Rural Caregivers Are Already Doing Accountable Care. Why Aren't We Paying Them for It?

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In rural communities across America, the largest health workforce is not employed by a hospital, clinic, or health system. It receives no formal training, appears in no workforce projections, and is rarely included in policy discussions about healthcare staffing shortages. Yet it provides billions of hours of care each year and serves as the backbone of long-term services and supports. These workers are family caregivers.

For years, I did not think of myself as a caregiver. I thought I was helping my mom. The irony is that I spent much of my career working in health policy and health system transformation. Yet even with that background, I did not recognize that what I was doing had a name. Like millions of family members across the country, I scheduled appointments, managed medications, coordinated transportation, communicated with providers, monitored changes in health status, and navigated a maze of Medicare and Medicaid rules and requirements. I was trying to make sure nothing slipped through the cracks.

At the time, I would not have described any of this as care coordination or care management. Looking back, that is exactly what it was. What strikes me today is not how unusual that experience was. It is how common it is.

Across rural America, millions of family caregivers are performing many of the same functions that accountable care organizations, value-based payment models, and population health initiatives were designed to improve. Yet while physicians, hospitals, health systems, and accountable care organizations can be rewarded financially for generating better outcomes and lower costs, caregivers who often help make those outcomes possible remain largely invisible within our financing systems. That omission is becoming harder to justify.

The workforce we refuse to count

America now has approximately 63 million family caregivers, representing nearly one in four adults and a dramatic increase over the past decade. More than 40 percent provide what researchers describe as high-intensity care. Roughly 70 percent help monitor health conditions and coordinate care. Yet only a small share report receiving formal training.

They schedule appointments, manage medications, monitor symptoms, communicate with providers, arrange transportation, navigate insurance systems, track follow-up care, and help prevent avoidable crises before they become emergency department visits or hospitalizations.

These activities are fundamentally care management functions. If they were performed by a health system, health plan, or accountable care organization, they would likely be recognized through quality metrics, performance incentives, or shared savings arrangements.

When family caregivers perform them, we tend to call it "helping."

That distinction has enormous policy consequences. We continue to discuss workforce shortages primarily through the lens of physicians, nurses, behavioral health providers, social workers, direct care workers, and other paid professionals. **Those shortages are real and deserve urgent attention. But they are only part of the workforce story.**

Family caregivers and direct care workers are often discussed separately, but both are part of the same care infrastructure. When home care aides and personal care attendants are unavailable because of workforce shortages, limited funding, or lack of availability in rural communities, family members frequently absorb those responsibilities. These are not competing workforce challenges. They are interconnected manifestations of the same care infrastructure crisis.

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Yet despite their scale and importance, family caregivers rarely appear in workforce discussions. We count hospitals. We count providers. We count clinic capacity. We count bed supply. We count emergency departments. We count workforce vacancies.

We rarely count family caregivers, even as shrinking rural capacity makes their labor more essential. **As hospitals close, provider shortages deepen, and access becomes more fragmented, families absorb more care coordination and support—making this omission one of rural health policy's most consequential blind spots.**

Rural Hospital Closures Reveal What's Really Happening

For years, conversations about rural health have focused on what rural communities are losing. Hospitals. Obstetric units. Primary care providers. Behavioral health services. Emergency medical services. Those losses are real, and their consequences are profound.

According to the University of North Carolina Sheps Center, nearly 200 rural hospitals have closed or converted since 2005. Federal analyses similarly show a steady erosion of rural hospital capacity over the past decade. Rural communities across the country continue to face growing challenges accessing timely care close to home. Yet the dominant narrative surrounding rural hospital closures is incomplete. We tend to view these developments primarily as access problems. They are certainly that. But they are also labor-transfer events.

When a rural hospital closes, the need for care does not disappear. Someone still has to coordinate primary care and specialty appointments across multiple clinicians and health systems. Someone still has to manage medications and monitor for side effects.

Someone still has to recognize when a condition is deteriorating. Someone still has to arrange transportation, communicate, navigate insurance requirements, track referrals, and ensure discharge instructions are followed. The work remains. What changes is who performs it.

As institutional capacity recedes, responsibility increasingly migrates to patients and families. **Rural hospital closures are part of a broader story unfolding across American health care.** For decades, care has been migrating out of institutions and into homes and communities. What we have paid far less attention to is the accompanying transfer of labor. Millions of family caregivers now perform work that previous generations would have expected institutions, professionals, or paid staff to perform.

A trip that once required a short drive to a local hospital may become a day-long journey across multiple counties. A care transition once supported by local infrastructure may require a spouse, adult child, sibling, or friend to assume new responsibilities. Tasks previously distributed across clinicians, care coordinators, social workers, and support staff increasingly become the responsibility of family members with little formal training and no compensation.

Rural hospital closures are not simply access failures. They are a form of labor redistribution. Care coordination responsibilities that were once supported by local institutions increasingly shift to patients and families. As formal capacity contracts, unpaid caregiving labor expands.

That invisibility allows us to describe rural health systems as shrinking without fully acknowledging where much of the work has gone. It has gone to families. **In effect, family caregivers are subsidizing the continued functioning of rural health systems by absorbing responsibilities that institutions are increasingly unable to provide.** The more rural healthcare infrastructure contracts, the more essential caregiver labor becomes. Yet that growing dependence remains largely absent from workforce planning, payment reform, and rural health policy.

The Workforce That Doesn't Know It Is a Workforce

One of the most important lessons from Community Catalyst's work supporting Goal 1 of the National Strategy to Support Family Caregivers is that caregiving often remains hidden in plain sight. Many people do not initially describe themselves as caregivers, even while performing substantial caregiving responsibilities every day.

They say: "I'm just helping my husband." "I'm just checking on my mother." "I'm just doing what families do."

Yet many of these individuals are performing substantial, skilled work that keeps care on track. They are caregivers. They simply do not always recognize that the work they are performing has a name.

The National Strategy to Support Family Caregivers correctly identified awareness, outreach, and caregiver self-identification as foundational priorities. People who do not recognize themselves as caregivers are less likely to seek out respite, training, peer support, financial assistance, workplace accommodations, and other resources designed to sustain them. But our experience suggests that self-

identification does something else that is equally important. It transforms caregiving from individual responsibility into a collective voice.

Repeatedly, we have seen caregivers move beyond simply seeking support for themselves. Once engaged, many become advocates, storytellers, coalition leaders, peer mentors, and policy advisors. They bring firsthand knowledge of transportation barriers, workforce shortages, care coordination failures, affordability challenges, and gaps in community-based services because they encounter those problems every day.

> ***"What would it look like to treat family caregivers as contributors to value rather than beneficiaries of support?"***

In other words, caregivers are not merely recipients of policy. They are among the most informed observers of how policy succeeds and where it fails. Caregiver awareness is often framed as a communications challenge. It is also a workforce challenge. People who do not recognize themselves as caregivers are less likely to access supports that help sustain them. When those supports are absent, caregiver burnout and financial strain increase, threatening the stability of the care infrastructure on which health systems increasingly rely.

Accountable Care Has a Blind Spot

For over a decade, policymakers have invested heavily in accountable care. **The logic is straightforward. Improve care coordination. Improve quality. Reduce avoidable utilization. Lower total cost of care.**

Those objectives remain as important today as they were when accountable care first emerged. But accountable care has a blind spot. It rewards organizations for producing outcomes that often depend upon people who are not formally included in the model. Accountable care organizations are rewarded for improving quality, strengthening care coordination, reducing avoidable utilization, and lowering total costs. Yet many of these outcomes are co-produced in homes and communities by family caregivers who remain largely absent from accountable-care models.

The daughter who catches a medication error before it becomes an emergency. The spouse who notices subtle changes in a loved one's condition before they become hospitalized. The grandson who coordinates transportation to dialysis when no other option exists. The family caregiver who makes sure prescriptions are filled, discharge instructions are followed, referrals are completed, and appointments are not missed.

Much of the work rewarded through accountable care depends upon someone performing these functions consistently and effectively. Yet family caregivers rarely appear in accountable-care discussions, quality metrics, workforce strategies, or payment models. That omission becomes particularly significant in rural communities, where provider shortages, transportation barriers, hospital closures, and workforce constraints increase reliance on family caregiving. The fewer formal resources a community has, the more the system depends upon caregivers to hold it together.

The overlap between accountable care and caregiving is difficult to ignore. Family caregivers routinely perform the coordination, disease-management, adherence, and transition work that helps prevent avoidable utilization and improve outcomes. Rural caregivers are already doing accountable care. They're simply doing it off the books.

The Hidden Subsidy Holding Rural Health Care Together

The contradiction becomes even more striking when economics enter the discussion. National caregiving research consistently finds that family caregivers pay a significant financial price for the care they provide. Many reduce their work hours. Others leave the workforce entirely. Many lose wages, retirement contributions, opportunities for promotion, and years of future earnings. Some take on debt. Others struggle to afford basic household expenses while simultaneously helping a loved one navigate illness, disability, or aging.

The financial consequences do not end when caregiving responsibilities end. Research shows that caregiving can reduce lifetime earnings, diminish retirement savings, weaken long-term financial security, and result in fewer Social Security earnings credits. The economic effects can follow caregivers for decades. Viewed individually, these may appear to be personal sacrifices.

Viewed collectively, they represent something much larger. They are a transfer of cost. At the very moment family caregivers are helping Medicare beneficiaries remain stable, supporting Medicaid recipients in the community, preventing avoidable hospitalizations, reducing institutional utilization, and helping rural health systems function despite growing workforce shortages, many are absorbing substantial economic burdens themselves. **In effect, family caregivers are financing part of the healthcare system with their own time, income, retirement security, and future economic opportunity.**

That reality forces an uncomfortable question. If family caregivers are helping generate value for healthcare organizations, health plans, accountable care entities, Medicare, and Medicaid, why are they also the ones bearing so much of the financial risk? In most sectors of the economy, people who help create value share in at least some portion of the returns. In caregiving, the opposite often occurs. The system captures the value. Caregivers absorb the cost.

That is why caregiving should not be viewed solely as a family issue or even a support-services issue. **Caregiving is not merely a family issue. It is simultaneously a workforce, retirement security, rural health, and health-financing issue.** Because one of the largest subsidies in American healthcare does not come from a government program, a grant, or a payment model. It comes from millions of family caregivers whose labor remains largely unpaid, uncounted, and economically invisible.

The RAISE Strategy Created the Foundation – The Next Step Is Integration

The National Strategy to Support Family Caregivers represented a watershed moment in caregiver policy. For perhaps the first time at a national scale, policymakers explicitly acknowledged that family caregivers are essential to the functioning of America's health care, long-term care, and community support systems. That recognition is incredibly important.

For too long, caregivers were treated primarily as private actors solving private family problems. The National Strategy helped advance a different understanding: family caregiving is a public issue with profound implications for health outcomes, workforce capacity, economic security, and community well-being.

Goal 1 correctly placed early emphasis on awareness, outreach, caregiver self-identification, and elevating caregiver voices. Those priorities remain essential. Invisible caregivers cannot access support. Invisible caregivers cannot receive training. Invisible caregivers cannot connect with other caregivers. Invisible caregivers cannot participate fully in policy discussions. Invisible caregivers cannot benefit from programs designed to help sustain them.

The next frontier of caregiver policy is not simply helping caregivers become visible. It is integrating them into the systems that already depend upon them. If family caregivers are contributing to care coordination, chronic disease management, care transitions, medication adherence, and other activities that health systems increasingly view as essential to value creation, then the question is no longer whether caregivers matter. That question has already been answered. The question now is whether our financing, workforce, and accountable-care frameworks will evolve to reflect the reality that caregivers are already part of the system. And if they are part of the system, we must eventually confront a much harder question: What does the health care system owe the people whose labor helps sustain it?

Recognition Is Not Compensation – The Next Step Is Testing Value

To be fair, policymakers have not ignored caregivers. Recent years have seen **meaningful progress**, including caregiver training reimbursement, greater emphasis on caregiver engagement, growing support for care coordination, and increasing recognition that caregivers are essential partners in care. Medicare, Medicaid, and health systems are beginning to acknowledge what families have long known: care does not stop when a patient leaves the clinic, hospital, or physician's office. These developments matter. But they largely position caregivers as supports for patients rather than contributors to value creation. And that distinction is important. **Support is not compensation. Recognition is not compensation. Training is not compensation.**

The healthcare system routinely compensates people and organizations for improving care coordination, preventing avoidable utilization, strengthening chronic disease management, supporting care transitions, and lowering total cost of care. We compensate physicians. We compensate hospitals. We compensate care managers. We compensate community health workers. We reward accountable care organizations through shared savings and performance incentives.

Yet when family caregivers help produce many of those same outcomes, we typically offer gratitude. Gratitude is important. But gratitude is not a payment model. This is where the next phase of caregiver policy should begin. The question is no longer whether caregivers matter. The evidence is overwhelming that they do. The question is whether recognizing and compensating caregiver labor could improve outcomes, strengthen care coordination, reduce caregiver burnout, increase caregiver sustainability, and generate value for patients, families, and the healthcare system itself.

That is precisely the type of question the Center for Medicare and Medicaid Innovation (CMMI) was created to test. For more than a decade, CMMI has examined new approaches to accountable care, primary care transformation, episode-based payment, specialty care reform, and health equity. Its purpose is not to preserve existing assumptions. Its purpose is to evaluate new models capable of improving quality and reducing costs. Caregiver

compensation should be one of those models. CMMI was created to test whether relatively small investments can produce outsized improvements in quality and spending. What if reducing caregiver burden by just ten hours per month across one million caregivers supporting Medicare and Medicaid beneficiaries improved caregiver sustainability, reduced burnout, and prevented even a fraction of avoidable crises and institutional placements? That is exactly the kind of question demonstration authority was designed to answer.

A logical next step would be a Rural Caregiver Accountable Care Demonstration. Participating accountable care organizations, Rural Health Clinics, Federally Qualified Health Centers, Critical Access Hospitals, Rural Emergency Hospitals, and other rural provider networks would be required to identify caregivers supporting high-risk Medicare beneficiaries and incorporate caregiver outcomes into model evaluation.

Caregiver burden could become a tracked outcome. Caregiver sustainability could become a performance metric. Most importantly, the model could test a range of approaches for recognizing and compensating caregiver contributions, including:

- Monthly care-coordination stipends.
- Caregiver participation payments.
- Shared-savings distributions.
- Incentives tied to successful care transitions.
- Retirement savings contributions.
- Demonstrations testing caregiver Social Security credits.
- Financial stabilization supports for caregivers supporting high-risk beneficiaries.

The objective would not be to put a price on love. The objective would be to recognize labor. Because much of what family caregivers are doing today is work. It is work that improves outcomes, helps avoid unnecessary spending, strengthens care coordination, and increasingly sustains rural health systems.

The Next Frontier of Health Policy

For decades, family caregiving has been framed primarily as an act of love. It is that. But it is also labor. Increasingly, it is labor that rural health systems, Medicare, Medicaid, and accountable care organizations depend upon. The first generation of caregiver policy focused on awareness.

The second focused on support. The next generation must focus on integration, sustainability, and shared value. The question facing policymakers is no longer whether family caregivers matter. The evidence is overwhelming that they do. The question is whether our workforce policies, financing systems, quality frameworks, and payment models will evolve to reflect the reality that caregivers have become an essential part of how care is delivered in America.

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Every rural hospital closure, workforce shortage, transportation barrier, and fragmented care transition reveals the same underlying truth: when formal systems lose capacity, families absorb responsibility. The work does not disappear. The costs do not disappear. The need for care does not disappear.

They shift. And increasingly, they shift to family caregivers. The result is perhaps the largest workforce in American health care operating largely outside the structures we use to recognize, support, measure, and reward value.

That should concern anyone who cares about the future of rural health. Because a system that depends on caregivers while failing to sustain them is not solving a workforce challenge. It is merely transferring it. If accountable care is truly about rewarding the people and organizations that improve outcomes, strengthen care coordination, and reduce unnecessary costs, then the next question is unavoidable:

What would it look like to treat family caregivers as contributors to value rather than beneficiaries of support?

Let's Keep the Conversation Going

What would it look like to build a health system that recognizes family caregivers as contributors to value rather than beneficiaries of support? Community Catalyst is working with caregivers, advocates, policymakers, and health care leaders to advance that vision. We welcome your ideas, feedback, and partnership.

Learn more and connect with us at communitycatalyst.org



About the Author

Brandon G. Wilson, DrPH, MHA serves as Executive Vice President & Chief of Staff in the Office of the Chief Executive at Community Catalyst. In this role, he partners closely with the CEO to advance enterprise strategy, strengthen organizational effectiveness, and drive impact in support of Community Catalyst's mission to build a more equitable and just health system. His work focuses on aligning vision, strategy, and operations to accelerate change and improve health outcomes nationwide.