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# Long-Term Care and Medicare Policy

Can We Improve the  
Continuity of Care?

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## Caring Communities: What Would It Take?

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WHEN WE ARE OLD, or when we are in need of help, we hope for loving care. When we need help caring for our parents, our children, or our sisters and brothers, we hope that the people who help us care for them are loving, too. Against all these hopes, we are tormented by a recurring nightmare: that we will end our days in a nursing home, or that someday we will have to put someone we love into one.

Care begins at home, in the family, among people who love one another. That kind of care is the most private and intimate and the kind we most cherish. At the other end is public care, the stuff we know by ugly names like long-term care, home- and community-based services, and skilled-nursing facilities, with its unfortunately pungent acronym, SNF. Simple words like *love* and *care* are notably absent from the public vocabulary. This discrepancy in the very language of care is only the surface crack of a deep chasm between the public and private worlds of caring, between our hopes and our nightmares.

Reality, of course, is far more complex than hopes and nightmares. It always is. Family caregiving begins in love and loyalty and springs from the heart before the head, but it can quickly become burdensome, conflictual, even hellish. Caregiving can drive people apart, strain marriages, fracture families. At the other end of the spectrum, public care, the care given by strangers trained in technique and beholden to accountants, can start out cold and distant but quickly ripen into loving, almost familial relationships.

Yet on the whole, there is a long distance between the kind of care we wish for ourselves and our families and the kind of care we are willing and able to provide for our fellow citizens. That the public sector sometimes has to help us in our private lives is a given. The questions we face are how and whether it is possible to make care in the public sector live up to our private ideals. Can we envision a world in which getting care for ourselves or someone we love is not a nightmare? Is there some place between the ideal world of family care (which

is often anything but idyllic) and the public world of institutional and programmatic care (which certainly has its glorious moments)? Is it possible to envision a caring community that can support family caregivers without displacing them altogether but without exploiting them, either?

"Caring community" is my shorthand for a space that offers the security of public responsibility and protection but also the warmth and intimacy that we imagine, and often practice, in families. Government and policymakers usually approach these issues by resolving to make changes in the way care is paid for, the way personnel are trained, the way quality is regulated and monitored. Caring communities cannot be created, however, simply by rounding up the usual suspects—pay, personnel, and procedures. Those of us in the policy arena need to change our thinking by stepping outside ourselves as policymakers and analysts and adopting instead the insider perspective—or, rather, three insider perspectives: first, the person who needs and gets care; second, family caregivers, who are the first line of defense and sometimes the constant presence; and third, direct-care workers, the aides at the bottom of the totem pole in the formal system, those who actually do the hands-on care.

Caring communities would embody the values of these people instead of the values of economists, managers, and planners. From the insider perspective, the most basic policy assumptions anchoring our system of long-term care appear warped.

### Policy Assumption 1: Care Can Be Rationalized and Made More Efficient

A home-care aide told me she was once reprimanded by her supervisor for taking too long with an elderly client. All the client really needed, it seems, was help putting on her elastic stockings. The aide billed thirty minutes for the visit. Her supervisor thought she ought to have been able to do it in ten. The aide saw the episode as emblematic of the trouble with home health care: "You can't just go in and get out. I'm sorry. You know, my grandmother had people taking care of her. I wouldn't want them to do the same—you know, just come in and wash her up and leave. They have to have some kind of relationship going."<sup>1</sup>

A policy analyst or manager might well agree with the supervisor. From that perspective, the aide's leisurely approach is just the sort of featherbedding public and private payers should be snuffing out. I would suggest, however,

1. Unless otherwise noted, anecdotes from interviews are from research I did in 1998–2000 and more fully reported in Stone (2000a and 2000b).

that the incident is emblematic of something else. It hints at the industrial revolution in care. Caregiving, like textile weaving, used to be done in private homes, mostly by women, using simple methods handed down through generations and learned at the hearth. Women gave care as it was needed, as they thought best, as they were moved by their sense of obligation and their concern for the people around them.<sup>2</sup>

Over the course of the twentieth century, a lot of caregiving moved out of the home into hospitals and institutions that were often called homes (nursing homes, Homes for Little Wanderers, group homes) but were in fact more like factories. At the same time, a lot of caring work (though not all—most is still done by families)<sup>3</sup> was organized into formal occupations with training and licensing requirements and with somebody higher up calling the shots—prescribing care plans, dictating schedules and pay scales, and generally controlling the content of care. Care became a service and, like most services, was now another kind of economic commodity, to be produced and packaged, bought and sold, counted and hoarded.

In the early twentieth century, Frederick Winslow Taylor went into the factory, timed the workers at their tasks, watched them carefully, and broke down their work into minute gestures and steps. He figured out the quickest, most efficient way for workers to do their jobs and then reconstituted those jobs, training workers with a stopwatch and standardizing the human components of work as much as possible, eliminating all quirks, spontaneity, and, most of all, independent thinking and judgment.

Prospective payment for home-care agencies and nursing homes takes Taylorization one step further. In the Taylor-inspired factory, a functional task was broken down into discrete physical motions. Now, in long-term care, people are reduced to their illnesses or disabilities, chalked off on a home-care admissions chart or squeezed into discrete nursing diagnostic categories. Their illnesses are then broken down into care tasks. Somewhere in computer land, someone models which tasks need to be done for the average person in each category; in professional argot, a patient classification system predicts resource utilization. Somewhere (is it Washington?), someone figures out how much money all this care (now called resource utilization) ought to cost—or at any rate, how much government is willing to pay for it. Before you know it, a woman is only a body that needs elastic stockings.

The stocking story is chilling because it captures the transformation of care into a package of standardized tasks and the transformation of the patient into

2. A wonderful history of family caregiving is *Hearts of Wisdom* (Abel 2001).

3. Arno, Levine, and Memmott (2000).

an object to which tasks are done.<sup>4</sup> Officially, the home health visit no longer represents a relationship, or even part of a relationship, between the giver and the recipient of care. The visit has become a container for discrete tasks—physical, observable, documentable, measurable tasks. When home health aides make a visit, especially if they are employed by agencies and even more especially if the client's care is paid for by third parties, they go into the home with a checklist, a plan, that tells them exactly what tasks they are supposed to do—no more, no less. When aides make the rounds in a nursing home, they, too, work by the book. Someone else has already decided what should be done for each patient and, often, how much time should be allotted for each task. Even if no one has actually decided or prescribed how much time it takes to put on elastic hose or give a person his pills, the workload assigned to aides is a de facto allocation of their time.

Standardization is the way of modern management. Quality and efficiency, policy analysts are taught, are gained by discerning common patterns and using simplifying rules. Moreover, this way of controlling costs is believed to have the supreme virtue of allowing caregivers discretion. They can provide whatever care they think necessary, including building relationships—as long as they stay within the budget. The only trouble is, in most cases, the reimbursement amounts do not begin to cover even half of what caregivers think their patients need.

The stocking story suggests one way policymakers ought to change in how they think about long-term-care policy. Care involves more than procedures. It involves relationships as well as tasks. For most people, in fact, the quality of the relationship is the most important element of care. Most people experience their need for help as an assault on their dignity. The extra twenty minutes an aide spends talking to a woman before helping her with a bodily task can sustain her identity as a person with a life and a history, loves and hurts, accomplishments and failures, hopes and fears—something other than a body that needs fixing up, emptying, cleaning, and feeding.

### Policy Assumption 2: Better Data Are the Key to Improving Care

There is a truism in long-term care that first visits are more costly than later visits. Whether it is hospice care, a nursing home, or home care, everybody

4. Actually, the stocking story is from the days just before prospective payment went into effect, so it illustrates how much the mentality of Taylor's scientific management had already permeated home care, even before the Taylorites enacted their reforms.

agrees the intake visit takes longer and costs more—as well it should. From the perspective of care recipients, though, the values are reversed. The thirtieth visit is often much more valuable than the first because, by then, a relationship has been built, and the caregiver is able to make the client feel like more than merely a case. Even before the new prospective payment system went into effect in home care, requiring a long survey on the first visit, the initial home-care visit was typically a two-hour affair. Although it was costly to an agency, it was nearly useless to clients, who simply answered questions and signed lots of forms giving their consent to things over which they had no control anyway, such as allowing information to go to an insurer and agreeing not to sue anybody.

My mother once had home care from a visiting nurse after some major surgery. I had brought her home from the hospital and was there when the nurse came. I valiantly fought all my urges to do field research on my mother and gave her privacy with the nurse. Two hours later, as soon as the nurse was out the door, I couldn't wait to ask Mom what the visit was like. "She didn't do a damn thing," my mother grumbled. "All she did was ask questions and take notes."

As a researcher who has studied home health care, I *know* what the nurse did that day. She gathered data, lots of it, for better patient assessment, better risk adjustment (another code word for predicting resource utilization), and better ability to measure outcomes and quality down the line. She would also use all that data to better "integrate" and "coordinate" my mother's care. She "informed" my mother about her choices and got her "informed consent" to treatment. My mother, on pain medication and still in a postanesthesia stupor, was hardly in a position to make informed decisions about anything. No matter. The visiting nurse gave my mother the toll-free hotline number to report any suspected fraud to the Office of the Inspector General. The nurse also created an electronic record by typing all the information directly into a laptop computer, the better to integrate my mother's care.

The visiting nurse was doing all the things that policy analysts agree are necessary to improve the quality of long-term care. Yet on the day my mother came home from the hospital, the day she was most frightened and most in need of reassurance and explanations and a little human warmth, her first and longest contact with home health care amounted to "not a damn thing." The nurse massaged her laptop and never once touched Mom.

### Policy Assumption 3: Managers and Analysts Are the Most Valuable Players in Long-Term Care

A few years ago, I met with the chair of my university's political science department to discuss my future research plans. The man studies presidents,

political parties, and elections—the usual topics of political science. I worried that when I told him I was studying home health care, he would think I had gone mushy and was a lost cause to his stellar department. Instead, he told me a story: His mother had had a home health aide for a long time before she died, and at his mother's funeral, he insisted that the aide ride in the limousine with the family. "She was my mother's best friend, the most important person to her, and I wanted her to have a place of honor."

In our long-term-care systems, no one is asking the lowly aides to ride in the limo. But the fact is, the person who is the least qualified and skilled member of the staff from the chief executive's perspective is often the most skilled, qualified, and valuable to the patient and, for that matter, to the patient's family. Yet frontline care workers are the lowest paid in the industry. The more training and degrees workers have, the less contact they have with patients and clients; the less contact they have with patients and clients, the more they are paid and the better they are rewarded.

In the industrial model, this hierarchy makes a certain sense (though even there, it comes under challenge): the most skilled and valuable work is performed by the people at the top—the brains: the managers, executives, planners, and professionals. These are the people Robert Reich calls "symbolic analysts." They manipulate symbols and abstractions. They see through particulars and individuality and uniqueness to the generalizable essence of things.<sup>5</sup> Unfortunately, in caregiving, symbolic analysts see right through the people who need care—and you cannot take good care of somebody you do not see.

What matters most to care recipients is how they are treated by frontline workers, the people who are at the bottom in the industrial model. Social workers or case managers may think they know how long it takes an aide to dress a client or to give a bath; a computer model may even think it knows how long it takes to dress and bathe five patients. Neither the case manager nor the computer, however, knows what the aide knows: exactly how a client's body moves and tires, where it aches, how to modify a standard routine to fit each client's needs. Nurses and doctors may have standards to guide them in setting up a care plan or may take such standards from carefully worked-out packages prepared by professional care planners. But it is the aide who knows the subtle arts of coaxing, joking, and soothing people into complying with the pieces of the plan.

Of course, policy matters. Eligibility for services is a matter of great moment to home-care clients. Whether Medicare will pay for Grandma's

nursing-home care is a decision of cataclysmic importance to her family. However, as Michael Lipsky pointed out long ago, from the perspective of the ordinary citizen gingerly entering a bureaucracy in need of help, the greatest power sits not in the corporate suite on the hundredth floor but down at street level, where gatekeepers decide the fates of supplicants, one by one.<sup>6</sup>

It is another truism that aides and nursing assistants are underpaid, woefully underpaid. Many policy analysts are thinking about how to upgrade these workers' pay and how to build career ladders and other devices to stem their extraordinarily high turnover rates. Little progress will be made on this front until policymakers and analysts get inside the perspective of care recipients and families and reenvision the work of care. Only from this perspective is it obvious that the people at the bottom of traditional hierarchies of skill, training, and authority are in fact at the top in terms of the care they give.

In a caring community, aides would ride in the limo. They would be paid something closer to what they are worth, and they would be made part of team meetings and case planning conferences. They would be taught not only how to protect their backs but also how to make their voices heard, how to articulate their patients' problems and needs.

#### **Policy Assumption 4: Overutilization of Care Is a Big Problem**

Much of the literature on Medicare and long-term care suggests that the biggest problem is excessive use: costs have skyrocketed because utilization has zoomed, and utilization has zoomed because too many patients are too quick to run for help and too many providers see a chance to make money by helping them. Most of the policy developments in the past fifteen years are aimed at curbing use of services. One would have to ferret deep into the collective memory bank to learn that the same government that now discourages use of long-term care services once touted first nursing homes and then home health care as cheaper alternatives to hospital care.

But memory fades as the polity ages, and now the reigning collective wisdom holds that because users do not have to pay for home health care themselves, they have no reason to hold down its use.<sup>7</sup> Co-payment, it is said, is necessary to encourage patients and families to evaluate the worth of care with a more realistic eye. In policy jargon, this is referred to as "setting the

6. Lipsky (1988).

7. This is almost dogma, repeated with the monotonous regularity of catechism among government officials and policy analysts alike; see Stone (2000, p. 18).

proper incentives," but what is really meant is discouraging people from availing themselves of help.

This theory makes sense only if we view long-term care as a good in the economic sense. In the economic sense, a good is a commodity or service that benefits people and enhances their welfare. According to the law of demand, people will consume more of a good if they can get it for less—or better yet, for nothing. Care, however, is not an unalloyed good. Home-care services do have value to people, sometimes very precious value but they are never unequivocally good. Few people want to be in a position to need home care, or medically care of any kind, and even fewer consider residence in a nursing-home as good they are eager to consume. To seek help is to cast oneself as dependent but American culture reveres independence, and in such a culture dependence is humiliating. Shame, humiliation, and the loss of one's autonomy are the ever-present deterrents to using care. Money isn't the half of it.

Home health aides have consistently told me that new clients hate to have help showering or bathing and frequently refuse to let an aide bathe them for weeks. I asked one aide if this was more often problem with men than with women, since aides are mostly women. "Oh, no," she said. "Both. Every single person says 'I haven't been bathed this way since I was a child. It really hurts my pride. It hurts my dignity'."

Family caregivers caring for their elderly parents or declining spouses know all too well how hard it is to persuade someone to accept care even absent the money issue. One of my friends watched her husband struggle to pick up a book he had dropped on the floor, then silently cry in frustration. He had had a hip replacement, and though he had every reason to expect full recovery, he would sooner put himself in pain and exhaust himself doing a simple task than ask his wife for help and make himself dependent on her.

A caring community would not fear exploitation of its capacity to care. It would not regard people who need care as predators on the common weal. Instead of erecting fences to limit access to care, it would ensure that its members could seek the help they need without threat to their dignity. In a caring community, dependence and the care it requires would be natural features of life rather than a badge of shame.

#### **Policy Assumption 5: Compassion Must Be Balanced with Hard-Nosed Fiscal Realism**

The Balanced Budget Act of 1997 introduced prospective payment in Medicare home health care. A year later, without any sense of irony, the

clinical director of a home-care agency told me that since its passage, her agency has had to "balance" short-term and long-term patients. She does not, for example, accept a patient leaving the hospital with chronic-care needs; she tells the hospital discharge planner that such placement would be "inappropriate." The owner of a Minnesota home-care agency was more blunt: "We will not take on a client who will be a six-month client because Medicare will not pay for it."<sup>8</sup>

Alongside the assumption that consumers are all too eager to consume long-term care, our long-term-care policy assumes that people in the business of caregiving are all too eager to give care. Prospective payment is nothing if not a system designed to curb caregivers' compassion. Prospective payment is a Ulysses contract: Ulysses had himself tied to the mast so he would be unable to respond to the siren calls that he knew he could not resist of his own free will.

Without a firm limit on reimbursement, policymakers believe, nurses, doctors, agencies, social workers, planners—anyone in a position to hear the siren calls of suffering—might be unable to control the impulse to help. Caregivers are famously incapable of closing the door on people in need. So prospective payment tells caregivers, "This much we will pay for. Any more you do out of your own pocket." Prospective payment is designed to make care providers husband their care, close their doors, and wheedle someone else—Medicaid, state waiver programs, or family members—into helping those in need.

Home-care nurses and administrators told me much about the increased importance of "planning" once prospective payment went into effect. "What kind of planning?" I would always ask. *Planning* turned out to be a euphemism for determining whether there were relatives who could take the patient in or whether the patient was eligible for Medicaid or the state waiver program. Planning, in short, means finding somebody *else* to take care of the patient.

Caregiving is a generous act. It is also addictive: people who start caring for others have a hard time stopping. Compassion feeds on itself. Whether family caregiving or paid caregiving, all the instincts are to give, to respond to the suffering of others. Very sick, frail, and disabled people have nearly unlimited needs. In the private realm, these needs can hijack a caregiver's life. In the public realm, they can hijack the public budget. Caregivers need ways to protect themselves in both the private and public realms.

For all the expansionary pressures of care needs, however, the rules are sometimes so rigid that they prevent people and institutions from responding to

8. Reported in Glenn Howatt, "Home Care Agencies Face a New Challenge," *Star Tribune* (Minneapolis), April 12, 1999, p. A1.

need. Caring communities have to strike a balance between permitting discretion and protecting caregivers from overwhelming demands. The supports that protect caregivers must be flexible enough to allow them to express compassion and to allow the community to expand its generosity.

### Policy Assumption 6: Love Is Taboo

Emily Abel and Margaret Nelson, sisters who are both academic social scientists and who study caregiving, had to hire someone to take care of their widowed father as he became more disabled and sick. They hired Jasmine, a woman their mother had first taken on as a housekeeper. Gradually, they asked Jasmine to do more and more personal care of their father, ultimately bathing him and helping him go to the toilet. When the sisters suddenly understood that "Jasmine should spend his final weeks, the sisters suddenly understood that "Jasmine had become more important than any of his children and that he had to remain where she could see him every day. We could reminisce and try to enact old roles, but she related to him on the basis of the life they shared together."<sup>9</sup>

As I interviewed home-care workers, from nurses and therapists to aides, I was most struck by how much they used the word love when talking about their clients. Caring and being cared for often create an intimate relationship. People in these formal caregiving relationships often come to feel like kin. Indeed, it is not unusual these days to read an obituary and find a caregiver listed among those left behind by the deceased.

*Love* is not a word that rolls easily off the tongue in policy settings. In fact we are scared of it, terrified. We are terrified because, like the unbounded needs of patients that threaten to devour budgets, love suggests the unbounded compassion of caregivers that threatens to defy all management controls. Either one could bankrupt the national treasury if not nipped in the bud.

Moreover, love is—ahem—unprofessional. One abiding lesson of professional education is the supreme importance of keeping one's distance. The good professional caregiver does not have favorites and does not get too attached (though it is never made clear just how attached is too attached). In my research, nurses, therapists, and aides reported that during their training, they were told not to share personal information with clients. They were warned against getting too close and against becoming emotionally involved. Nevertheless, as they all said, "You just do—if you're human, you do"; "you can't help it."

9. Abel and Nelson (2001, p. 29).

Perhaps this is the biggest difference between care in the private and public spheres. In families, people take on caregiving out of necessity and love. They may not want to become primary caregivers, but when circumstances arise, they let themselves be drafted into the role out of sheer loyalty. In agencies and institutions, caregiving is a job. For many caregiving professionals, however, it quickly turns into a labor of love. In a caring community, the overseers of care for the elderly and the infirm would make room for love. To paraphrase Robert Frost, a caring community would be a place where someone not only has to take you in but also has a chance to love you.

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