Published on *Peterson Center on Healthcare* (https://petersonhealthcare.org)

Issue Brief
Improving Healthcare for High-Need Patients

Americans deserve a healthcare system that provides high-quality care at a reasonable cost. The current system is failing many people, but especially those who have the greatest health needs and the fewest resources to pay for it.

Many solutions have been proposed to better serve the growing number of high-need patients. Unfortunately, efforts have been largely ineffective and sporadically coordinated with social services, resulting in great variations of outcomes and cost. That variation is cause for concern because the result is an underperforming healthcare system—leading to lower-quality care for people who need it most, and threatening the financial sustainability of the overall healthcare system. At the same time, however, the variation suggests that there may be pockets of excellence where better care is being delivered at a lower cost—and this is our great opportunity.

With 5% of Americans accounting for almost 50% the nation's healthcare spend,[1] doing better in this key area of healthcare could improve millions of lives and free up wasted resources. To make progress, we need to know more about the people with the most significant healthcare needs and the services they use; identify and validate the care delivery models that generate above-average health outcomes at lower-than-average costs; and transfer the knowledge and know-how to promote their broad adoption so that the models of excellence can become the community standard.

This issue brief offers an overview of the "state of play" in addressing the challenges of high-need patients. It sets the stage for a research effort designed to find examples of excellence, learn what makes them work, and facilitate the spread of replicable high-performance models on a national scale.

Who Are the Patients With the Most Complex Needs?

High-need patients are ethnically diverse, male and female, rural and urban, and their health and personal histories are diverse.

Not surprisingly, they are often seniors, but other patients with difficult circumstances need a lot from the healthcare system as well, including many younger, disabled adults. They often have several chronic illnesses, such as diabetes or heart disease, that require both immediate interventions and long-term care. Individuals with significant needs also include those with behavioral health and substance use challenges, who typically cycle through multiple institutions, such as hospital emergency departments and inpatient units, detox centers, homeless shelters, and jails.

For these patients, the strain of managing multiple chronic health conditions is exacerbated by the financial demands of the healthcare system. Among the top 5% of healthcare spenders, almost one-fifth (18%) spend more than 20% of their total family income for out-of-pocket health expenses; an additional 34% spend more than 10% of their income to cover those expenses.

Among these high-need patients are the nine million Americans who are covered by both Medicare and Medicaid. Sixty-one percent of these dually eligible beneficiaries are low-income seniors who qualify for Medicare on the basis of age and for Medicaid on the basis of income. The remaining 39% receive Medicare because they qualify for Social Security Disability Insurance, and their incomes additionally qualify them for at least partial Medicaid benefits.[2]

Dually eligible patients often face more complex health problems and require more care than individuals who qualify for just one of these programs. For example, they are significantly more likely—in some cases twice as likely—than all other Medicare beneficiaries to have pulmonary disease, stroke, congestive heart failure, diabetes, or some kind of mental or cognitive disorder.[3]

The social determinants and complexity of their health problems is compounded in a healthcare system that performs poorly and over-uses resources. Annual spending for a single dually eligible consumer averages over $19,400 and can exceed $38,500 if more than one mental condition is present.

Behind any dollar figures are vivid human stories, as the Henry J. Kaiser Family Foundation, which conducts policy analysis on national health issues, highlights in its report, *Faces of Dually Eligible Beneficiaries*.[4] The youngest patient profiled is Don, age 41, of Owosso, Michigan, who was born with developmental disabilities, requires three medications to manage his obsessive-compulsive disorder, and is able to live independently only through a complex

package of services assembled by his sister. The oldest profile is of Wanda, 78, in Tulsa, Oklahoma, who lives in senior housing, and manages a host of medical challenges that include degenerative joint disease, poor circulation, high blood pressure and a thyroid condition.

Other high-need patients have been characterized as “super-utilizers” by many in the industry because of the amount of interaction they have with the system.[5] In October 2013, the Center for Health Care Strategies, a health policy resource center focused on publicly financed healthcare, hosted a Super-Utilizer Summit, in partnership with the National Governors Association. A brief report about that event defined this group as:

“Individuals whose complex physical, behavioral, and social needs are not well met through the current fragmented system. As a result, these individuals often bounce from emergency department to emergency department, from inpatient admission to readmission or institutionalization—all costly, chaotic, and ineffective ways to provide care and improve patient outcomes.”[6]

Absent a uniform research definition of high-need patients, it is difficult to generalize across studies how the system performs in its care for this population, but a few studies describe the scale of inefficient, potentially ineffective care a poorly performing system is generating:

- A study of hospital emergency departments in Washington State found that the most frequent users made between 78 and 134 emergency department visits over a 15-month period.[6]
- In Camden, New Jersey, Jeffrey Brenner, MD, identified “hot spots” of high medical care use and found that residents in just two buildings—a nursing home and a low-income housing tower—made a total of 4,000 hospital visits and rang up $200 million in healthcare bills over a six-year period. One patient was admitted to the hospital 324 times.[7]

While the composition of high-need patients is coming into clearer focus, much remains unknown about just how they interact with the healthcare system, what services they receive, and what outcomes result. If we can understand more about the care they need and what is working, we can design more targeted, coordinated, and effective clinical services.

The Healthcare System Is Failing Patients Who Need It Most

The challenges presented by high-need patients are echoed in the complexities of the healthcare system itself, which too often frustrates patients and clinicians alike as it often provides suboptimal outcomes and drains resources. Medicare and Medicaid, for example, have different delivery, financing, and administrative procedures and requirements, contributing to care that is often poorly coordinated, fragmented, or episodic.

“Good doctors at good hospitals go to work every day and deliver disorganized and fragmented care.” —Jeffrey Brenner, MD, Camden Coalition of Healthcare Providers

“Poor care coordination contributes to the revolving door syndrome at America’s hospitals in the name of readmissions.” —Promising Practices for Reducing Hospital Readmissions, Robert Wood Johnson Foundation

Most of these high-need patients, including those who are eligible for both programs, are part of a fee-for-service system that rewards providers for the quantity of care they offer, rather than the quality of that care.[8] The fee-for-service payment model provides little incentive for improving quality and lowering costs. In fact, providers are often penalized for increased efficiency because it can often result in reduced volume and revenue. The lack of coordination between clinical and social services further results in great variations of the quality and cost of care.

As important as payment models and incentives are, however, they are not the whole story. Regardless of the payment structure, the healthcare system itself is not delivering care optimally for high-need patients.

New Approaches and Bright Spots Are Emerging

Recent public policy has driven certain systemic changes designed to shift incentives toward higher quality care at lower costs. New organizational strategies for care delivery, such as accountable care organizations (ACOs) and Medicaid health homes, have emerged with the goal of improving the design, coordination, and reimbursement structure of the package of services often required by high-need patients. This package typically includes some combination of primary care, specialty care, long-term-care, and non-clinical supports outside the purview of the traditional healthcare system.

Additionally, the Medicare-Medicaid Coordination Office and the Center for Medicare and Medicaid Innovation (both within the federal Centers for Medicare and Medicaid Services) have funded *State Demonstrations to Integrate Care for Dual Eligible Individuals and Financial Alignment Demonstrations.* These initiatives are designed “to encourage innovative financing and delivery models that better integrate Medicare and Medicaid services, improve care delivery and beneficiary experience and reduce unnecessary spending for this population,” according to the Center for Health Care Strategies.[9]

Other efforts to understand and experiment with models of care designed to provide compassionate, coordinated care that drive better outcomes at lower cost include:

- Community health teams: Researchers identified Medicaid medical home initiatives in eight states that use multi-disciplinary care coordination teams to manage complex illnesses across providers, settings, and systems of care. As described in a Commonwealth Fund brief, each team typically includes nursing, behavioral health, pharmacy and social work staff that offers a shared resource to a number of small and medium-sized primary care practices in a region.[10]
- High-utilizer learning collaborative: Five Pennsylvania health systems that work with high-need patients have formed a collaborative to share lessons learned across their programs, which aim to deliver high-quality, comprehensive care, while simultaneously encouraging self-advocacy and personal accountability.[11]
- Complex Care Innovation Lab: The Center for Health Care Strategies created this venue to bring together innovators working to improve care for vulnerable populations with complex medical and social needs. The goal of the "lab" is to break down silos in order to promote learning and influence the local, state and national dialogue on how to better serve this population.[12]
- Others: Other promising models, such as the Commonwealth Care Alliance, CareMore, CareOregon, The Everett Clinic, and Marshfield Clinic, have adapted a range of approaches that include medical homes in safety-net clinics, multidisciplinary case management, patient stratification to better target care delivery, early intervention strategies, and vigorous discharge follow-up.

We need to better understand these approaches, what features of these approaches drive higher performance and spread those that work best to deliver more effective services that support all patients, but especially those who have the most complex care.

What Are the Ingredients Necessary to Provide High Quality Care at a Lower Cost?

There is not yet consensus about how best to measure the quality and outcomes of models designed to provide care to high-need patients, but efforts are underway to advance the state of the evaluation science. One example is a package of quality measures used in eight states participating in the federal Financial Alignment Demonstration. However, at least one critique suggests that the framework does not adequately measure quality of life or long-term services and supports, highlighting the fact that developing uniform standards here remains unfinished business.[13]

Despite the shortage of rigorous evaluation data, however, a number of experts have highlighted key features of high-performing models targeted at high-need patients. For example, seven integrated healthcare organizations brought together by the Commonwealth Fund identified characteristics of high performance within four areas:[14]

- Leadership and organizational culture
- Infrastructure to "scale up" and "stretch out" while maintaining quality and value
- Financial and non-financial incentives and related mechanisms to align plan, provider, and member interests
- Coordinated care provided through comprehensive, accessible networks and person/family-centered care planning and coordination

In other work, researchers at Boston's Massachusetts General Hospital[15] identified common features across eighteen care management programs that coordinate closely with primary care teams to serve high-need patients:

- Programs are tailored to their context, such as practice size, urban or rural location, governance, and experience with team-based care.
- Selected patients are those at the highest risk for poor outcomes and most likely to benefit from planned care management.
- Members of multi-disciplinary care teams are determined by the needs of the target population and consider care coordination one of their key roles.
- Trusting relationships are established between care teams, patients and primary care providers.
- Providers share information, secure referrals and help patients find needed resources, both in health systems and in communities.
- Appropriate training and use of health information technology helps to build capacity.

The Super-Utilizer Summit, which brought together leaders of high-need patient programs, the Centers for Medicare and Medicaid Services, RWJF's Aligning Forces for Quality alliances, health plans and other key stakeholders, identified the following features of interventions designed to manage complex care and control costs:[6]

- Extensive outreach and engagement strategies
- 24-hour on-call system
- Frequent contacts with patients, with priority placed on face-to-face contact
- Comprehensive medication reconciliation and management
- Patient/caregiver self-management education
- Timely outpatient follow-up post-discharge

- Linkage to a primary care provider/medical home
- Goal setting and care plan development
- Health education and health coaching
- Pain management
- Management of chronic conditions
- Preparation for provider visits
- Linkages to housing, substance abuse treatment and other community resources

Despite different data sources and methods, these analyses all suggest that the active ingredients of high-performing approaches include vigorous strategies for coordinating care, information sharing, and building trusted relationships among providers.

Toward Better Care for High-Need Patients

As this issue brief indicates, some data have been generated about Americans with the greatest health needs, and pilot programs are underway across the country to address the great variation in their care.

However, significant gaps remain in our knowledge of how best to support high-need patients, and how to engage more providers in meeting their needs. We know, for example, that only a subset of dually eligible beneficiaries require particularly costly care, but we do not fully understand what drives the difference. A more granular analysis of medical claims data will help answer core questions such as: How do service use and patterns of care (e.g., hospitalizations, medication, and long-term care) and demographic composition (e.g., age, disability status, and place of residency) differ across different high-need patients? What characteristics explain variation in outcomes?

The answers, coupled with a comprehensive scan of the care landscape for high-need patients, will allow experts to identify the active ingredients of high performance, as well as best-practice models. Key analytic questions include: Where do the models of excellence exist? What are the common ingredients that drive higher quality at lower cost? What attributes need to be replicated to meet these twin goals?

The next step then becomes determining how best to facilitate adoption of what works so that similar results can be obtained in diverse care settings, with different patient populations, resource levels, and provider mix. Financial incentives are surely part of the equation, but transfer of know-how from high-performance care organizations to others is also essential. Among the questions to answer: What systems and processes need to be in place to raise the standard of care? How does know-how get transferred and used? What must be done so that innovation becomes universal practice? What policy constructs will reduce the fragmentation of care delivery?

With the answers will come great strides towards the twin goals of providing high-quality care at lower cost, for the Americans who need it most and the health of all Americans.

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