

# Blueprint

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## New UHF Efforts Respond to Family Caregiver Needs

*"I was scared, really scared."*

*"They should have sent someone to show me how to do it, not just leave it to a lady on the phone."*

*"When my wife goes to the dark side because of the chemo, it all falls on me to bring her back."*

The voices are those of family caregivers, just a few of the more than 30 who spoke candidly about their experiences in a series of six discussion groups—one in Spanish and one in Chinese—organized by United Hospital Fund. The goal of those sessions: to capture caregiver perspectives on the medical and nursing tasks they are expected to perform at home for their family members.

Since 1996, when UHF began its work to support family caregivers, understanding their specific needs and developing resources to help have been priorities. UHF's Families and Health Care Project has also focused intensively on building strong and effective partnerships between family caregivers and health care providers.

Caregivers—approximately 43.5 million of them nationwide—are often overwhelmed and in desperate need of better support and resources. That's particularly true as changes in health care—shorter hospital stays, new technology, and community-based care—put pressure on families to take over what used to be professional responsibilities.

At the same time, there are strong signs that health care providers are recognizing, including, and valuing family caregivers in important new ways—and that caregivers' vital role as part of the health care workforce is increasingly becoming part of a broader public discussion.



"Twenty-five years ago, when I first became a caregiver for my late husband, I had no idea what a 'family caregiver' was," says Carol Levine, director of UHF's Families and Health Care Project. "Today, I see news articles almost every day about family caregivers. More health care providers are finding that families can be valuable members of the health care team. But while these are heartening developments, family caregivers caring for aging adults with multiple chronic conditions for long periods need more support now than ever before."

### DEEP DIVE INTO FAMILIES' PERSPECTIVES

UHF's recent discussion groups with family caregivers, conducted under a contract with the AARP Public Policy Institute, captured their perspectives on two medical/nursing tasks in particular—medication management and wound care—and probed how video instruction and other training materials could be improved to help them perform those and other tasks with less anxiety and stress. A resulting report, *"It All Falls on Me": Family Caregiver Perspectives on Medication Management, Wound Care, and Video Instruction*, co-authored by

*continued on page 2*

## Family Caregiving *(continued from page 1)*

Ms. Levine and AARP’s Susan C. Reinhard, lays out their insights and includes a list of “do’s and don’ts” for video instruction and communication in general.

A number of common themes stand out. Family caregivers felt unprepared to perform complex tasks and often needed to solve problems that no one had warned them about. They reported a lack of coordination among health care professionals and said the sample training videos they were shown in the discussion groups failed to address the emotional aspects of family caregiving and often struck the wrong tone. Valuable feedback like this has guided the development of new videos for family caregivers on medication management, produced by AARP in collaboration with UHF and other partners and available at [www.nextstepincare.org/videos](http://www.nextstepincare.org/videos). Forthcoming videos will address other common responsibilities, including caring for wounds, preventing pressure ulcers, and facilitating mobility.

This latest exploration of caregiver perspectives was spurred by the 2012 report *Home Alone: Family Caregivers Providing Complex Chronic Care*, also produced by UHF and AARP. That work found that 46 percent of family caregivers across the country were performing medical and nursing tasks at home and felt they were not adequately prepared for those responsibilities by the health care system. As a result caregivers were often stressed, depressed, and worried about making harmful mistakes.

Carol Levine is also participating on the research team of a major national study analyzing patient care transitions, such as the move from hospital to home, from the patient and family perspective. The Patient-Centered Outcomes Research Institute (PCORI)—a nonprofit, nongovernmental agency authorized by Congress in 2010—funded the three-year, \$14.9 million Project ACHIEVE, which will survey more than 18,000 patients and family caregivers, visit health care facilities across the country, and examine clinical and claims data in order to develop best practices in the design, implementation, and dissemination of services and programs to improve care transitions.

Complementing these research efforts is new

legislation in New York and dozens of other states that creates requirements supporting family caregivers in the hospital discharge process. The Caregiver Advise, Record, Enable (CARE) Act has been introduced by 42 states and passed by 32.

Under New York’s CARE Act, which became law in April 2016, hospitals are required to ask patients if they want to name a person to be their family caregiver who will then be a part of the planning for discharge and care at home. If the patient consents, hospital staff can share information with that caregiver about the patient’s diagnosis, treatment, and plans for follow-up care, and must also provide the caregiver with education and instruction on the medical tasks he or she will need to perform when the patient returns home.

### GUIDANCE FOR PATIENTS AND PROVIDERS

With its commitment to helping ensure that patients, families, and hospital staff understand the new law and make it work as effectively as possible, UHF will soon release a guide for patients and caregivers on what the CARE Act means for them. It will also publish a toolkit to help hospital staff implement the new requirements. In addition to step-by-step guidance and FAQs on all aspects of the law, the toolkit will summarize the “crosswalk” of federal and New York laws and regulations governing hospital discharges, including proposed regulations by the Centers for Medicare and Medicaid Services that would require hospitals to take specific steps to ensure that patients and caregivers are more fully included in the discharge planning process. Both were supported with a grant from the Fan Fox and Leslie R. Samuels Foundation.

“Support for family caregivers and strong partnerships between providers and families are increasingly recognized as the linchpin for smooth transitions between care settings and for the highest quality of care,” says UHF President Jim Tallon. “UHF is uniquely poised to help amplify patients’ and caregivers’ important voices—and to help ensure that the health care system is listening and responding most effectively.”

## Blueprint

Published three times a year by United Hospital Fund’s Communications Division. We welcome your comments and suggestions.

United Hospital Fund is an independent, nonprofit organization working to build a more effective health care system for every New Yorker.

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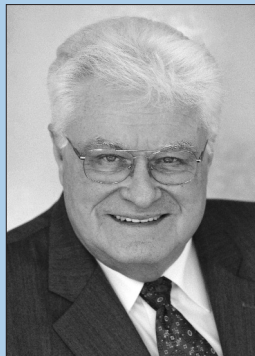
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# A Word...

WITH JIM TALLON

## The Certainty of Uncertainty



In the wake of the presidential and congressional elections, a host of questions about the short- and medium-term future have inevitably arisen, but some things

remain relatively certain.

For New York, health policy will be governed by a set of at least four givens: the diversity of our population and the extensive needs that must be met, regardless of potential shifts in federal policies; a significant commitment to the Medicaid program, the anchor of care for people in need, including those who would otherwise be uninsured; an equal commitment to coordinating services for greater efficiency and effectiveness, in pursuit of payments based on value, not volume; and the intention to maintain the leadership role New York has played over the decades, in administrations of both political parties.

### NO CLEAR PATH

Simultaneously, tremendous uncertainty exists, notably on the federal relationship with the states as manifested in Medicaid budget policies—including whether current waiver arrangements will continue, and whether Congress ultimately restructures Medicaid to include a capped allocation in the form of a block grant. In both cases, the degree to which New York can continue to depend on substantial reimbursement for its comprehensive Medicaid program is by no means sure.

Medicare—critical to the financing of care for more than three million New

Yorkers—is a topic of uncertainty as well. Previous discussions in Washington have offered the notion of a substantial restructuring of the program, effective perhaps five to seven years in the future, so that Medicare beneficiaries would be provided access to financial support to purchase a health plan or maintain traditional Medicare benefits but with a fixed subsidy payment. This approach, known as premium support, has been a mainstay of efforts in the House of Representatives to craft an alternative Medicare policy to reduce long-term cost growth in the program.

The Affordable Care Act will, of course, continue to come under attack. Senate rules requiring a supermajority for legislative

*Work on coverage will be more critical than ever. Insurance and Medicaid policy remain central to our mission.*

action may be able to avert outright repeal, but there will doubtless be proposals for diminution of subsidies under the law. New York has taken extensive advantage of the ACA through its New York State of Health insurance exchange. The challenge for the State will be maintaining expanded insurance coverage should federal payments be dramatically curtailed.

### UHF'S CENTRAL FOCUS

In the face of these potentially significant changes, United Hospital Fund's focus on the key policy areas of health insurance and Medicaid remains steady. We may have to take several steps back—concentrating, as in decades past, on efforts to maintain

expanded coverage—but both of these areas are central to our mission of building a better health care system for all New Yorkers. Work on coverage will be more critical than ever. Helping guide and support New York's efforts at value-based payment, in part through coordination of services and improvements in primary care, is also an essential element of our work.

Equally important, for both patient outcomes and health care financing, is attention to the quality dimension of care. The three pillars on which we based our recently launched Quality Institute—improving the effectiveness and efficiency of measures of quality, boosting the capacity of health care providers to promote quality improvement, and increasing patient and family engagement in and understanding of health care quality—remain legitimate, and urgent, targets for us. So too does our newest program area, attention to the health care system's role in children's long-term emotional, cognitive, and social development, through early interventions for children and families alike. Similarly, we look to continuing the gains we have made on family caregiving and on the linkages between health care and community organizations that support healthier aging.

With an enormous injection of uncertainty into the health care landscape, the election clearly poses a challenge to the current relationship between Washington and the states. But while the political winds of change will present significant budget challenges, in this new climate of leadership issuing from state governments, New York will remain very much at the center of the continuing challenge to deliver comprehensive services to all of our very diverse population.

## GRANT SPOTLIGHT

# Adapting Value-Based Payment for Children

Nearly 40 percent of New York’s Medicaid enrollees are children and adolescents, which raises important questions as the State embarks on major Medicaid reform efforts—particularly the move toward value-based payment, or VBP. By 2020, New York hopes to have 80 percent of its Medicaid managed care payments based on the *value* of provided services, rather than the number of procedures performed.

Figuring out value in health care for kids, however, isn’t the same as determining value for adults, for a host of reasons. Runny noses aside, kids are essentially healthier than the typical adult on Medicaid, and generate little medical expense. They’re far less likely to need a visit to the emergency room, surgery, or ongoing care for a chronic condition. Their care is also centered around preventive services, which have obvious long-term benefits but can be surprisingly hard to evaluate in the short term.

“Promoting a solid foundation of good health in children will yield enormous benefits for decades to come,” says Suzanne Brundage, project director of United Hospital Fund’s Children’s Health Initiative. “Finding the right metrics is key to assessing how well the health care system is doing in promoting that good health. This is challenging work—but because of the growing importance of VBP, now is the time to get those metrics right.”

## PAYMENT THAT ENCOURAGES CHANGE

Addressing these tricky issues has become a priority for UHF, in both policy and grant-making activities. Recent work by UHF’s Children’s Health Initiative and Medicaid Institute has suggested the need

for a framework for measuring value in primary care. To examine the issues of developing a child-centered approach to value-based payments, UHF turned to the Schuyler Center for Analysis and Advocacy. With a grant from UHF, the Center and national experts at Bailit Health have proposed two payment models to address children’s unique issues.

Their report, *Value-Based Payment Models for Medicaid Child Health Services*, was based on interviews with experts, both policy leaders and clinicians. The payment models it details would be based in primary care and emphasize coordination between pediatric practices and community-based organizations.

Such coordination would foster and support screening for psychosocial risk factors such as trauma and maternal depression, promote integration of behavioral health services in primary care, and help address social determinants of health. One model is specifically designed for use with the small portion of Medicaid child enrollees who are medically vulnerable—most with very complex medical conditions that require intensive use of specialty health care services.

The kind of multidisciplinary efforts and cooperation the Schuyler Center report calls for are especially relevant for New York’s children, nearly all of whom see pediatricians multiple times before reaching 18 months of age. Those regular well visits are a point of contact for children’s families and other caregivers, too, providing an important platform for assessing systemic problems that affect



long-term physical, emotional, and cognitive well-being—issues like housing and food insecurity, and exposure to neighborhood or family violence.

## CASTING A WIDER NET

By bringing this broader perspective on children’s health into New York’s Medicaid reform discussions, particularly through its newly launched Children’s Health Subcommittee and Clinical Advisory Group, New York is emerging as a national innovator in improving how the health care system promotes children’s health and well-being. “Effectively caring for children and putting them on a path toward life-long health requires payment models that promote screening and interventions to address social determinants of health—theirs and their caregivers’—that are not now a routine part of pediatric primary care,” says Kate Breslin, president and CEO of the Schuyler Center.

Addressing the many obstacles to optimal value in children’s health care fits neatly in the intersection of UHF’s grant-making and policy work. “Improving our approach to value-based care and payment for children may not generate short-term savings, but the long-term dividends are unquestionable,” says Jim Tallon, president of UHF. “Focusing on children’s unique needs by incentivizing the health and social services they need to thrive is itself a valuable investment.”

# Big Picture Distills Changing Insurance Markets

Understanding where losses and gains in the insurance industry are centered is key to understanding the dynamics of what’s happening in the various markets that make up the sector—and how new policies are affecting them. UHF’s sixth annual *Big Picture* report looks at the most recent data available—this year, for 2014, the first full year since implementation of the Affordable Care Act.

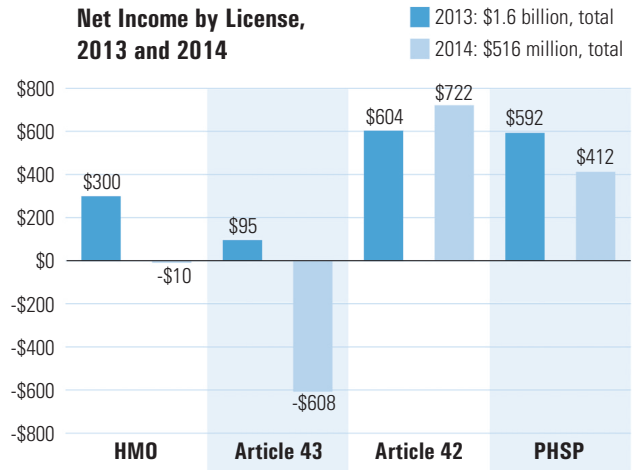
One eye-catching statistic from the report is that while individual insurance coverage increased sharply in 2014, overall net income for New York’s health plans dropped by over 67 percent from 2013 to 2014. The dramatic reduction, from \$1.6

billion to \$516 million, was not across the board, however, but concentrated in particular segments: losses by nonprofit (Article 43) insurers and health maintenance organizations (HMOs) were offset by solid numbers from for-profit (Article 42) insurers and Prepaid Health Services Plans (PHSPs), which specialize in public programs.

The fact that Article 43 insurers play a prominent role upstate means that their losses are a particular concern for that region; early numbers from more recent years suggest that those losses are slowing. PHSPs continued their steady growth in enrollment and market share: when the ACA increased eligibility for Medicaid, PHSPs were poised to take advantage of it,

and many new enrollees ended up signing up with them, a factor in their relatively solid performance.

*The Big Picture VI: New York’s Private and Public Insurance Markets, 2014* also highlights issues to watch going forward: sustaining a stable individual market, the shrinking small-group market, and signs of an aging regulatory infrastructure.



## RECENT GRANTS

In October 2016 United Hospital Fund awarded grants totaling \$602,642. For additional information, please see [www.uhfny.org/grants](http://www.uhfny.org/grants).

### GREATER NEW YORK HOSPITAL ASSOCIATION \$130,000

To increase provider capacity and enhance the quality of care within health systems across the greater New York region by 1) building quality improvement leadership through the continuation and expansion of the Clinical Quality Fellowship Program, including modification of the curriculum to add content relevant to ambulatory care; and by 2) supporting hospitals and nursing homes in developing antibiotic stewardship programs to address antibiotic resistance and the misuse and overuse of antibiotics, through a learning network and hands-on support.

### MONTEFIORE MEDICAL CENTER \$188,320 over two years

To pilot-test a new framework for integrating behavioral health care services into primary care—developed and disseminated with earlier UHF support—in four primary care medical practices in New York City. Project leaders will provide technical assistance to support the use of the framework, identify implementation challenges, and fine tune the framework based on project findings and results.

### NEW YORK UNIVERSITY SCHOOL OF MEDICINE \$135,000 over two years

To foster the identification of Emergency Department patients at

significant risk for future homelessness, and develop effective preventive interventions, by conducting survey research and cross-system data analysis supporting development of a first-of-its-kind risk screening tool, protocols for future ED-based homelessness prevention interventions, and a Social Determinants of Health (SDH) Registry that will connect survey and hospital utilization data to assess the effects of SDH on hospitalizations.

### PATIENT-REPORTED OUTCOMES IN PRIMARY CARE [PROPC]-NY \$149,322 total over 18 months

- THE INSTITUTE FOR FAMILY HEALTH (\$49,978)
- MONTEFIORE HEALTH SYSTEM (\$49,344)
- NORTHWELL HEALTH (\$50,000)

To better understand patient perspectives and help prioritize the patient “voice” in the delivery of high-quality primary care in New York by advancing the use of Patient-Reported Outcomes Measures (PROMs). UHF’s Quality Institute will facilitate a learning collaborative of primary care practices to test the feasibility and utility of integrating PROMs into routine workflow; practices will pilot-test standardized patient questionnaires, eliciting data from patients about their concerns, to inform care planning and monitor outcomes. The initiative will be led by a faculty of nationally recognized experts and the UHF Quality Institute team.

# Gala Honors Outstanding Leaders in Health Care

“The individuals we celebrate tonight truly embody our mission and values,” UHF President Jim Tallon told more than 560 health care, business, and community leaders at this year’s Gala. “Their specific goals and approaches differ but they share a vision for better health and health care that benefits all of us.” The September 26 event honored Risa Lavizzo-Mourey, MD, with the Health Care Leadership Award, Scott B. Salmirs with the Distinguished Community Service Award, and Herbert Pardes, MD, with a Special Tribute.

Dr. Lavizzo-Mourey, president and CEO of the Robert Wood Johnson Foundation, was cited for her visionary work to build a national “culture of health.” In nearly 14 years as head of RWJF she has led a transformation of the Foundation’s role from that of grant making to “effecting social change.” Emphasizing strong collaborations with both traditional health care stakeholders and sectors as diverse as finance and criminal justice, the Foundation focuses on four themes: Healthy Children, Healthy Weight; Healthy Communities; Transforming Health and Health Care Systems; and Leadership for Better Health. Its \$1 billion investment in efforts to combat childhood obesity have been lauded nationally, with Michelle Obama noting “RWJF wasn’t just stepping on the bandwagon, they were building [it] pretty much from scratch.”

For Scott Salmirs, the knowledge that 10,000 New Yorkers await organ transplants, and that the state ranks last in the nation in the percentage of people registered as organ donors, has inspired a tireless effort to reverse those statistics. The president and CEO of ABM Industries, an international facility management provider, Mr. Salmirs is a

founder of Donate Eight, which brings together members of New York’s real estate, building management, and building services communities to help address the issue. Since its founding in 2012 Donate Eight has raised more than \$3.2 million in support of LiveOnNY, the metro area’s federally designated organ procurement agency, and the LiveOnNY Foundation’s work to increase donor registration, raise awareness, and support donor families.

As his colleagues are quick to point out, “empathy” has been a signal trait in the illustrious career of Herb Pardes, MD, executive vice chairman of the board of trustees of NewYork-Presbyterian Hospital. From clinical practice and departmental leadership as a psychiatrist, through directing the National Institute of Mental Health, to his 2000-2011 presidency of NewYork-Presbyterian Hospital, he has been noted for his deft leadership and his uncompromising commitment to research, medical education, and patient care. A gifted fundraiser as well, he has brought some \$3 billion to Columbia’s College of Physicians and Surgeons and to NewYork-Presbyterian. Above all, Dr. Pardes is known for his compassion and his commitment to easing the struggles of patients and families, while pushing every institution with which he has been affiliated to the unstinting pursuit of excellence.

Chaired by board chairman J. Barclay Collins II, the 2016 Gala raised more than \$1.5 million to help further UHF’s work of improving health care and health for all New Yorkers.



*Gala presenters and honorees (from left) Ron Pressman, CEO of Institutional Financial Services at TIAA, the underwriter of the Distinguished Community Service Award; Herbert Pardes, MD; Risa Lavizzo-Mourey, MD; Scott Salmirs; Jim Tallon; and Barclay Collins.*

## GALA DONORS

### UNDERWRITER, 2016 DISTINGUISHED COMMUNITY SERVICE AWARD

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## Data Driving CBO Efforts to Improve Health of Seniors

“I first found out I had diabetes when I went blind,” says Ramona,\* a senior living in public housing in Bushwick, Brooklyn. “I learned to manage my condition but always have trouble with diet and exercise. Since training as a community health navigator, though, I’ve been exercising and eating better—and I lost seven pounds. My doctor asked me, ‘What happened?’”

One thing that happened was a community engagement project that’s gotten seniors like Ramona to help themselves—and others. Ramona lives in a “naturally occurring retirement community” or NORC, where supportive services are provided by JASA, the Jewish Association

Serving the Aging. JASA has been partnering with UHF to implement results-oriented health and wellness programs as part of UHF’s Health Indicators–Performance Improvement project (HIPI), funded by the Altman Foundation. HIPI helps community-based organizations (CBOs) learn to use data to tailor interventions to their unique populations, and measure their impact.

A UHF grant helped JASA set up a peer navigator program. After going door-to-door in the NORC, engaging seniors to join a blood pressure monitoring or diabetes self-management program, JASA went further and identified six seniors eager and able to be peer navigators, leading self-management classes and serving as ambassadors to the residents. The result: increased interest in JASA’s programs, stimulated by word-of-mouth, a much more effective way to engage residents in services—like nutrition and

exercise classes—than just putting up posters and hoping people show up.

By using data to target the very people who need the support and health education that the organization and its peer navigators can provide, JASA can bridge the gap between health care and community services. On the strength of its ability to act with this deeper, data-driven knowledge, JASA was able to set up a new partnership with nearby Wyckoff Hospital Center to improve discharge planning.

Ramona is now helping lead a walking club, performing blood pressure screenings in her community, and visiting patients with diabetes hospitalized at Wyckoff. She’s an inspirational figure whose own engagement in managing her diabetes has inspired her to help others to do the same. She says it well: “I’ve really started to see how just a few changes, step by step, can make you feel much better and happier.”

*\*Not her real name*

## Business and Philanthropy Leaders Elected to UHF Board

Bettina Alonso and Eugene Keilin have been elected to UHF’s board of directors.

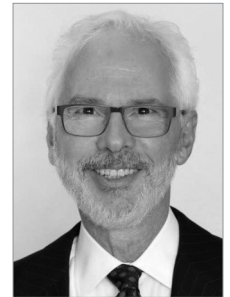
Ms. Alonso is the executive director of development for the Archdiocese of New York, providing strategic direction for initiatives including the Cardinal’s Annual Stewardship Appeal and the Alfred E. Smith Memorial Foundation. She previously served as vice president of global development at Oceana, an international conservation advocacy group, and as marketing manager for the Embassy of Austria. Born in Spain and fluent in English, Spanish, and German, Ms. Alonso earned a BA in political science, MS in international affairs, and diploma of advanced studies from the Universidad Nacional de Educacion a Distancia. She

also received a certificate of business excellence from the Columbia Business School and attended NYU’s Heyman Center for Philanthropy and Fundraising.

Mr. Keilin is the chairman of Maimonides Medical Center, and the co-founder of KPS Capital Partners, a family of private equity funds. He was founding principal of Keilin & Co. LLC, investment bankers specializing in advisory services on financial restructuring and bankruptcies, and, earlier, a general partner of Lazard Frères. Mr. Keilin was executive director and then chairman of the Municipal Assistance Corporation for the City of New York, and later chaired the Citizens Budget Commission, where he remains an executive committee member. He is



*Bettina Alonso*



*Eugene Keilin*

emeritus director of the international relief organization Concern Worldwide, U.S., and serves on the advisory board of the Curtis Institute of Music. Mr. Keilin is a graduate of Rice University and Harvard Law School.

“Our new board members bring vast experience—in philanthropy, nonprofit development and marketing, and in private and public sector finance and health care governance,” said UHF President Jim Tallon. “I know they will make great contributions to our work.”



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ON THE CALENDAR

MAY 1

The annual Tribute to Hospital Trustees luncheon and awards ceremony, recognizing exemplary community

service and leadership. Cipriani 42nd Street.

OCTOBER 3

United Hospital Fund Gala,

presenting the Health Care Leadership and Distinguished Community Service Awards, and a special tribute. Cipriani 42nd Street

OFF THE PRESS

These and other UHF reports are available at [www.uhfnyc.org](http://www.uhfnyc.org).

*"It All Falls on Me": Family Caregiver Perspectives on Medication Management, Wound Care, and Video Instruction* describes caregivers' reports of feeling unprepared for the complex clinical tasks they are expected to perform, and offers valuable guidance on making training videos more effective in helping caregivers perform those tasks with less anxiety.

*A Strategy for Expanding and Improving the Impact of the Medical Home Across New York City*, produced in partnership with New York City and the Population Health Improvement Program, focuses on prioritizing medical home adoption in communities facing the greatest health burdens, and in the small practices that are the key to addressing health inequities.

*The Growth of Medical Homes in New York State, 2014-2016* examines adoption of this practice model by region, certification, and type of facility, and discusses logistical issues—encouraging multipayer support, implications for medical homes within value-based payments, and others—raised by the proliferation of competing models.

ON THE WEB

[WWW.UHFNyc.ORG](http://WWW.UHFNyc.ORG)

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