The Gaps in America's Aging Experience: Why They Appeared and How to Fill Them*

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Summary

Over the past six decades, the U.S. system of care for older adults has evolved in ways that no longer align with increasing longevity and extended periods of frailty. Originally designed to provide continuous, long-term care, nursing homes have been reshaped into highly specialized, short-term, rehabilitation-focused facilities. As assisted living and home-based services have also narrowed their scope, care settings no longer overlap, leaving older adults to face significant gaps as their needs change.

The actual dynamic that is shaping modern aging is the Law of Interchangeable Interventions, that describes the wide array of interventions that operate inside the body, outside the body, and beside the individual. This dynamic allows people to remain at home safely and less expensively by enabling them to continually fill potential gaps by selecting interventions that are least expensive, least medicalized, and most consistent with earlier life. CarersUK's *Jointly* is a practical app designed to enable families to manage and coordinate all the various needs and interventions.

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How we got here

In 1965, when Medicare (federal) and Medicaid (federal-state) health insurance programs were created, homes for the aged did it all. They cared for minimally frail older people, very frail older people, the wealthy and the poor, those with mild dementia, those with profound dementia. They provided rehabilitation. They took care of the dying and took care of the recovering. Average lengths of stay were 5–8 years. There were only one million people 85+ in the U.S., and 500,000 nursing home beds to accommodate their needs. And government promised to pay the entire cost of care for those without means to pay for themselves.

How did the homes do it? All residents received the same basic care: they were fed, helped to the toilet and with other activities of daily living, and kept clean and safe. Costs were kept low by setting up assembly lines for efficient care where tasks were broken down and standardized. Not much was known about aging.

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By 1990, 25 years later, increasing costs were beginning to strain nursing home budgets, so government changed its reimbursement system. Rather than the same flat fee for everyone, government would reimburse for a covered resident based on how many resources her care took. By now there were new interventions available. Because the facility's care was based on replicating tasks on assembly lines, it made business sense for a nursing home to specialize in a particular type of residents' care need it would address.

A cycle was set. Government increasingly set rates that encouraged facilities to admit people with higher needs. People with lesser needs were no longer attractive admissions. The level of sophistication of care and therefore costs rose to care for increasingly more compromised admissions, who had shorter life expectancies. Lengths-of-stay shrank dramatically, to about two years for a "long-term" patient. But as states' Medicaid budgets tightened further, nursing homes could not survive even with those clients, and turned to focus on Medicare clients, mostly rehabilitation cases, whose needs and stays were even shorter (average three months).

So, over 60 years, these facilities had transformed from long-term care homes for the aged to short-term mini hospitals; from once a community's foundational institutions for aging to a boutique health care facility. In 1965 we had 500,000 beds for 1 million people 85+ (a ratio of 1:2). Today we have 1.24 million beds for 6.4 million people 85+ (1:5). In 10 years (2036) there will be fewer[1] than 1.24 million nursing home beds for 12 million people who are 85+ (1:10).

This is the current system and logic of our health delivery system for aging. Even as the nation experiences a longevity revolution, with people living longer and accumulating chronic health conditions, the health delivery system has abandoned long-term care. The assisted living sector uses the same economies-of-scale operating system, narrowing the range of resident profiles to service them efficiently. Costs increasingly go up, average lengths-of-stay go down (currently about two years), toward short-term and away from long-term care. Care from traditional homecare services delivered by aides and nurses is now based on economies of scale, narrowing the range of their tasks or procedures to increase the number possible to accomplish in an eight-hour day.

As levels of care and programs for aging become ever-more specialized, they no longer overlap or even touch one another. What happened in the former homes for the aging, where a resident received more care, or moved to another unit in the building as needs increased, is now no longer possible. A person may outgrow one program (for example, assisted living) but not be "appropriate" for a skilled nursing facility. As the programs narrow, more and more gaps appear, and a person's long-term care journey becomes unnavigable, no longer a continuous path.

[1] In the last 10 years, 5% of the nursing home beds closed.

The financial underpinnings for the system increase the chaos. As Medicare shifts to Medicare Advantage, contracts with participants are of one-year duration, providing no incentive for insurers to invest in their wellbeing for the long-term. To the contrary, because older people with complex, expensive needs drain profits from the insurer, they may be encouraged to go elsewhere.

What's really happening

All of this misses the basic societal dynamic. It was not the increase in population (from 194 million in 1965 to 330 million in 2025) that created the aging challenge. If that was the case, we would have had a 70-percent increase in people 85+, or an additional 1.7 million today. Instead, we have had a 640-percent increase, to 6.4 million Americans 85+ today. The exponential increase in life expectancy comes *at late age*.

How did that happen? It has been the bounty of modern society that reduces risk and provides new approaches, new interventions from all dimensions of our generally fortunate American life. Our world is a cornucopia of interventions. All the functions of daily life are currently subjects of intense investigation to find ways to stretch an older person's competencies. This massive array of new, often less expensive interventions, do not fit within the historic framework of legacy assembly-line facilities. Instead, they exist in the community, where they have enabled the increase longevity and correlated frailty to accumulate.

The new interventions arrive in three basic categories: interventions that work *inside* the body, such as food and medications; ones that provide help from *outside* of the body, such as braces and wheelchairs; and ones that exist *beside* the older person, like a granddaughter or an aide, who can steady him with a hand on his elbow or an encouraging word.

These categories of intervention affect one another, they merge, and they compete. New interventions—whether *inside, outside,* or *beside*—are continuously remodeling the experience for older people. An innovation in any of the three categories can have direct ripple effects on the other two. If an *outside* innovation has real impact, it should change both the way the individual functions (*inside*) and as well as reduce or change her service needs (*beside*).

What I call the Law of Interchangeable Interventions systematizes these interventions. That law, which is simply a description of a natural phenomenon, says that from the panoply of available and effective interventions, the *least expensive, least medicalized, and most consistent with a person's earlier life* is the most desirable. This drive to find the option that is cost-effective, and palatable, and effective will become the basic dynamic of the future of aging in the community, throughout the nation.

Why don't we factor the power of this rather obvious dynamic in our thinking about aging? Because we can't see it.

When interventions are successful, such as when you are so comfortable using the backup camera in your car that you are no longer aware that it replaced craning your neck and so has allowed you to continue to drive later in your life, that intervention becomes an unconscious extension of yourself into the external world. It's no wonder that the present-day cascade of interventions, coming from almost every angle, competing and setting up new opportunities for ever-newer interventions, is too ubiquitous to be visible.

The fact that many frail older people and their families are making consumer choices, and that the market is responding to them, has transferred a portion of their care back into their own hands. As we develop more interventions we are slowly coming to realize that many conditions we assumed to be unavoidable as "natural" aging can actually be mitigated. The locus of control in aging has moved from controlled environments like nursing homes to the home that can be continually adapted to Mom's changing needs and wishes and respond to her control, and to Mom herself.

<u>Filling the gaps—A new system for aging in the community that enables older people, their families, and communities to truly benefit from the Law of Interchangeable Interventions.</u>

Eighty million Millennials in the U.S. are now facing the aging of their 72 million Boomer parents and are overwhelmed by the responsibility. Already, 1-in-4 U.S. adults (63 million) are now family caregivers, facing rising stress, health risks and financial strain. Their parents continue in their homes that are not programmed to support their needs as they age.

Being responsible for the care of a loved one at home can be overwhelming. The fundamental challenge lies in coordinating the various *inside, outside* and *beside* interventions to address the changing an older person's needs.

Managing the care of an older person involves coordinating a wide range of tasks that may involve multiple caregivers and service providers. The responsibility requires constant attention to the wide variety of daily activities related to toileting, walking, eating, sleeping, dressing, medications, bathing, home care visits, treatments, glasses, hearing aids other equipment, daycare, transportation and doctors' appointments. Since the older person's needs are dynamic, staying on top of things requires identifying changing needs and finding the appropriate intervention. Many adjustments impact other chronic needs, which may set off a cycle of interacting repercussions.

The key to successful care lies in the timing and coordination of activities. But intricacy makes it difficult to explain to others and therefore a challenge to delegate. That leaves the primary caregiver who is responsible for caring for a parent stressed and often having to do it alone.

Now there is a proven system to help families manage their parents' care— an easy-to-use software tool to stay on top of all the interrelated tasks and manage everyone involved in the care.

Carers UK (a national charity in the UK) has developed an app, called *Jointly,* that provides primary caregivers a single easy-to-use platform on which to store and share basic information about the person being cared for with those involved in the care. Everyone in the person's circle of care has access to the app which runs on all smartphones and tablets.

The app enables the primary caregiver to build a circle of care with family members, neighbors, community volunteers and paid aides. The app enables the primary caregiver to assign tasks to others in the circle of care. Everyone can see a shared calendar that includes all the daily and hourly tasks that need to be accomplished.

The app's simple messaging system makes it easy for everyone in the circle of care to stay current with the tasks that have been delegated to them. The app makes it easy to share all the details of the older person's current state as well as such critical items as the schedule for the medications they are taking.

The person's healthcare provider(s) can also be connected to the circle of care and can be immediately updated to the person's current status including any new symptoms.

The app also makes it possible to export essential information that can be shared with designated others, if, for example, the primary caregiver is unable to provide care at any moment. This can also be useful in transferring critical documents (e.g. insurance policy, power of attorney, healthcare proxy) when the person being cared for is being transferred to a facility.

In summary, *Jointly* makes it possible for a family to recognize and manage their resources and have them flow together naturally. It also makes it possible to connect the family with existing resources in the community and eliminates the isolation of the older person and their primary caregiver.

Jointly is easy to use and it costs the family nothing. It has been successfully used in the UK for over 10 years, currently by 30,000 people households. It has been continually refined with the ongoing feedback from hundreds of families. The non-profit Community Aging Circles has partnered with Carers UK, to make the *Jointly* app available to U.S. families for free.