Medicare and Medicaid are partners in providing health insurance protection to older people and people with disabilities. But when it comes to helping the very same people with long-term care—assistance with the basic tasks of daily life (like bathing, eating and toileting)—no such partnership exists. Instead, there is a gaping hole in protection that leaves people who need care, along with their families, at risk of catastrophe.

That hole is not an accident. From Medicare’s inception, long-term care was explicitly excluded from its social insurance benefits, despite the close tie of many long-term care needs to medical conditions. With some short-lived lapses, Medicare rules have restricted the program’s benefits to avoid financing long-term care, even as it has overpaid long-term care providers for medically-related “post-acute” services.2 Ironically, Medicare has fueled growth in expenditures on long-term care providers without actually covering long-term care.

By contrast, since 1965 Medicaid has become the nation’s long-term care safety net. But access to its services varies enormously from state to state and, in general, falls demonstrably short of providing needed care. Families, accordingly, bear enormous responsibility for caregiving at substantial physical and economic cost, and impoverishment remains a condition for receipt of its essential services. Rather than protecting people and their families from catastrophe, Medicaid provides support only after catastrophe strikes.3

1. The issues covered in this post will be more fully treated in Judith Feder, The Missing Piece: Medicare, Medicaid and Long-Term Care, in Medicare and Medicaid at 50: America’s Entitlement Programs in the Age of Affordable Care (Alan B. Cohen et al. eds., 2015).

2. Judy Feder, Bundle with Care – Rethinking Medicare Incentives for Post–Acute Care Services, 369 NEW ENG. J. MED. 400, 400–01 (2013).

Often forgotten is that the need for extensive, expensive long-term care is precisely the kind of catastrophic, unpredictable risk for which we typically rely on insurance to spread costs. These costs are obviously unpredictable for people under the age of 65, only two percent of whom need Long-Term Services and Support (LTSS). But they’re also unpredictable after age 65. An estimated three in ten people aged 65 today are likely to die without needing any LTSS, while two in ten will likely need care for five or more years. Half of the people turning age 65 will have no private out-of-pocket spending for LTSS, while a small percentage are projected to spend hundreds of thousands of dollars.

If, as is often claimed, we want people to be financially “prepared” to manage this risk, we need a reliable insurance mechanism to which they can contribute. Private insurance does not provide that mechanism for long-term care. Fledgling efforts have never really gotten off the ground and—in recent years—several insurance companies have given up on trying to market a successful product.

To effectively spread risk and reach the broadest possible population, public social insurance must be at the core of future policy. Private insurance can play a complementary role, but even its proponents recognize that building future policy around a private market will likely leave eight in ten Americans uninsured for long-term care.

In an environment in which existing Medicare and Medicaid commitments are under attack, the necessity for greater public investment is hard—and unpleasant—for policymakers and even the voting public to accept. At the same time, it is hard to label as over-funded a system that underserves people in need, overburdens family caregivers and underpays workers. Support for better policy requires that the public and policymakers come to recognize the need for long-term care as the kind of unpredictable, catastrophic risk that individuals and families cannot be left to bear by themselves—that it is, a shared, not just a personal, responsibility.

As baby boomers become caregivers and then care recipients, political leaders may come to demand better access to affordable quality care on their
behalf and gain support for the additional revenues required to finance it. If baby boomers mobilize, they will have allies in their children who will face the financial challenges of raising their own families, younger people with disabilities who regard support for independent living as a civil right and workers who have a right to expect decent pay in decent jobs. Together, we may yet fill the long-term care hole in the nation's social insurance.