Where Will Aging's New Leadership Come From*

Summary

Today, most frail older adults remain at home, families shoulder overwhelming caregiving demands, and the existing system is financially unsustainable for all but the very wealthy. Digital tools can decentralize and better coordinate care, enabling older adults to remain safely in their homes while rebuilding local community responsibility. New leadership will emerge from both aging boomers who recognize systemic failure and millennials who will carry much of the caregiving and financial burden and are well positioned to harness technology. Ultimately, the neighborhood-level community—people within reach of one another—will become the foundation for future aging care.

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When I entered the aging field in the 1980s, and then for another decade or two, community nursing homes did it all. We cared for minimally frail older people, very frail older people, the wealthy and the poor, those with mild dementia, those with profound dementia. We provided rehabilitation. We took care of the dying and we took care of the recovering. We even prepared meals for people living in the community.

Which is not to say that this was some golden era. In light of today's understandings, it was incredibly primitive. There were often two or four in a bedroom, shared bathrooms, no air conditioning, minimal understandings of aging and few interventions. Try as we did, the people we were caring for tended to languish. But whatever its limitations, the home was supported by community obligations and community assets. And people could truly age in place, remaining in the same building, the same care system through all the evolving tribulations they confronted.

But this community venture, this generations-long obligation to aging neighbors, the very centrality of the community in the care of its aging, had effectively disappeared by the early 21st century. Beginning in the mid-1960s, the federal government, in partnership with state governments, took over much of the cost and much of the responsibility of caring for the frail old, displacing community from its central role. Government support reduced the need for funding from the community and, as a consequence, for community leadership to raise those funds and maintain the community's commitment to the aging among them.

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Administrators of institutions became professionals, rather than religious or cultural leaders. Priests, rabbis and social workers were replaced in aging care institutions by MBAs.

This development came when the late-stage culture of America's industrial era was still dominant, and the response to the dramatically increasing number of older people needing care was the development of specialized mini-factories of care (nursing homes, assisted living, low-income housing) where operating expenses could be reduced through economies-of-scale, i.e., assembly lines of repetitious care tasks.

During the same period, an increasing dispersion of formerly geographically tight religious groups worked against the possibility of faith communities raising commitment and capital to build new facilities in the suburbs. As a result, corporate chains bought up and created specialized cookie-cutter facilities that generated their profits from governmental programs.

Corporate nursing home chains focused more on medical care and aligned themselves with Medicare reimbursement which was purposely designed at its inception to discourage a cross-disciplinary coordination that would integrate various interventions under one provider. As a result, fragmented care emerged.

The medical programs and the physical facilities, that once were community systems providing integrated (however limited) care as peoples' conditions evolved over many years, have become so specialized, so fragmented and increasingly designed for short-stays that they now provide minimal security for the aging experience—and are now financially unsustainable for almost everyone. Only the very wealthy have access to a secure older age, and even those with ample financial assets grapple with coordinating appropriate care or settle for well-appointed but antiquated, unresponsive facilities. Today, most frail older people remain in the community and nearly one in five adult Americans (63 million) provide ongoing care to a family member with a complex medical condition or disability. This is an increase of 20 million over the last decade. Families are overwhelmed.

It may be that digital networks for information sharing, communication, health surveillance that once required the co-location of frail older persons for efficiency, can now allow older persons to remain safely in their homes and take us back, in a new way, to community involvement with the aging neighbors we've lost.

We find ourselves at the threshold of a new age that has two dominating features: first, a fast-growing number of people present among us who live longer and carry a burden of chronic conditions that the existing health system is rapidly losing its effectiveness to treat; and second, the ubiquity of digital tools to decentralize care for chronic conditions and integrate older people into their community settings. After a long journey through a twentieth century dominated by institutions, we are returning to a greatly changed version of where we started.

Our natural inclination to reach out to one another has been stunted in relation to frailty by the belief that institutionalization was the only safe and appropriate venue for frailty care. Today, lay community leaders who look see that they can no longer address their frail community member's challenges through old institutional approaches that require more and more funds just to stay open. The nature and scale of frailty in communities will force us to engage with one another. We are about to re-create community from the ground up. While digital systems can provide information and fantastic technological supports, it will nonetheless be the human element that enables community to sustain profound frailty in its midst and make older age as good a time of life as any other, one that is important for all ages to know and cherish.

Communities will look among themselves for leadership in caring for the aging in their midst. Leaders will arise from the 72 million boomers (in four years all of whom will be 65+) who are awakening to the reality that for most, there is no functioning system that addresses the realities of their older years. With the recognition that they can't do it alone, they will welcome technology that can reframe this dimension of their lives as it has already done with so many other dimensions of American life.

Leaders will also arise among the nation's 80 million millennials. It is this generation, born between 1980 and 2000, that will be caring for and actually assuming the financial burden for the nation's aging population, and they are the ideal group to comprehend the possibilities of the new digital paradigm. Many are resourceful, civic-minded and optimistic about their own economic futures. We can reasonably hope that they will come to the fore with their own orientation towards recreating aging and aging care for their grandparents and parents. They won't expect or want to depend on government to take the lead. They will start with small local efforts to unleash new interdependent forms of community.

As communities move toward integrating their oldest members interests into mainstream community life, their civic organizations will evolve. Leadership will come to understand the threat of chronic conditions and the advantages of digital programs and begin to facilitate community support networks. The kind of community that will be most

relevant to aging from now on will be the community created by people who live within sight and reach of each other. The neighborhood, with the comfort of proximity and the strength of shared interest, is the bedrock on which the future of aging care rests.