of caring for an elder in the community may be greater than in an institution. I argued:

If one follows this reasoning to its conclusion, we may decide that the institution is indeed the way of solving many of the problems of elders. I think it is very important at the very beginning of my remarks to meet this line of reasoning head on. The community is not an alternative to the institution. Rather, the institution is an alternative, and a very specialized alternative, to community living. (Hearing Before the Special Committee on Aging, 1977)

Finally, I believe there is now substantial evidence on HCBS to be evaluated. There is a long history of research and institutional memory in the federal government. Frank Caro (2000), in a proposal for a major conference on long-term care, has recently noted:

From time to time, the Aging, Disability, and Long-Term Care unit in the Office of the Assistant Secretary for Planning and Evaluations of DHHS, Administration on Aging, the Health Care Financing Administration, the Agency for Health Research and Quality, the National Institute on Aging, the National Institute on Mental Health, and the National Institute on Disability and Rehabilitation research have all supported research on long term care. (p. 6)

There is the output of gerontological research programs and centers. There are growing bodies of market analyses revealing the preferences of older people. And there are new books on relevant evidence. I reviewed two recently: Home Care Advances: Essential Research and Policy Issues edited by Binstock and Cluff (2000), and New Ways to Care for Older People: Building Systems Based on Evidence edited by Calkins, Boult, Wagner, and Pacala (1999). A significant number of evidence-based reports on home care were presented at the American Public Health Association’s recent annual meeting in Boston. Clearly, the time is ripe for a new national synthesis on HCBS, which a surgeon general’s report could achieve.

A surgeon general’s report would give credibility and visibility to this area of elder service. It will become a tool that can be used by proponents and planners of HCBS. Recently, Mike Hammond of the Kansas Department on Aging made a presentation at a Center for Mental Health Services conference. His paper was entitled “Elderly and Aging Issues: Putting the Surgeon General’s Report to Work for Older Adults” (Hammond, 2000). It is a wonderful example of using the surgeon general’s report on mental health to identify issues, describe outreach approaches, and provide substantive knowledge of mental health and aging. A report on HCBS could be put to similar use.

A surgeon general’s report could become a platform for further research, as well as for specific policy recommendations. The process of engagement with people and ideas could energize the field, just at the time when gerontologists need such energizing, amidst the chaos of the health care world. Solutions to the problems are not easy. But one thing is certain: there will be many old people dealing with their needs and problems (many gerontologists among them) and they deserve the resolve of researchers and policy makers to provide answers.

References

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