Designing a New Aging Delivery System—Lessons From the Past*

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Summary

Long-term care has been repeatedly forced into settings, regulations, and organizations built for an earlier era. Institutional long-term care evolved too late. Community systems mirror institutional failures. Patching together analog programs cannot meet today's scale. The path forward is a new delivery system designed around the older person in the home, enabled by network-era information sharing and community-level orchestration rather than institutional congregation.

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Introduction

For the past 60 years, the field of aging care has been repeatedly disoriented. Changing circumstances have rendered major programmatic components of aging care not only inappropriate, but incapable of adapting productively to the new realities. The result is an aging care industry rife with programs and services attempting to perform tasks in overly complex, convoluted, and impractical ways.

I spent most of my career working in aging care in Buffalo, New York. In the following pages, I will extract basic lessons from my experiences that can provide guiderails in the development of a new, sustainable system for aging in the era of accumulating chronic conditions correlated with increased age.

Aging's Institutional Settings Innovated Too Late and Missed the Boat

In 1965, the passage of Medicare and Medicaid transformed predominantly community- and religious-led homes for the aged (old folks' homes), into Skilled Nursing Facilities. Buildings that were originally designed like hotels for ambulatory residents, were forced to accommodate a new cohort of residents, profoundly frail people. They did so by converting the former walkway-corridors into assembly-lines serving the wheelchair-bound. Now, the corridors that had been the scene of elderly but ambulatory women and a few men coming and going to meals and activities were the scene of lines of wheelchair-bound residents waiting to be taken to the bathroom or down to meals.

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This new, less ambulatory population, living in facilities not designed for them, suffered the consequences of bad fit. The erosion in quality of life, general vitality, health, and outlook was so devastating, and so consistent, that the result was assumed to be the true nature of aging, rather than an artifact of an inappropriate delivery system.

By the mid 1990s, there was an early realization that the standard nursing home design, the physical platform, was not supportive of, if not antagonistic to the daily tasks and activities of residents and caregivers. But, for various reasons—primarily lack of funds and lack of recognition of problems—the field of institutional aging care did not respond. Assisted Living facilities, created in 1981, matured with more appropriate design, but are financially inaccessible to most older people, and average lengths of stay have reduced to 22 months. Most long-term care will remain in the community.

Through community daring, the organization I led had the opportunity to create a new nursing home. We started the redesign process by trying to describe the desired result: what did we want the older person's experience to be? It was clear that our residents could not get to distant services easily, so we determined that services should come to them. We wanted appropriate privacy, a dignified way for the residents to toilet, bathe with as much space that they could manage safely. And we wanted our caregivers (primarily nurse's aides) to have the means to take care of residents flexibly and conveniently. We did so by enabling them to tailor and coordinate for each resident all the various supports and interventions rather than following the assembly-line service delivery that was pervasive in all the institutions we knew.

We put the frail older person in the center of every presentation, paper, discussion, and whiteboard diagram when we planned the new place. In fact, we later realized that we could trace many of our eventual difficulties in adjusting to the new home to the moments in the planning when we had lost our focus on the older person herself.

Our re-conception of the facility resulted in an environment with private rooms and bathrooms, with living rooms rather than corridors as shared space. And we cross-trained staff rather than providing care through separate, specialized departments.

It took three years for regulators to accept a design that challenged their fundamental framework. Our simple proposition was that the state health department's regulatory template for the nursing home no longer addressed the needs of current residents. Eventually, we presented our ideas to a panel representing all the bureaus in the department, more than thirty people. Halfway through the presentation, the head of the architecture bureau said, "Mr. Dunkelman, what you are saying is that for the last ten or twenty years we've been approving the wrong projects." Everything about aging had been changing, and no one was noticing or responding.

Our design worked. But by the time we could show that, it was too late for most nursing homes to fundamentally redesign their physical environments. Overwhelmed by a combination of the inrushing deluge of profoundly frail older people and tightening government resources and reimbursements, they were forced to specialize and triage. The facilities medicalized, lengths-of-stay shortened dramatically, and nursing homes assumed the role and rhythms of mini-hospitals. While approximately 1/3 of older adults 85+ will spend some time in a nursing home, the medium length of stay for this age group is but six months. The sheer numbers tell the tale. In 1980 there were 1.5 million nursing home beds for a 2.2 million 85+ population. In 2024 there are slightly fewer nursing home beds for a now 6.5 million 85+ population. In five years (2030) there are projected to be dramatically fewer beds for a 10 million 85+ population. Ten years from now, the 85+ population will be 12 million. As a result, most frail older people will experience their long-term care in the community.

The Unpreparedness and Failures of Institutional Aging are Mirrored in Community.

Early in October 2006, the Buffalo area was hit with a freak storm that piled two feet of snow on the region. Trees, still fully leafed, fell by the thousands, power lines went down, electricity was out for more than a week in some 300,000 households, roads were so choked with fallen trees that opening them took days.

Most Western New Yorkers were stranded. As the authorities went door to door, checking to make sure families were equipped to survive, they discovered hundreds of older people, many frightened, confused, frail and hungry. They were stranded with nowhere to turn for help. Most were evacuated and deposited at hospitals and nursing homes, including ours. Facilities throughout the region were inundated. For those who care for the region's older people, it was our "Katrina Moment."

The natural disaster suddenly shone daylight on a portion of the community that had been frequently forgotten: the old, frail Buffalonians living at home alone, largely hidden away from the rest of the world. We were shocked by their numbers and by the scale of their needs. It took me a while to realize how extreme their circumstances were. They were living without any safety net, in tenuous circumstances, at great risk.

I suddenly understood the desperate plight of the profoundly frail older people living invisibly in my own community. Over the decades of my working experience, supports for complex, long-term frailty had mutated. Too many needy older people, I realized, had fallen off the grid. They were the ones who did not qualify for nursing homes, could not afford assisted living, and didn't know how to access other parts of the care system for the aging. So, they remained where they had lived in their earlier years, despite their

changed physical, emotional, cognitive, and financial circumstances, in an environment that had become alien and with no one to help them.

We were already aware that widespread institutionalization was not feasible, that assisted living was unaffordable, housing was not sufficiently supportive, and existing homecare was inadequate. PACE programs (we were operating one) were not capable of expanding to the scale of the aging population, and senior centers were effectively only for those who were still well and largely capable for self-maintenance.

We thought that a way to learn how a frail person received community services was to meet with hospital dischargers whose role was to transfer frail older people from hospitals back to their homes safely. Our initial working assumption was that the interaction between the hospital system and the community system was likely not properly managed, and that with better communication and coordination, transfers could be conducted in an acceptable manner, with better outcomes.

We convened a meeting of discharge planners from the major local hospitals. Once they became comfortable talking to us, the floodgates opened. They were under enormous pressure from the hospitals to discharge frail older people, but, they explained, there were minimal community resources to help with the transition. By and large, the traditional community agencies were not responsive, or they responded too slowly and finally had no capacity to coordinate their programs with other necessary services. Our original hypothesis had been wrong: the reality was not that the hospital and community gears did not mesh, but rather that the effective community gears were not substantial enough. Those community programs that are effective are often rather isolated and not integrated into a robust framework that can provide an appropriate safe quality of life and care in the community.

Many community agencies were at risk because of reductions in government and private support. Each had thrived earlier when government grants were available, when their boards were filled with businessmen who raised and donated money for them, and when staffing had been relatively inexpensive.

But by the early twenty-first century, everything had changed. The business leaders who created and supported the non-profit organizations no longer provided help, because the government had replaced their role. Then governments had reduced financial support and local foundations had become overwhelmed with requests. So historic, specialized community agencies found themselves struggling. At the same time, since fewer and fewer profoundly frail older people were leaving the community for placement in institutions, community agencies were being asked to serve a greater number of clients, many with more frail profiles than they were accustomed to help. Their staff members were constantly frustrated by the complexity of their clients' needs and their agencies' inability to coordinate the interventions that would reduce suffering.

The Failed Attempt to Build a New Framework of Community Agencies

We believed we needed a brand-new concept, a place where Mom—frail and still at home—could have access to the integrated care of a nursing home but sleep in her own bed. It seemed to us that there were resources available that could be combined to do the job, but that they were distributed throughout various disconnected programs and agencies. If we could link them together through co-location, perhaps we could create a support system for the profoundly frail old who were living outside of institutions. The new organization that we were planning was conceived to be a true collaboration among agencies. Each agency would have its own space and would control its own operation in the building. The new factor would be the building itself, which would house them all in one location. We called it the Town Square for Aging.

Simply co-locating agencies, of course, is not sufficient for providing truly integrated services. But, we thought, that by listening and analyzing the needs of a client in one agency and then walking with the client to the next resource that could help on another need, the Town Square for Aging would organically develop a cumulative and multifaceted approach to the varied and interacting challenges confronting the client and his or her family. The co-location of services in the Town Square for Aging would also foster informal interactions between the agencies that would enable them to work together to the benefit of the aged clients.

We raised millions of dollars to refit a building, allowing each agency to fashion a space appropriate for its operational needs. We spent years meeting, discussing, sharing, and uncovering potential synergies

The need for integrated care was great and was increasing every day as fewer older people were finding suitable places in facilities. The co-location plan was logical and compelling. The participating agency executives were all well intentioned, but even after years of collaborative energy, the Town Square for Aging was never fully realized.

While the benefits to frail clients seemed clear, the benefits to the organizations themselves were not as obvious. There was no mechanism for passing back to the Town Square or its participants any of the savings from reduced hospitalizations or unnecessary health costs. The CEOs of the participating agencies did not know one another well. Even if they saw some potential benefits to their own organizations from having a place in the Town Square, it was hard for them to think in terms of the larger group that was gathered. Their responses would often rebound back to loyalty to their individual agencies. The divisions and boundaries between agencies that had developed during the highpoint of the Industrial Era in the 1950s remained firmly in

place, even though this meant that they were unable to meet the needs of the population.

The co-located organizations were also daunted by the task of learning to coordinate with one another. Almost everyone recognized that it was critically important to share information. Along the way we recognized that each agency had no easy way to understand what others were doing. We all used very different features of Medicaid, Medicare, and other programs, and each group had developed their own ways to navigate the system. We were swimming in a chaotic sea of data, with little ability to make sense of it for clients or for ourselves.

The hospitals, community physicians, and large service organizations, all of which could have sent us clients that were of no financial benefit to them, chose not to engage. They tended to see the Town Square effort either as inconsequential and not worthy of their time, or as a potential threat to their control of the patient within the old medical paradigm. Even though it was based in part in the familiar business concept of co-location of space, using centrality to extend services, it could not garner the engagement of the existing health care players, who remained in their traditional roles. Health care leadership was unalterably institution bound.

The Town Square concept required that everyone involved take risks with new behaviors, relationships, and constructs while continuing to maintain ongoing responsibilities for their survival in their current paradigm. It was an attempt to knit together elements of the existing landscape to create something new and more effective. It required leaps from the existing paradigm that were dramatic and required an allocation of resources that was not yet imaginable. In the end, it was too different from the traditional methods of care delivery for the organizations, their clients, and even the community at large to engage. Tying the existing programs together in a new way, even with sincere cooperation and hard work, was inadequate to address the challenges that motivated the effort.

A New Aging Delivery System

In 2016 I retired and moved to New York City. I recognized that after five years of preparation and thirty years of effort to build, adapt, and innovate robust appropriate aging settings and programs, I had failed to find a framework that would work in today's world with its enormous numbers of older people living with frailty for the last years of their lives. Each of the aging settings and programs we developed seemed to have its own internal limits, in addition to being repeatedly stifled by the difficulties of overcoming the complex regulations and the silos of bureaucracy. Each setting was like a tree covered with ivy so thick and lush that it girdled the tree's trunk and covered all of its limbs. Eventually the thick vines of regulations, court precedents, tight administrative scrutiny, and protectionism within the industry itself, strangled the system. The

suffocating foliage of restrictions and barricades quickly covered each spurt of growth. The branches and leaves could no longer reach for the sun and each new entity failed to thrive.

What were we missing as we tried to break through this tangled web? Could it be something so fundamental it never came to mind? There is an old Gary Larson cartoon with two cowboys riding along the range, one rears back and says, “Whoa, we forgot the cattle!” I wondered why I had arrived without the cattle.

Very simply, I came to understand that aging and chronic disease were not considered or understood when our healthcare system evolved to its present state in the past half century.

Aging, as it developed, was simply absorbed and grafted onto the predominantly acute-care health delivery system. Not only does aging not fit, but, indeed, aging has become such a predominant presence that the entire existing health system is teetering and tottering, top heavy with inappropriately addressed health needs of a huge aging population. Health care for the aging sits on an old creaking foundation. Our existing conceptual framework can’t be made more useful (maybe ameliorated a little) because patches and repairs will not right a system that, however successful previously, is fundamentally inappropriate to address the new challenges of our age. We can’t get there from here. But we can get here from there.

Over the next few years, I continued to search for ways to address the unmet aging challenge. I looked at how the nation’s economy had shifted and I realized I had no real understanding of the way the new network era was affecting various industries. As I read and learned, I recognized that in this network era, we don’t need proximity in order to communicate, so we no longer had to congregate all the people, equipment, and stuff in one place to manufacture care. All around us digital technologies have created dispersion. The new era eliminates the need for congregation in retail (Amazon), banking (at home), entertainment (Netflix), libraries (online), and hotels (Airbnb). Likewise, it will soon replace the congregation of frail older people for care.

And I began to think through this hypothetical: what if the digital era came to aging. This resulted in a book, *Aging Forward*, within which a major idea is that by accumulating and sharing information among geographically distributed people, we can address the complex needs of even profoundly frail older people in their homes, where they wish to remain. As in other sectors of American life, the concept of centrality, of collocation, of the physical aggregation of people and stuff, is no longer the appropriate organizing principle of long-term care.

Lessons from the Past for the Design of a New Aging Delivery System

1. Recognizing that there is a new venue for long-term care, the home. Generally, the home was designed for able-bodied people. Suddenly it is asked to support a client with very different needs. It may require ongoing adaptations as an older person's needs change.

2. The focus for the changes must be on the older person and how her supports actually function. To the degree possible, a care-providing organization's needs will be sublimated, giving priority to the older person.

3. Distant bureaucracies, however well-intention, will not be helpful in designing or regulating the actual frail living dynamic. It is not simply that they are far away, it is that the administrative branch is not tasked to design anything new. Rather, they focus on regulating within the existing Medicare and Medicaid framework. Many of the new interventions come from outside those traditional boundaries. And in order for others, such as community, to engage fully, they must have sufficient discretion and control.

4. Traditional community programs for aging generally will not be able to meet the challenge. Based in the analog era, they have inadequate resources to adapt to the needs of the new frail in the community. Nor do they have the range of resources necessary to become the foundation of community-based aging.

5. Cobbling together existing analog programs will not work to create a new sustainable framework. Efforts to create one through coalitions will result in a Tower of Babel. There are too many overheads and incentives cannot be aligned.

6. The network era will enable older people to remain in their homes and orchestrate complex, interactive interventions. No longer will they need to be physically congregated. The critical innovation is the generation and distribution of information.

7. No one can do this alone. Communities can make possible such orchestration of interventions, recognizing that all manner of care provision can be outsourced. But community is the only organization with a capacity to access a community's full resources. It is also the only organization with no incentive other than the care of its own.