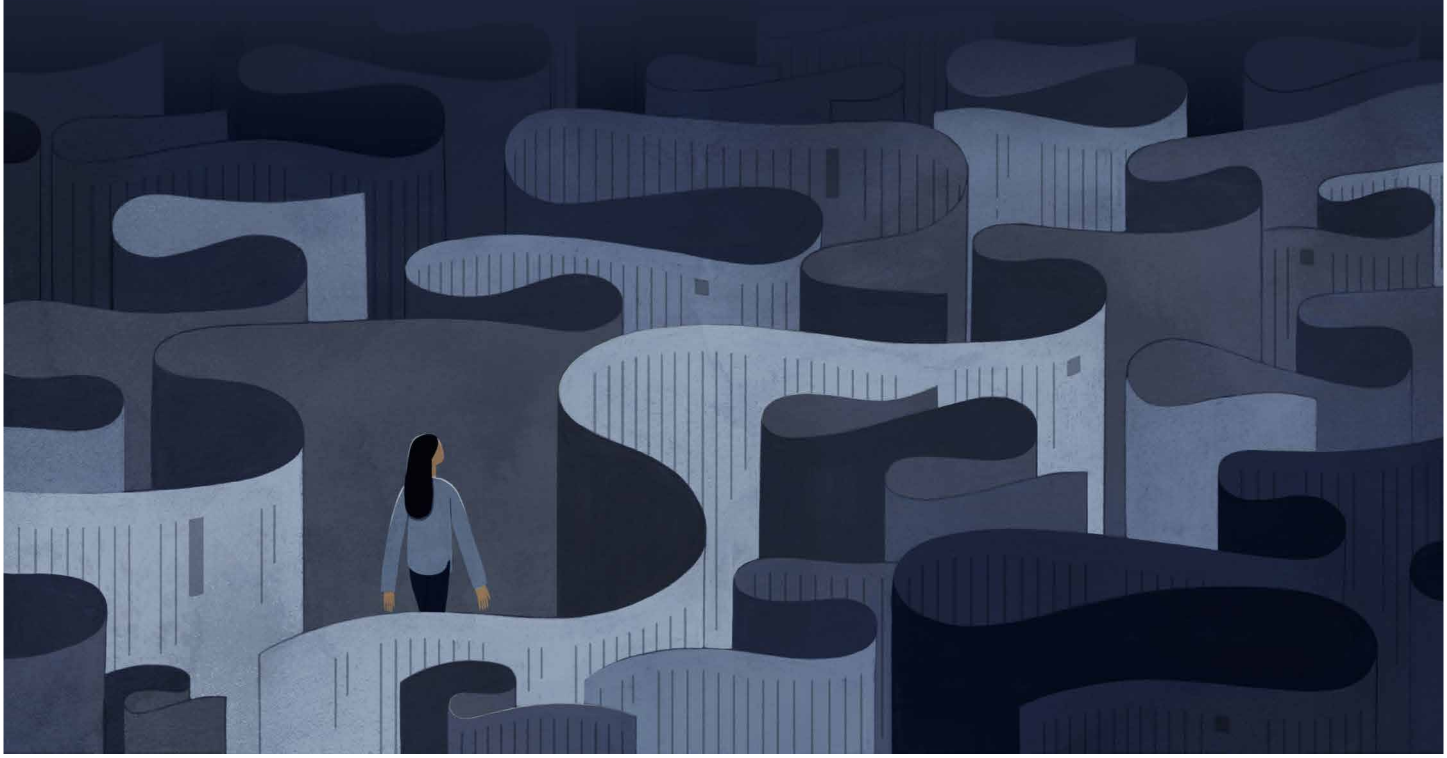
HEALTH CARE IN AMERICA

The Experience of People with Serious Illness



Eric Schneider, Melinda Abrams, Arnav Shah, Corinne Lewis, and Tanya Shah

OCTOBER 2018

1918
2018
The Commonwealth Fund
A Century of Advancing Health Care for All

Listening to People with Serious Illness

> I heard the words
> **‘you have cancer’**
> and that was the end.
> It was like I was in a dark tunnel.
> I didn’t hear another word they said.

> I am so much better after stopping the chemotherapy.
> **People were so happy to see me back at church.**
> Even though it wasn’t a cure, I gained back all that weight I lost.

> I was diagnosed with asthma-exacerbated pneumonia, and I came very close to dying. And the reason why I got that bad was because I stopped taking my asthma medication, because it was
> **too darn expensive.**

> The doctors didn’t talk to each other, so I got
> **conflicting information**
> from different ones.

These are just a few of the many voices of people with serious illness. They express the bewilderment and the loss of control. They convey fear that the system is indifferent to their needs and that the cost of care is beyond their reach. They reflect the joy of feeling well enough to get back to the familiar parts of life.

Most Americans expect the health care system will deliver effective treatment and support them through trying times when they get sick. But in reality, health care in America sometimes hurts even as it helps. Appointments can be difficult to get. Clinics and emergency rooms are often overcrowded. Doctors’ recommendations can be confusing and difficult to follow. And when the bills arrive, the costs can be unexpected and devastating. More than 40 million adults in the United States experienced serious illness in the past three years.[1] More than 41 million provided unpaid care to elderly adults during the past year.[2]

Health Care in America: The Experience of People with Serious Illness, a project of the Harvard T.H. Chan School of Public Health, the *New York Times*, and the Commonwealth Fund, is examining the experiences of Americans with serious illness — the sickest of the sick — and those who help care for them. Our goal is to understand whether our health care system is doing all it can do not just to treat illness but to help people *cope* with illness. Where is the system failing to meet people’s needs? How is it adding to already heavy burdens? Can the most seriously ill Americans afford the care our health system delivers?

To help answer these and other questions, we surveyed nearly 1,500 Americans with serious illness and the friends or family members caring for them. We considered someone to have serious illness if, within the past three years, they had two or more hospital stays and visits with three or more doctors. Below we discuss what we found. We then point to opportunities to help ensure that American health care not only saves people but also supports them in their time of need.

Serious Illness: A Life-Altering Journey

People going through serious illness often experience profound loss: loss of control, loss of independence, loss of time, and the loss of capabilities that most of us take for granted. The physical, emotional, and financial toll can be life-altering. It can mean an end to the activities that give life pleasure; growing isolation from friends, family, and familiar places; and an inability to work or support others. And there is the worry of being a burden on family and friends.

People with serious illness experience distress over and above the physical symptoms of their specific condition. And our new survey reveals that many are distressed. Sixty-two percent feel anxious, confused, or helpless at some point. Nearly half have emotional or psychological problems. Social isolation, a known risk factor for worse health outcomes, is common, with one-third of respondents reporting feeling left out, lacking in companionship, or isolated from others.[3]

> ***One of the hardest things about being chronically ill is that most people find what you're going through incomprehensible — if they believe you are going through it. In your loneliness, your preoccupation with an enduring new reality, you want to be understood in a way that you can't be.***
>
> **Meghan O'Rourke**
>
> "What's Wrong with Me?," *The New Yorker,* Aug. 26, 2013

People with serious illness experience distress over and above the physical symptoms of their specific condition

62%
feel anxious, confused, or helpless

48%
have emotional or psychological problems caused by their condition

32%
reported feeling left out, lacking in companionship, or isolated from others

Many people with serious illness want to continue working or continue to provide care for family and friends who need their help, but they face high hurdles. Nearly three of four have had problems related to work or their ability to care for others (Appendix 1). Half reported being unable to do their job as well as they could before. Twenty-nine percent lost a job or had to change jobs. Half reported wanting to work but being unable to do so.

Our Health Care System Often Adds to the Burden of Illness

It's fair to say that several consequences of serious illness — the distress, isolation, confusion, and lost earnings — are simply part of being sick. In some cases, they are probably inevitable. But being sick in America also means carrying some burdens that our health care system foists upon us.[4]

Americans have high expectations for their health care. Most believe that when serious illness strikes, their health professionals will be fully prepared to make a diagnosis and provide appropriate treatment. This belief is not wholly unwarranted, of course. News stories brim with pioneering medical advances. For people with what were once fatal and untreatable diseases, there are now cures. Once harrowing chemotherapy regimens have been replaced by pills taken once a day. New technologies are improving the quality of life for many people with serious disabilities.[5]

A health care system that promises so much would seem capable of minimizing the burdens of illness and care, of helping people cope. But for too many, American health care does the opposite: it places unexpected and unnecessary burdens on the sick. People struggle to obtain effective treatments and services. Pervasive fragmentation and lack of coordination across the health system make obtaining services heavy labor for people with advanced illnesses or frailty.

61% **of people with serious illness reported at least one problem while receiving care, such as**

- understanding a medical bill or what their health insurance covered
- being sent for duplicate tests or diagnostic procedures
- getting conflicting recommendations from different health professionals

How common are such problems for this vulnerable group? In our survey, six of 10 people with serious illness reported at least one problem receiving care (Appendix 2). The difficulties people reported are symptomatic of the confusing patchwork that is health care in the United States. Nearly a third of those with serious illness spoke of trouble understanding what their health insurance covered. Twenty-nine percent reported being sent for duplicate tests or diagnostic procedures by different doctors, nurses, or other health care workers. Twenty-three percent of respondents said they experienced a problem with conflicting recommendations from the health professionals that saw them. One of five had difficulty understanding a doctor's bill — a confusion not just about the costs of care but about what services were provided.

Unnecessary tests and procedures are not only redundant and costly. They carry their own risks to health. Safety in health care is, in fact, an ongoing challenge, especially for patients requiring complex care plans. Nearly one of four adults in our survey reported a serious medical error in their care.[6] We know from other studies that people with serious illness are especially prone to diagnostic errors, prescribing errors, and communication mishaps.[7] Every doctor and many patients can recall missed abnormal lab results, failure to account for allergies, and lost information that led to terrible side effects, or even death.

Of the people surveyed

23%

reported a serious medical error in their care

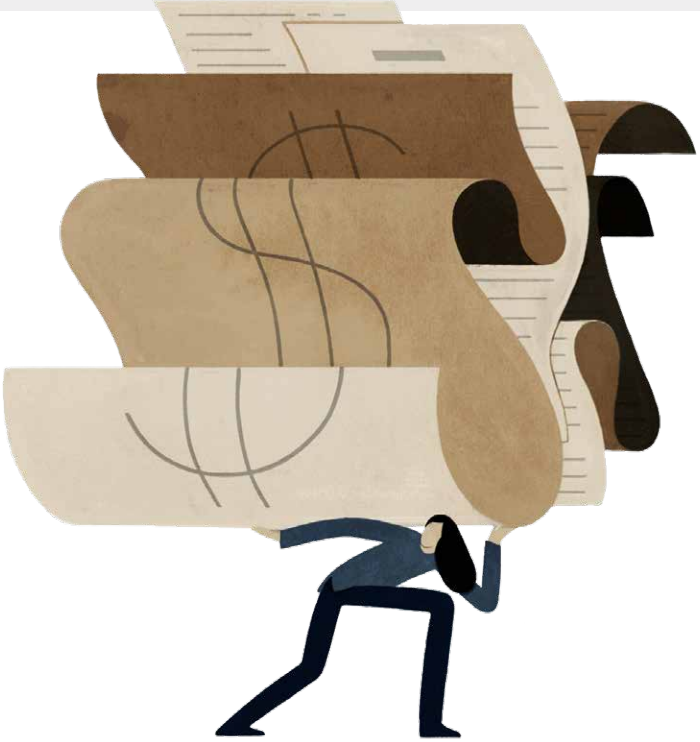
Paying for Care: Teetering on the Edge of Financial Ruin

Health care can be expensive for anyone, but extraordinarily so for people with serious illness. Millions of Americans are ruined financially by the costs of their treatment. Although most survey respondents reported having insurance coverage, about one in 10 were uninsured.[8] Even many people with insurance learn too late that they are not adequately protected from health care costs. More than half of people with serious illness in our survey (representing more than 21 million people) experienced one or more dire financial consequences related to their care (Appendix 3).

53% **of survey respondents experienced one or more dire financial consequences related to their care, such as**

- using up most or all their savings
- being unable to pay for necessities like food, heat, or housing
- borrowing money to get a loan or another mortgage

despite 9 out of 10 having insurance coverage



Apart from its sometimes-lasting health consequences, serious illness also appears to cause long-term financial problems for many. More than one-third of survey respondents used up most or all their savings. Nearly one-quarter were unable to pay for necessities like food, heat, or housing. Thirty-one percent were contacted by a collection agency for unpaid bills. And the financial consequences are not felt by patients alone. More than one of four survey respondents reported that the costs of care placed a major burden on their family.[9]

What Can Be Done to Improve the Experience of the Seriously Ill?

The burdens described above are not an inevitable companion to serious illness. They are a consequence — at times inadvertent, but no less real — of how our health system operates today. But things could be different. It is fully within our means as a nation to improve the experience of the millions of Americans living with serious illness and the millions more who help care for them.

In fact, strategies for delivering a better health care experience — one that ensures comprehensive, holistic care while always respecting the dignity of the individual — already exist. They just need to be adopted on a much wider scale.

1. **Build the capacity to identify and manage the behavioral health needs of patients and their caregivers.** Integrating behavioral health services into medical care requires more than simply improving communication among siloed professionals. Multidisciplinary care teams that include behaviorists, social workers, and patients working together can ease the sense of helplessness, the loss, and the social isolation that seriously ill people commonly experience.[10]

2. **Assess and address social service needs.** Our findings illustrate that the impact of serious illness extends well beyond the medical realm. Many people cannot work while dealing with a life-threatening condition. This means fewer resources at a time when expenses can increase dramatically. Access to and support for reliable transportation, supportive housing, nutritious meals, and other services are critical to helping the seriously ill maintain a level of well-being.[11]

3. **Make it easier for patients, caregivers, and professionals to work in close coordination with one another.** Patients want their clinicians and other providers to talk to each other — and they want in on the conversation, too. Providers can improve communication with each other, with patients, and with caregiving family members and friends by taking full advantage of advances in consumer-friendly digital tools like secure texting, email, telehealth, and social media platforms. Coordination could be further enhanced by care managers or community health workers who check in on patients and caregivers between appointments and connect them to needed services.[12]

4. **Make care more affordable.** *Universal health insurance coverage* is a fundamental protection against the cost of unexpected illness. It not only guards against the threat of financial ruin but minimizes the costs incurred by everyone else when sick people who are uninsured (or underinsured) show up in emergency rooms or hospitals, which by law must treat everyone in need of care. *Guaranteed coverage of preexisting conditions* is especially important to those who have experienced serious illness and would otherwise be denied coverage by insurers. *Keeping out-of-pocket costs like copayments and coinsurance reasonable* not only prevents bills from going unpaid but makes it easier for patients to stick with their preventive care regimen, avoid repeated emergency room visits and hospitalizations, and maintain progress in their treatment.[13]

Conclusion

Americans have high expectations for their health system. They spend more than the citizens of any other country with the hope that the right care will be there for them when serious illness strikes.

But along with the treatments and services that can improve life for the seriously ill come an unwanted and unnecessary set of physical, emotional, and financial burdens. These burdens result from the choices made by policymakers, practitioners, payers, and others. Listening to the voices of people with serious illness, reckoning with the human costs of our current system, and lifting the burdens that health care places on us when we become sick may be the most important work health care can undertake.

> “
>
> ***Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.***
>
> **Susan Sontag**
> *Illness as Metaphor,* 1978

HOW THIS STUDY WAS CONDUCTED

The survey *Being Seriously Ill in America Today* was conducted for the Commonwealth Fund, the *New York Times*, and the Harvard T.H. Chan School of Public Health by SSRS, an independent research company. Interviews were conducted via telephone (landlines and cell phones) in English and Spanish from July 6 to August 21, 2018, among a nationally representative probability-based sample of 1,495 adults age 18 or older. The margin of error for the total respondents is +/– 3.2 percentage points at the 95 percent confidence level.

The seriously ill were defined in two ways: 1) adults who themselves in the past three years have had a serious illness or medical condition that required multiple hospital visits and visits to multiple physicians; or 2) adults with a close family member who had had such an experience in the past three years but who was not available to be interviewed. Thus, throughout this report, the responses of the "seriously ill" include those who responded about their own experiences as well as those who reported about the experiences of a close family member. The data were combined to obtain an overall national picture of the experiences of the seriously ill.

NOTES

[1] Analysis of Commonwealth Fund/*New York Times*/Harvard T.H. Chan School of Public Health survey, *Being Seriously Ill in America Today*, conducted July 6 to August 21, 2018, among 1,495 U.S. adults.

[2] Bureau of Labor Statistics, "Unpaid Eldercare in the United States—2015–16 Summary," news release USDL-17-1292 (BLS, U.S. Department of Labor, Sept. 20, 2017).

[3] Analysis of Commonwealth Fund/*New York Times*/Harvard T.H. Chan School of Public Health survey, *Being Seriously Ill in America Today*.

[4] Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the 21st Century* (National Academies Press, 2001).

[5] See, for example, Emily M. Agree, "The Potential of Technology to Enhance Independence for Those Aging with a Disability," *Disability and Health Journal* 7, no. 1 (Jan. 2014): S33–S39; and Ana R. C. Donati et al., "Long-Term Training with a Brain-Machine Interface-Based Gait Protocol Induces Partial Neurological Recovery in Paraplegic Patients," *Scientific Reports* 6, no. 30383 (Aug. 11, 2016).

[6] Analysis of Commonwealth Fund/*New York Times*/Harvard T.H. Chan School of Public Health survey, *Being Seriously Ill in America Today*.

[7] Michael Laposata, "The Definition and Scope of Diagnostic Error in the U.S. and How Diagnostic Error Is Enabled," *Journal of Applied Laboratory Medicine* 3, no. 1 (June 2018): 128–34.

[8] Analysis of Commonwealth Fund/*New York Times*/Harvard T.H. Chan School of Public Health survey, *Being Seriously Ill in America Today*.

[9] Analysis of Commonwealth Fund/*New York Times*/Harvard T.H. Chan School of Public Health survey, *Being Seriously Ill in America Today*.

[10] Martha Hostetter, Sarah Klein, and Douglas McCarthy, *CareMore: Improving Outcomes and Controlling Health Care Spending for High-Needs Patients* (Commonwealth Fund, March 2017).

[11] Ruben Amarasingham et al., *Using Community Partnerships to Integrate Health and Social Services for High-Need, High-Cost Patients* (Commonwealth Fund, Jan. 2018).

[12] Maritt Kirst et al., "What Works in Implementation of Integrated Care Programs for Older Adults with Complex Needs? A Realist Review," *International Journal of Quality in Health Care* 29, no. 5 (Oct. 1, 2017): 612–24.

[13] "Roads to Universal Coverage," Commonwealth Fund, Nov. 6, 2017.

APPENDIX 1. HELPLESSNESS AND ITS CONSEQUENCES AMONG THE SERIOUSLY ILL

	%	Populaton estimate (millions)
In recent years, there was a time when they were receiving health care and felt anxious, confused, of helpless about their situation	62%	25.1
As a result of medical or health condition, any of the following happened:	73%	29.7
Wanted to work but were unable to	53%	21.6
Unable to do their job as well as they could before	51%	20.6
Condition caused them emotional or psychological problems	48%	19.5
Lost a job or had to change jobs	29%	11.6
Had a problem caring for another family member who was dependent on for their care	26%	10.4
Stayed in a job longer than otherwise would in order to maintain health insurance coverage	20%	8.0

Data: Commonwealth Fund/*New York Times*/Harvard T.H. Chan School of Public Health, *Being Seriously Ill in America Today*, July 6–Aug. 21, 2018. n= 746.

APPENDIX 2. PROBLEMS WHEN RECEIVING CARE AMONG THE SERIOUSLY ILL

	%	Populaton estimate (millions)
When getting care from a doctor/hospital staff for your medical or health condition, were any of the following a problem?	61%	24.7
Understanding what your health insurance covers	31%	9.1
You were sent for duplicate tests or diagnostic procedures by different doctors or nurses	29%	8.5
Receiving conflicting recommendations from different health professionals	23%	6.8
Hospital staff was not responsive to your needs	22%	8.9
Understanding your doctor bill	21%	6.3
Your medical records or test results did not reach your doctor's office in time for your appointment	17%	5.2
You could not understand what was being done to you (hospital)	15%	6.1
Understanding the instructions for a prescription medication you were taking	14%	4.2
Difficulty scheduling hospital admissions, tests, or discharges	13%	5.3
Transportation to/from hospital	13%	5.4

Data: Commonwealth Fund/*New York Times*/Harvard T.H. Chan School of Public Health, *Being Seriously Ill in America Today*, July 6–Aug. 21, 2018. n=616–750.

APPENDIX 3. FINANCIAL BURDEN OF CARE FOR THE SERIOUSLY ILL

	%	Populaton estimate (millions)
In recent years, have experienced any of the following as a result of dealing with medical or health condition:	53%	21.4
Used up all or most of savings	37%	15.0
Contacted by a collection agency	31%	12.5
Unable to pay for basic necessities like food, heat, housing	23%	9.3
Borrowed money to get a loan or another mortgage	13%	5.2
Couldn’t buy health insurance because of having another medical or health condition	11%	4.4
Declared bankruptcy	4%	1.6

Data: Commonwealth Fund/*New York Times*/Harvard T.H. Chan School of Public Health, *Being Seriously Ill in America Today*, July 6—Aug. 21, 2018. n=746.

ABOUT THE AUTHORS

Eric C. Schneider, M.D., M.Sc., is senior vice president for policy and research at the Commonwealth Fund. A member of the Fund's executive management team, Dr. Schneider provides strategic guidance to the Fund's research on topics in policy, health services delivery, and public health as well as scientific review of its initiatives, proposals, projects, and publications. Prior to joining the Fund, Dr. Schneider was principal researcher at the RAND Corporation and he held the RAND Distinguished Chair in Health Care Quality. From 1997, he was a faculty member of the Harvard Medical School and Harvard School of Public Health, where he taught health policy and quality improvement in health care and practiced primary care internal medicine at the Phyllis Jen Center for Primary Care at Brigham and Women's Hospital in Boston. Dr. Schneider has held several leadership roles including editor-in-chief of the *International Journal for Quality in Health Care,* cochair of the Committee for Performance Measurement of the National Committee for Quality Assurance, member of the editorial board of the National Quality Measures and Guidelines Clearinghouses, as a member of the scientific advisory board of the Institute for Healthcare Improvement, as chair of the Performance Measurement Committee of the American College of Physicians, and as a methodologist on the executive committee of the Physician Consortium for Performance Improvement of the American Medical Association. Dr. Schneider holds an M.Sc. from the University of California, Berkeley, and an M.D. from the University of California, San Francisco. He is an elected fellow of the American College of Physicians.

Melinda K. Abrams, M.S., is vice president and director of the Commonwealth Fund's Health Care Delivery System Reform program. Since coming to the Fund in 1997, Ms. Abrams has worked on the Fund's Task Force on Academic Health Centers, the Child Development and Preventive Care program, and most recently, she led the Patient-Centered Coordinated Care Program. Ms. Abrams has served on many national committees and boards for private organizations and federal agencies, and is a peer-reviewer for several journals. Ms. Abrams was the recipient of a Champion Award from the Primary Care Development Corporation and a Primary Care Community/Research Leadership Award from the Patient-Centered Primary Care Collaborative. Ms. Abrams holds a B.A in history from Cornell University and an M.S. in health policy and management from the Harvard School of Public Health.

Arnav Shah, M.P.P., is research associate for the Commonwealth Fund's research and policy department. In this role, Mr. Shah provides support to a department charged with adding value to the Fund's work in all of its core areas. Prior to joining the Fund, Mr. Shah was a research assistant in the Health Policy Center of the Urban Institute. From 2011 to 2012 he was a health policy intern for the Center on Budget and Policy Priorities, where he researched and wrote on the Affordable Care Act, Medicare, Medicaid, and CHIP. During graduate school he worked for the Center for Healthcare Research and Transformation and the University of Michigan's Center for Value-Based Insurance Design. Mr. Shah holds a master's degree in public policy from the University of Michigan's Gerald R. Ford School of Public Policy.

Corinne Lewis, L.M.S.W., is the research associate in the Commonwealth Fund's Delivery System Reform Program, where she performs a variety of duties including writing, editing, and research, as well as general program-wide coordination and management. Before joining the Fund, she was a health research analyst with Mathematica Policy Research, Inc., where she gained extensive experience in mixed methods research on federal demonstrations of innovative models of care. While at Mathematica, Ms. Lewis worked on a number of projects relevant to delivery system reform, including a toolkit for state Medicaid programs on provider network adequacy, the evaluation of the Independence at Home demonstration, and a project designing an evidence-based geriatric home visiting model to prevent medical and psychosocial issues among older adults. Before joining Mathematica, she was a project coordinator at the Laboratory for Youth Mental Health at Harvard University and had internships with the Centers for Medicare and Medicaid Services and NYU Augustana Center at NYU Lutheran Medical Center. Ms. Lewis holds a B.A. in psychology from Boston University and a master of science in social policy from Columbia University's School of Social Work.

Tanya Shah, M.B.A., M.P.H., joined the Commonwealth Fund in November 2015 as Senior Program Officer in the Delivery System Reform Program with responsibility for the high-need, high-cost population portfolio. Previously, Ms. Shah was Assistant Commissioner, Bureau of Primary Care Access and Planning with the New York City Department of Health and Mental Hygiene, where she was responsible for creating the mission and developing the strategic plan for the bureau. She oversaw all functions including policy analysis, program management and evaluation, and budgeting and resource allocation. She helped guide planning related to primary care, Affordable Care Act implementation and the New York State legislative agenda. Recent work has included policy analysis on the impact of DSRIP, health planning for the New York's State Health Improvement Plan, and health access for immigrants. Ms. Shah also served as the principal investigator on a number of ongoing studies that focused on the primary care provider landscape in New York City, as well as emergency planning and response for primary care. Ms. Shah worked at the Boston Consulting Group from 2005 to 2012, where she advised Fortune 500 companies, coordinated a climate change strategic planning process for Mayor Bloomberg's office, and led the "International Consortium for Health Outcomes Measurement" for Harvard University's Institute for Strategy and Competitiveness. From 1998 to 2004, Ms. Shah was a senior consultant for Accenture in their Health Services group. She holds a B.A. in International Development Studies, an M.B.A., and an M.P.H. in Health Policy and Management from the University of California at Berkeley.

Editorial support was provided by Christopher Hollander.

ACKNOWLEDGMENTS

The authors are grateful to Robert Blendon and John Benson of the Harvard T.H. Chan School of Public Health and Ishani Ganguli of Brigham and Women's Hospital for their expert contributions to the survey. We thank Barry Scholl, Chris Hollander, Jen Wilson and the Commonwealth Fund communications team for shaping and producing this report. We thank David Blumenthal, Michelle Doty, and Sara Collins for valuable advice along the way.

About the Commonwealth Fund

The Commonwealth Fund, among the first private foundations started by a woman philanthropist — Anna M. Harkness — was established in 1918 with the broad charge to enhance the common good.

The mission of the Commonwealth Fund is to promote a high-performing health care system that achieves better access, improved quality, and greater efficiency, particularly for society's most vulnerable, including low-income people, the uninsured, and people of color. Support for this research was provided by the Commonwealth Fund. The views presented here are those of the authors and not necessarily those of the Commonwealth Fund or its directors, officers, or staff. To learn more about new publications when they become available, visit the Fund's website and register to receive email alerts.

1918
2018
The Commonwealth Fund

A Century of Advancing Health Care for All