RUTGERS
Center for State Health Policy

Improving Care for Complex Patients:
Stories from Four Super-Utilizer Pilot Programs

It was graduation day in Aurora, Colorado, and guests streamed into a large tent festooned with colorful balloons and congratulatory banners. This was no ordinary commencement – no caps and gowns, no processionals, no bagpipes. Rather than marking the completion of studies and entry into the "real world," the honorees here were commemorating a different, but no less impressive, achievement: fewer medical crises, better managed chronic conditions, and hopes for a healthier future.

The celebrants were "graduates" of Bridges to Care (B2C), a community-based intervention that provided intensive services to high-need, high-cost patients and empowered them with the skills and confidence to take charge of their health. Run by the Metro Community Provider Network (MCPN), a nonprofit group of federally qualified health centers (FQHCs) in Aurora, the 60-day program delivered personalized care through home visits at no cost to recipients. The late summer festivities, held outside one of MCPN's 22 health centers, were organized to recognize the patients' hard-earned accomplishments.

"The day Bridges to Care found me was a blessing," said Adam, a tall, strapping man in his 30s, who told the assembled crowd how the program transformed his life.

Plagued by a litany of ailments since age 19 when he was viciously shot and stabbed during a robbery, Adam was a repeat customer at the emergency department (ED). His mother's health insurance had covered the thoracic surgery and wound care that he needed right after the attack, but since aging out of the coverage, he had no regular source of care for the foot paralysis, gout and other problems that continued to haunt him. Poor health prevented him from holding a steady job or attending school, and he had racked up thousands of dollars in health care bills.

Once Adam enrolled in Bridges to Care, a nurse practitioner paid him visits at home and evaluated his needs, both medical and non-medical; a multidisciplinary care team then arranged appropriate services to address the factors hindering his health. In addition to clinical care and social support, Adam received behavioral health care, which he said helped to get his life back on track. With his emotional and physical well-being improved, he was able to find a job, be a better husband and father, and start to develop his own marketing and communications business.

"Since Bridges to Care, I have access to medical care and attention to my problems," said Adam, who now receives primary care at an MCPN clinic.

Marsha, another Bridges to Care graduate, related a similar story of deteriorating health and emotional despair. She had been taking an array of drugs for multiple chronic illnesses that were always out of control. Frustrated by years of ineffective, disjointed care, she decided one day to stop all her medications cold turkey. Not surprisingly, she ended up in the hospital. "I had no transportation and no income," Marsha recalled. "I was very scared and very sick."

Super-utilizer pilot programs at a glance

		Jan 2013 – Jun 2015	
Program name	**Organization and location**	**Enrolled**	**Graduated**
Lehigh Valley Super-Utilizer Partnership (LVSUP)	Neighborhood Health Centers of the Lehigh Valley (NHCLV), Allentown, PA	111	84
Guided Chronic Care (GCC)	Truman Medical Centers (TMC), Kansas City, MO	265	150
Bridges to Care (B2C)	Metro Community Provider Network (MCPN), Aurora, CO	489	360
Patient Health Improvement Initiative (PHII)	MultiCultural Independent Physicians Association (IPA), San Diego, CA	154	102

Recruited by a Bridges to Care community health worker in the hospital ED, Marsha received home visits from a nurse practitioner, a clinical care coordinator, a behavioral care specialist and a health coach, who all worked with her to carefully re-introduce her medications, stabilize her conditions and reduce her anxiety. With their assistance, she also obtained Social Security disability benefits and became more independent.

"It was the most phenomenal care I've ever had!" Marsha exclaimed. "The behavioral health therapy helped a lot and I have a whole new way of looking at my health care."

Adam and Marsha were among more than 1,000 people enrolled in a special initiative developed at four clinical sites across the country and targeted toward "super utilizers," complex, chronically ill patients with excessive rates of hospitalizations and emergency department visits. In addition to Bridges to Care in Aurora, a city of about 347,000 located 15 miles from Denver, super-utilizer programs were developed in three other locations: the Lehigh Valley Super-Utilizer Partnership (LVSUP) at the Neighborhood Health Centers of the Lehigh Valley (NHCLV), a small FQHC in Allentown, Pa.; Guided Chronic Care (GCC) at the Truman Medical Centers, a safety net hospital in Kansas City, Mo.; and the Patient Health Improvement Initiative (PHII) under the MultiCultural Independent Physicians Association (MultiCultural IPA), a physician group in southeast San Diego, Calif. The multi-site project was funded by a $14.3 million Health Care Innovation Award (HCIA) from the federal Center for Medicare and Medicaid Innovation (CMMI) and overseen by the Rutgers Center for State Health Policy in New Brunswick, N.J.[1] The four pilot programs, which began in spring 2012 and ran through June 2015, sought to improve the care of these challenging super utilizers, avoid preventable hospital stays and ED visits, and ultimately reduce costs.

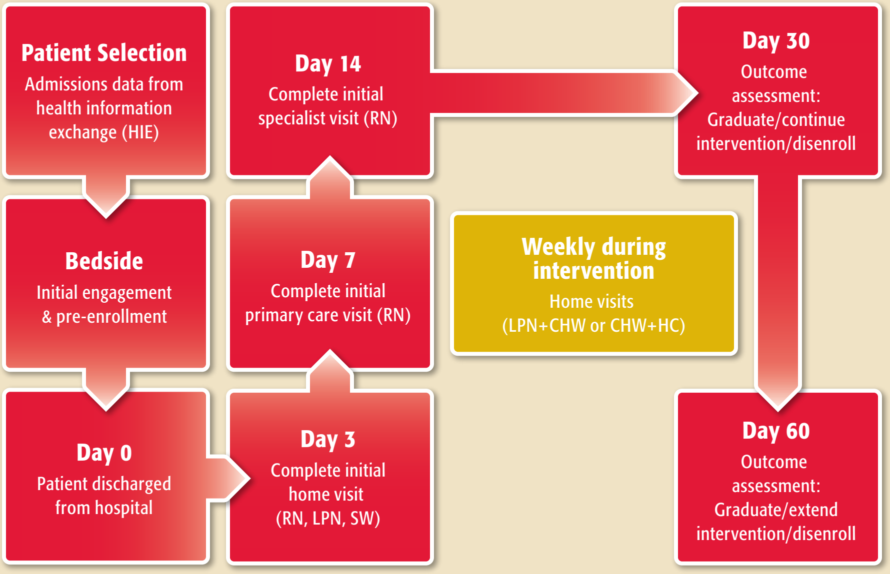
Camden's care model*

Enrollment criteria

- 2+ admissions in 6 months
- Medical and/or social comorbidities
- Selected exclusions

Team composition

- Nurse (RN) team leader
- Social worker (SW)
- Licensed practical nurse (LPN)
- Community health workers (CHW)
- AmeriCorps Health Coaches (HC)



*As presented to the clinical partners at start of program; model continues to undergo adjustments.

The intervention was based on a health care model developed in Camden, N.J., by Dr. Jeffrey Brenner, a family physician deeply troubled by the health system's inadequacy, fragmented care and health disparities. He collected data from Camden's low-income and underserved areas and employed a unique analysis to pinpoint community "hot spots" where high medical service users lived. Brenner then convinced others in Camden to join in building teams to go into the community and give these complex patients more cohesive, effective health care and, at the same time, tackle the social and other non-medical problems that contributed to their poor health status. The innovative approach was featured in a 2011 *New Yorker* article[2] by Dr. Atul Gawande and on a subsequent PBS *Frontline* broadcast.[3] In 2013, Brenner won a MacArthur "Genius" Fellowship for his pioneering ideas.

Brenner's hot-spotting model—which has since grown into the Camden Coalition of Healthcare Providers (CCHP)—served as the template for the CMMI project, but each site adapted the intervention to meet specific community needs, demographics and characteristics. Physicians were involved, but at the heart of each program were nurses and social workers who led the health care teams that worked directly with patients. Each program cultivated relationships with community partners to provide a range of coordinated services for the vulnerable individuals enrolled. The major goals were to improve the care and health of these complex patients, teach them how to manage their conditions and navigate the health care system, and create super-utilizer programs that could be sustained beyond the life of the HCIA grant.

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[1] The project described was supported by Grant #1C1CMS-330995 from the Department of Health and Human Services, Centers for Medicare & Medicaid Services.

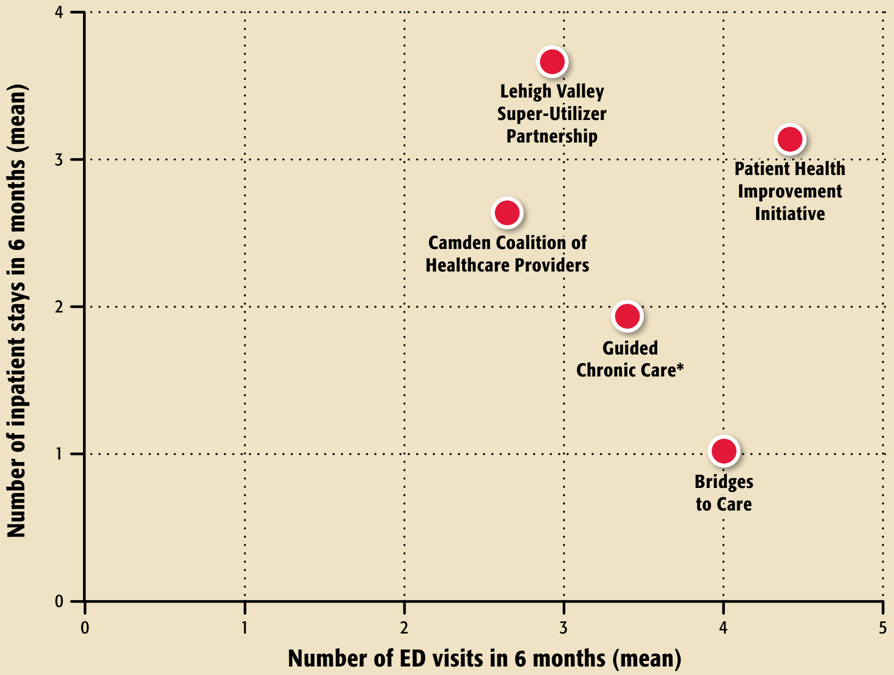
[2] Gawande A. "The hot spotters: Can we lower medical costs by giving the needest patients better care?" *The New Yorker*, January 24, 2011.

[3] Frontline, "Doctor Hotspot," *WGBH Boston*, 2011, http://www.pbs.org/wgbh/pages/frontline/doctor-hotspot/

This report reflects the experience of the four pilot programs and describes the challenges, findings and lessons associated with the demonstration. It is intended to inform providers, policymakers, insurance plans and other potential stakeholders who might have an interest in developing a similar health care model. It is *not* meant to be the "playbook" or plan for establishing a super-utilizer program. Such health care designs must be tailored to the particular communities they serve and compatible with the local medical infrastructure.

The stories and anecdotes discussed here have been compiled from interviews and real-time observations; to protect the privacy of program participants, patient names have been changed.

Inpatient stays & ED visits 6 months before enrollment



*Inpatient admission and ED visit data in 12-month timeframe divided by two.

Selecting the "Right" Patients

Super utilizers, or "frequent fliers" as some in the health field call them, are not an especially large segment of the U.S. population, but they consume an inordinate amount of health care resources. Health care experts estimate that 1 percent of the population are responsible for 25 percent of health care costs, and 5 percent incur more than 50 percent of health care expenses. The Agency for Healthcare Research and Quality (AHRQ), using data from the Healthcare Cost and Utilization Project (HCUP), found that Medicaid super utilizers have more hospital stays than the rest of the population; in 2012, for example, super utilizers averaged four to six hospitalizations a year and had four times as many inpatient stays as other patients. They also had considerably more readmissions: fewer than 4 percent of privately insured and Medicaid super utilizers were responsible for approximately half of all U.S. hospital readmissions. Chronic illnesses such as diabetes and chronic obstructive pulmonary disease (COPD) were among the top 10 reasons for hospitalizations; mood disorders, mental health problems and substance abuse also were among the top 10 principal diagnoses for super utilizers' hospital stays.[4]

The HCIA funding allowed the selected clinical sites to focus on super-utilizer adults in their regions and experiment with a highly personalized delivery of care that was both patient-centered and coordinated. The "care" went beyond attention to clinical needs and included addressing other social determinants of health—such as financial strains, transportation difficulties, housing scarcity, food insecurity and family turmoil—that prevented these patients from getting and staying well. The health care teams organized in the summer and fall of 2012, trained and prepared for their new roles, and developed protocols to identify and recruit appropriate patients. Rutgers personnel established a "learning network" so staff could share, via calls, meetings and site visits, technical assistance, strategies, problem-solving techniques and other matters that arose.

The programs set enrollment criteria according to Camden's model, with the initial baseline requirement at three sites being two or more inpatient admissions in the previous six months; Aurora required three or more inpatient stays *or* ED visits over six months. (Truman's program, Guided Chronic Care, later expanded its criteria to include three or more admissions over 12 months.)

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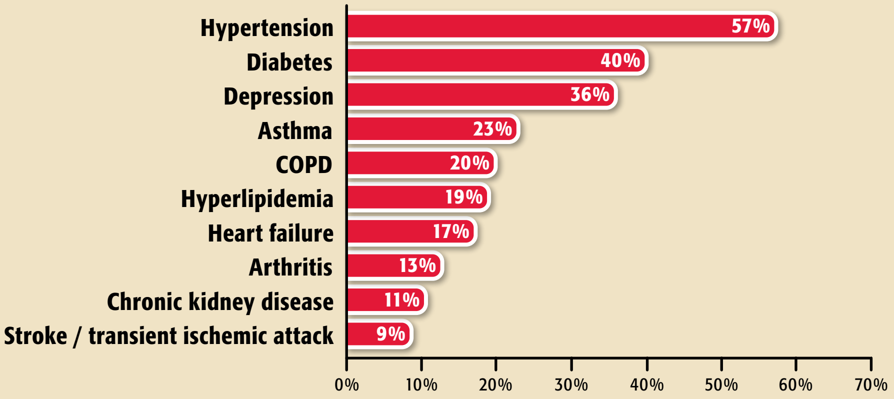
[4] Jiang HJ, AJ Weiss, ML Barrett, and M Sheng. "Characteristics of Hospital Stays for Super-Utilizers by Payer, 2012." *Healthcare Cost and Utilization Project (HCUP) Statistical Brief, no. 190.* Rockville, MD: Agency for Healthcare Research and Quality, 2015.

Admittance to the programs required that patients have medical and/or social comorbidities and at least two chronic illnesses (Truman's Guided Chronic Care in Kansas City required only one). Certain conditions, such as pregnancy, cancer, terminal illness and a primary mental health diagnosis, excluded patients from consideration. The most common chronic illnesses seen were hypertension, diabetes, and depression. The teams reported that nearly 90 percent of participants reported two or more chronic conditions at enrollment and more than 40 percent reported five or more.

Mental illness and substance abuse also were prevalent among the super utilizers and obvious contributors to the patients' difficulties. "Behavioral health is a huge driver to the emergency room," noted Heather Logan, Bridges to Care's co-director.

The sites all were located in regions with large pockets of low-income and minority populations, particularly African American and Hispanic/Latino. In Aurora and San Diego, sizable refugee populations from the Middle East, Asia and Africa added to the mix. Like Brenner, who used hot spotting to identify concentrated super-user neighborhoods, the four programs started out targeting certain zip codes; however, most expanded the coverage areas to capture more patients. Overall, slightly more females than males enrolled and the majority of patients were in their mid-to-late 50s (although Bridges to Care patients on average were younger). Enrollees tended to be on Medicaid or Medicare; a substantial number in Bridges to Care were uninsured, and San Diego's program, the Patient Health Improvement Initiative, also had patients with private insurance coverage.

Top 10 chronic conditions across pilot programs



Demographics & coverage status

	LVSUP	GCC	B2C	PHII	CCHP
Race & ethnicity					
% Hispanic	48.1	1.9	30.4	32.7	39.8
% Non-Hispanic black	12.0	70.5	30.4	34.0	48.7
% Non-Hispanic white	35.2	26.1	29.2	23.3	10.6
% Other/unknown	4.6	1.1	10.1	10.0	1.0
Age					
Mean years	55.7	55.8	43.3	59.3	57.1
Gender					
% Female	47.3	50.8	69.3	53.9	49.4
Coverage status					
% Medicare	27.0	20.4	5.3	14.3	20.8
% Medicaid	35.1	41.9	46.6	44.8	47.1
% Dual*	21.6	22.3	7.6	36.4	26.3
% Uninsured	9.9	12.8	39.6	0.0	1.0
% Other	6.3	2.6	0.8	4.5	4.8

*Dually eligible for both Medicare and Medicaid.

Brenner's model recommends initially engaging with patients at bedside, either in a hospital emergency department or inpatient unit, when they are ill and clearly in need of support. At Truman Medical Centers, a large urban hospital, registered nurse "health coaches" perused daily electronic lists of hospital admissions for eligible patients and then visited them in house to explain the program and invite them to participate; other referrals came from nearby clinics and homeless shelters. MCPN carved out a special arrangement with the University of Colorado Hospital on the Anschutz Medical Campus in Aurora that gave Bridges to Care community health workers posted in the University Hospital Emergency Department privileges to access patient information and approach individuals who met the program's criteria. Neither the NHCLV in Allentown nor the MultiCultural IPA in San Diego had formal relationships with hospitals in their areas and thus could not mine large databases for potential patients. However, their staffs worked diligently to spread word about their super-utilizer programs and succeeded in receiving patient referrals from physicians, health insurers and other providers.

While most patients welcomed the opportunity for attentive care and expressed a desire to feel better and stay out of the hospital, staff said the key to achieving improved health was motivation and commitment. "The biggest challenge was finding the right patient and keeping that patient engaged," noted Sophia Alires, the Bridges to Care manager of clinical care coordination.

Experienced nurse found her calling in San Diego program for chronically ill

Montrula Donaldson started her nursing career working with the sickest patients in the hospital intensive care unit (ICU); she moved up the ranks, and by 2012, after more than three decades in the profession, she held a top administrative post in the licensing and certification division of the California Department of Public Health.

But Donaldson was restless. Retirement or perhaps some other adventure already was in the back of her mind the day she paid an office visit to her internist, Dr. Rodney G. Hood, in southeast San Diego.

Hood, president of the MultiCultural Independent Physicians Association (McIPA), told Donaldson his medical group had received a federal grant to design a program for the area's sickest, most costly patients – "super utilizers" who had frequent emergency department (ED) visits and hospital stays. The intervention, which emphasized coordinated care, was going to send multidisciplinary teams into patients' homes to provide more personalized care, link them to community resources for social needs, and equip them with skills necessary to navigate the health care system. Hood asked Donaldson if she could recommend an experienced registered nurse (RN) to help establish the San Diego initiative and oversee the care team.

He never expected her response: "Wow! This could be for me."

For Donaldson, the doctor had described the perfect prescription. "I told him I needed something different to do," she explained. "I can use all my knowledge to do this job. I can touch and talk to patients one on one, and make a positive difference in their lives."

The first staffer hired for the Patient Health Improvement Initiative (PHII), Donaldson collaborated with Hood, the program's medical director, in setting the clinical protocols, and then served as nurse case manager for the PHII home visit team, which also included a social worker and community health worker. Donaldson monitored patients' conditions and medications and frequently accompanied them to physician appointments. She and her team advocated for patients and helped them acquire anything they might need – medical equipment, housing, food resources or financial assistance.

"I love doing this!" exclaimed Donaldson, who is the picture of professionalism with her stylish outfits and matching fedoras. "It's all about the patients. It's empowering them and letting them know there's somebody who cares."

Howard N., a morbidly obese patient suffering from multiple chronic conditions and severe depression, was among those Donaldson helped turn around. She and her team prayed with him on their first visit and formed a quick bond. "They were a godsend!" Howard noted.

Donaldson and her patient discovered they shared a love for singing and church, and over the months the PHII team visited, providing support and encouragement, his condition and outlook improved. In fact, the friendship continued after his "graduation" from the program. "We become very close," she said of the relationships with patients. "Sometimes we're like their family -- they have no one else."

Though the federal grant ended in June 2015, the MultiCultural IPA has used other funds to keep the team intact and maintain the super-utilizer program on a smaller scale. Hood said Donaldson's experience, empathy and knowledge of the area have been invaluable to the effort.

"She's kind of like the mother of the group, not just for the patients, but our staff, too. Many rely on her," he noted. "She really loves what she does."

Faces of the Care Team

Nurses, social workers and community health workers were the purveyors of care and support for the super-utilizer programs. Teams ranged from three to five members whose makeup and job titles varied, but generally a registered nurse served as the case manager and team leader. LVSUP in Allentown and PHII in San Diego each had only one team, while B2C in Aurora and GCC in Kansas City had up to three teams because of their larger caseloads. While all the programs assessed patients' behavioral and mental health status, Colorado's B2C was the only one to have a behavioral health provider on its teams.

Face-to-face home visits from a nurse and social worker usually occurred within days of hospital discharge, and the priority, in addition to evaluating medical and psychosocial needs, was on building trust and acceptance. Getting patients to officially enroll, consent to program requirements and agree to cooperate with team members sometimes called for patience and gentle persistence. Individuals eager to enroll when in crisis occasionally changed their minds once they returned home.

"Because of their medical conditions, they tend to isolate themselves. It's become a way of life—they're hesitant to let someone come into their home," explained Evelyn Kramer, a social worker who was on the Allentown team. "Others want a lot of people because they are so isolated."

Team members spent time with patients assessing problems, discussing expectations, setting personal goals and determining what was needed to attain those goals. Nurses oversaw the clinical care, while others on the teams—health workers who went by such titles as community client liaison, community connector, clinical care coordinator, health coach and community health advocate—dealt with patients' social and financial dilemmas and connected them with proper resources for assistance. Because of the desperate needs of these patients and their families, team members' tasks went beyond acquiring walkers, commodes, and medications to obtaining groceries, furniture, transportation, housing and often financial assistance.

To lessen reliance on the emergency department, efforts were made to establish

Aurora mom finds way back from pregnancy complications with support from Bridges to Care

Carol had never paid much attention to her health. She rarely got sick, and as a mother of four, she couldn't take time for herself anyway. She had a stable warehouse job, health insurance and a 401K savings plan. It wasn't easy being a single parent, but she was managing.

Then the 29-year-old became pregnant with her fifth child, and in her seventh month she began suffering brutal migraines. She became a regular at the hospital emergency department (ED), but her blood pressure, urine and other vitals checked out fine. Doctors attributed her headaches to stress.

At delivery, Carol went into crisis – the result of undiagnosed HELLP syndrome, a dangerous disorder and form of pre-eclampsia characterized by hemolysis (the breakdown of red blood cells), elevated liver enzymes and a low platelet count.

Carol's daughter was born healthy, but the Aurora, Colo., woman sustained a host of problems linked to the HELLP syndrome: vision loss, a painful liver lesion, gastroesophageal reflux disease, high blood pressure, ongoing headaches and panic attacks. In subsequent months, Carol made more than 10 visits to area EDs. "I was in distress every day," she recalled. "I thought I was going to die."

With her health declining, Carol's life started to unravel. She couldn't care for her older children and sent them to stay with family members. She no longer could work and lost both her job and benefits. Caught in a downward spiral, she felt hopeless and unglued: "I cried all the time. I didn't know what to do."

During one ED visit, a community health worker approached Carol, telling her she qualified for Bridges to Care, an intensive program run by the Metro Community Provider Network (MCPN) for patients with high needs. She enrolled, and right away, members of a multidisciplinary team started visiting her at home three to four times a week, inquiring not only about medical problems but difficulties with stress, housing, child care, finances and transportation. "Everything was taken care of step by step," Carol noted. "They gave me every answer I needed."

A nurse practitioner monitored Carol's medical condition and a behavioral health specialist taught her coping skills, such as deep breathing exercises, for her panic attacks and anxiety. From a health coach, Carol gained knowledge about her health problems and improving her diet and well-being; she also received training in communicating effectively with health providers. A clinical care coordinator assisted with insurance and disability matters. "They were awesome!" Carol said of team members. "They brought my spirit alive."

Carol "graduated" from Bridges to Care in May 2014. Though she wasn't out of the woods medically, she had achieved her goals: she knew how to manage her conditions and was capable of coping when problems arose. Team members set her up in a "medical home" at MCPN, where she could receive primary care.

"This program is wonderful," Carol said. "The staff came into my home and made sure I could be a good mom. They listened and didn't rush. They made it possible for me to live."

patients with a primary care provider or "medical home"; a nurse or community health worker accompanied enrollees on clinical appointments to ensure that they understood what transpired and to foster an open dialogue between patient and provider. The community health workers, who in some cases were licensed practical nurses or people highly experienced in the health field and knowledgeable about the local community and its vulnerable populations, educated patients about their chronic conditions and how to maintain a healthy diet and lifestyle. Scales, blood pressure cuffs, pillboxes and similar paraphernalia were dispersed to help enrollees with health maintenance. Patients also received instruction in steering through the health system's intricate web and in communicating effectively with doctors and caregivers. The idea was to empower patients so they became proficient and assertive enough to handle health matters on their own.

Roles varied at the different sites. For instance, at three sites, nurses visited patients in their homes to administer care. However, the Truman nurses, who oversaw patients' individualized health plans, were not licensed for home visits, so the community client liaisons and community health advocates made the visits and served as the "eyes and ears" for the nurse health coaches. In Aurora, a behavioral health expert on the Bridges to Care team assessed patients and provided therapy if needed; Truman's teams shared the services of a psychologist, while teams at the other two sites sought referrals for behavioral and mental health care or relied on social workers with training in behavioral therapy.

As part of the multidisciplinary design, the programs engaged partners in the community—volunteers, social welfare agencies, food banks, homeless networks, faith groups—to complement the teams' care with a variety of supportive services. Allentown's program, the Lehigh Valley Super-Utilizer Partnership, integrated a faith-based component; its initial team leader was a "parish" nurse trained in a holistic "body, mind and soul" approach to healing that the team followed in its patient care. LVSUP also included a clergy member on its team to offer patients spiritual guidance and connect those interested with faith communities; it forged partnerships with the Parish Nursing Coalition and Congregations United for Neighborhood Action for further support. To promote self-worth and social interactions, LVSUP linked willing patients to a local Community Exchange that used "time banking," a practice in which individuals volunteered time and services to accrue hours that could be exchanged for assistance when they needed it.

Volunteers from local churches and the faith-based San Diego Organizing Project offered a spiritual aspect to the San Diego program, which also trained pre-med students, recruited by Dr. Rodney G. Hood, president and co-founder of the MultiCultural IPA, for data entry and weekly follow-up after patients completed the program. Other involved partners were health insurance plans, such as HealthNet, Care 1st Health Plan and Molina Healthcare, which not only referred patients for the PHII, but helped in case management and linkage to other community resources.

In addition to University Hospital, MCPN partnered with Aurora Mental Health Center for behavioral health services and with Together Colorado, a multi-faith, social justice organization that recruited patient graduates for advocacy work, encouraging them to share their stories and enlighten others about the shortcomings of the health system and the benefits of coordinated care. Truman's team, which had the advantage of being able to tap into a myriad of on-site offerings at the medical center including a weekly, open-air "healthy market," also worked with a homeless network in Kansas City to help find suitable housing for those with unhealthy living situations.

The programs differed as to whether they required weekly in-person home visits or operated with more flexible scheduling. At all sites, however, nurses and community health workers maintained regular contact with patients via phone calls and text messages. Patients were encouraged to call a team member with any concerns, particularly if a medical issue flared, and it was not unusual for them to call frequently and at all hours. This was a new experience for many who, despite frequent interactions with health care professionals in EDs and hospitals, remained distrustful of authority and the health system. After years of experiencing neglect, anger and hopelessness, many patients were stunned by the responsiveness of the care teams. "Everything I needed they brought me," said Gloria, 47, a former Bridges to Care patient and mother of six who fought her way back from a heart attack, stroke and depression. "I loved it!"

As teams found, dealing with the health system's toughest patients is demanding, frustrating and sometimes disappointing; the work requires empathy, fortitude and perseverance. As important as it was to recruit patients who were appropriate and could benefit from the programs, it was perhaps more crucial to find the right staff — people passionate about helping the underserved, comfortable with making home visits and eager to bond with patients.

"This work is very hard on people and it requires a lot of reflection," noted Dr. Shauna Roberts, Truman's former corporate medical director for quality who oversaw the center's super-utilizer program, Guided Chronic Care. "You have to do it because it feels like a mission or you can't do it."

Social Determinants of Health

Public health experts have long known that a person's overall health involves more than genetics, behavior and medical care—it encompasses living conditions, income, education, transportation, social support and numerous other factors outside an individual's control. These social determinants affect health risks and outcomes, and research shows that health is poorer among people living in communities with lower incomes, substandard housing, unsafe streets and inferior schools. Those are the kinds of neighborhoods where many of the super-utilizer patients in these programs lived, and not unexpectedly, these factors have impacted their health and well-being.

Consider southeast San Diego, home of the MultiCultural's PHII; studies show that people living there have a higher disease burden and a greater risk of dying from illnesses such as diabetes and heart disease than residents in higher-income parts of San Diego County. Despite the limited reach of the super-utilizer program, those working with the model have hoped that identifying the socioeconomic factors most detrimental to enrollees' health, and addressing them with suitable resources, might lessen the negative consequences of these social ills.

The site teams were unequivocal on this point: Home visits were "intimate" encounters to be carried out with dignity and respect for patients and families, regardless of whether a visit took place in a house, a room, a tent or a homeless shelter. When conducted with thought and care, these visits could provide unique insight into a person's daily struggles. Looking at environmental factors that influence health, such as the floor a person lived on, the nearest bus stop, the home's cleanliness, neighborhood safety, and the closest pharmacy and grocery store could convey a lot to a perceptive observer, team members said. Checking a patient's pantry and refrigerator could reflect diet and food security; seeing the family dynamics might suggest relationship conflicts.

Mobility & social comorbidities

	LVSUP	GCC	B2C	PHII	CCHP
Mobility difficulty					
% Bed bound, or needing help from people or equipment	68.2	35.1	31.8	71.5	66.9
Housing challenge					
% Living on street, shelter, or with friends/relative	21.5	21.0	7.0	13.3	24.5
Insufficient social support					
% Having limited or no social support	46.8	52.5	32.9	31.4	43.9

The Camden model emphasizes "trauma-informed care," which recognizes that past traumas can have a major impact on health and behavior. This approach recommends asking open-ended questions during interviews and giving patients the opportunity and freedom to describe their own hopes and goals. Linda Neal-Baker, a community client liaison with the Truman program, said she learned to "listen with intent"—that is, to be an active listener and concentrate on understanding a patient's predicament without being judgmental. To ease communication with non-English speakers, the programs all employed Spanish-speaking team members to work with Hispanic patients and additional staff to interpret for those who spoke other languages.

Due to their significant health issues, many patients in these programs lived with some disability—visual impairment, prosthetic limbs or reliance on oxygen, walkers or wheelchairs. In fact, in the Allentown and San Diego programs, more than 70 percent of participants reported having mobility limitations and thus restrictions in their physical activities. Having no car or lacking access to public transportation—common predicaments in low-income neighborhoods—aggravated the problem. To help patients with these types of issues, team members arranged delivery of prescription drugs, meals and other necessities; they also scheduled special medical transportation for physician appointments and critical treatments such as kidney dialysis. In some cases, fixes appeared simple, yet had a profound effect: Allentown staff installed a doorbell to the second floor apartment of a blind patient confined to a wheelchair so he would know when his transport or deliveries had arrived.

Despite good intentions, efforts sometimes fell short. After one severe snowstorm, several diabetic patients in Allentown missed their dialysis treatments and ended up hospitalized because of unreliable transportation or having no one to help them maneuver uncleared, snow-covered sidewalks. "Crises for these people occur when the system fails," remarked Dr. Abby Letcher, medical director of LVSUP in Allentown. "If we had planned ahead, we could have helped."

Finding a stable residence was a personal objective for some enrollees, and it could pose challenges or require a waiting period since affordable and low-income housing were limited in the four site communities. In Kansas City, which has a sizable homeless population, Truman team members said a few patients had been recruited at homeless shelters. All the site teams reported instances of meeting with patients at nontraditional venues, such as fast-food restaurants, libraries, front stoops, even crack houses.

Quality of life improved for many in the programs. The Allentown team helped patient Marco, a 61-year-old suffering from COPD, hypertension and the after-effects of a stroke, move from an Allentown motel to a bright efficiency apartment in a subsidized high-rise. The team also rallied to find and furnish an affordable apartment for Mike, a young man with kidney and heart disease who had been couch surfing and missing dialysis appointments before an injury sent him to inpatient rehab. Once he had the apartment and his conditions better controlled, he started to consider bigger goals—like a car and college. "He has golden plans, which he didn't have before we met him," said Lisa Cordero, the LVSUP nurse who worked with him. "It's so cool to see."

Having a roof over one's head wasn't always enough, however; some patients were barely hanging on because of other troubles. At time of enrollment, 40 percent said they had intermittent or little social support, and the emotional effects showed. The Kansas City team members described the unexpected reaction of one patient, a previously homeless man, whom they helped move into a comfortable apartment in a safe, tree-lined neighborhood. Although a social worker had taught him how to budget his finances and pay bills, he was accustomed to having so little that he grew anxious about the responsibilities associated with managing his money and residence. At one point, he contemplated returning to his former drug dealing trade. His health coach talked him out of it, but needed to stay in regular contact to boost the man's confidence and offer reassurance that he could handle his new life.

In Allentown, a patient almost had to forego the chance for a double lung transplant because she had no support network to provide necessary assistance after the surgery. The LVSUP team advocated for the woman, lined up relatives who promised to help her and even found the patient a church to attend. Unfortunately, the woman died before compatible organs could be found.

Such situations, often related to the consequences of poverty and social alienation, were not uncommon during the intervention, and they highlight the importance of having team members with diverse talents, experience and perspectives. It also points to the value of the "huddles" held regularly at all the sites so team members and community partners could share updates on patients, brainstorm creative approaches for seemingly intractable cases and offer one another moral support. The teams' insights served another purpose as well: educating providers about the typical obstacles—such as inadequate transportation, lack of day care, multiple jobs—that might be the reasons behind patients' missed appointments, rude behavior or failure to follow medical instructions.

"As a doctor, you don't see the holistic picture. You see noncompliance," said the MultiCultural IPA's Hood. "I learned how noncompliant the system was. Sometimes the social barriers are more important."

Behavioral and Mental Health Concerns

Despite their diverse backgrounds, many super utilizers bear a common burden: the scars of abuse, trauma, violence or addiction. These experiences, layered onto the challenges of chronic illness and poverty, can penetrate the soul and impact well-being. Not surprisingly, mental illness and behavioral health problems were pervasive among program participants and considerable obstacles to improved quality of life. Data collected by MCPN showed that 80 percent of patients enrolled in Bridges to Care had some behavioral or mental health diagnosis; anecdotal evidence from the other sites seemed to confirm this finding.

The Camden model proved especially useful in this arena: Seeing individuals in their home surroundings gave team members—the behavioral health experts, in particular—a clearer picture of the types of difficulties patients wrestled with regularly. A visit could expose problems such as hoarding, or depression in a harried single mom, but it also could reveal personal strengths conveyed through a well-kept residence or loving care for a pet. Each piece of information added to determining an accurate diagnosis and proper treatment.

"When we recruit patients from the ED we're only getting part of the story," said Erin Loskutoff, a nurse practitioner who served as a Bridges to Care team leader. "When we dig deeper, we find a tremendous amount of behavioral health needs."

Depression, anxiety, bipolar disorder, post-traumatic stress disorder, substance abuse and smoking were among the more common mental health and behavioral health problems seen among enrollees at all the sites. The Bridges to Care program, which partnered with the Aurora Mental Health Center, could offer therapy right away, while the other programs either found local specialists or relied on the expertise of their social workers. Treatment was not always welcomed, staff noted, because patients either were in denial or embarrassed by the perceived stigma of mental illness. However, staff found that starting therapy at home or having a team member accompany a patient to an appointment often eased entry into treatment, which could provide enormous benefits to individuals who were motivated and open to the care.

The team approach also allowed each staffer working with a patient to reinforce prescribed behavioral strategies. Members of one team described their tactics for dealing with a forgetful, disorganized patient: they all posted sticky notes throughout her home to remind her of tasks she had to do. For another patient suffering from anxiety and panic attacks, team members continuously emphasized deep breathing exercises as a coping mechanism and adjunct to talk therapy.

"Most of our patients are dealing with so many social and physical stresses. Most have had a mental health issue that was unidentified," noted Eric Gaugh, a psychologist with the Truman intervention. "This might be the first time they've formally been introduced to the mental health system."

One patient, Wallace, recruited by Jamilah Zahir, a licensed practical nurse at Truman, had multiple burdens at the time of enrollment in GCC: anti-social personality disorder, bipolar disorder, anxiety, depression, inability to control anger and cocaine addiction. "On paper, he was the client anyone would dread having to work with," Zahir said. "I never treated him as any of those diagnoses. I treated him like a human being with a heart and soul."

Wallace completed drug rehab, and GCC team members bolstered his recovery with medical care, social support and sessions with a clinical psychologist. Despite some setbacks, Wallace graduated from the program and eventually learned to manage on his own. "They gave me what I needed, but they made me do it," he recalled. "It was scary at first, but they always said, 'You can do it!'"

The San Diego program did not have a behavioral health specialist on its team, but did not neglect the mental health needs of its enrollees. Patient Howard became one of the team's proudest success stories. The day team members met Howard, he was drowning in depression, spawned by a multitude of serious health problems. He and his wife had always been the pillars of their family, the ones others counted on for aid. Now that he was ill, the couple felt overwhelmed and didn't know where to turn. The PHII team helped the couple acquire necessary medical equipment, linked them to food resources and provided information on Howard's health conditions and medications. Most of all, team members called and visited often; their encouragement and support boosted his self-worth and helped to lift him out of the darkness.

"They cared," he noted. "They showed me I didn't have to just sit around."

Graduation: When to Let Go

From the start of patient enrollment in January 2013 to the end of June 2015, the four programs served a total of 1,068 individuals,[5] fewer than half the 2,425 participants originally projected. However, staff "touched" many more people, who either failed to complete enrollment requirements or dropped out early. Overly ambitious enrollment goals eventually were scaled down because it became obvious by the second year that signing up, engaging and managing patients took longer than anticipated and teams struggled with deciding when patients should graduate. "It takes a tremendous amount of time to do outreach," noted Allentown's Letcher.

Team members encouraged patients to embrace change—even small changes, such as eating more vegetables, switching to brown rice from white rice or broiling foods instead of frying—that could lead

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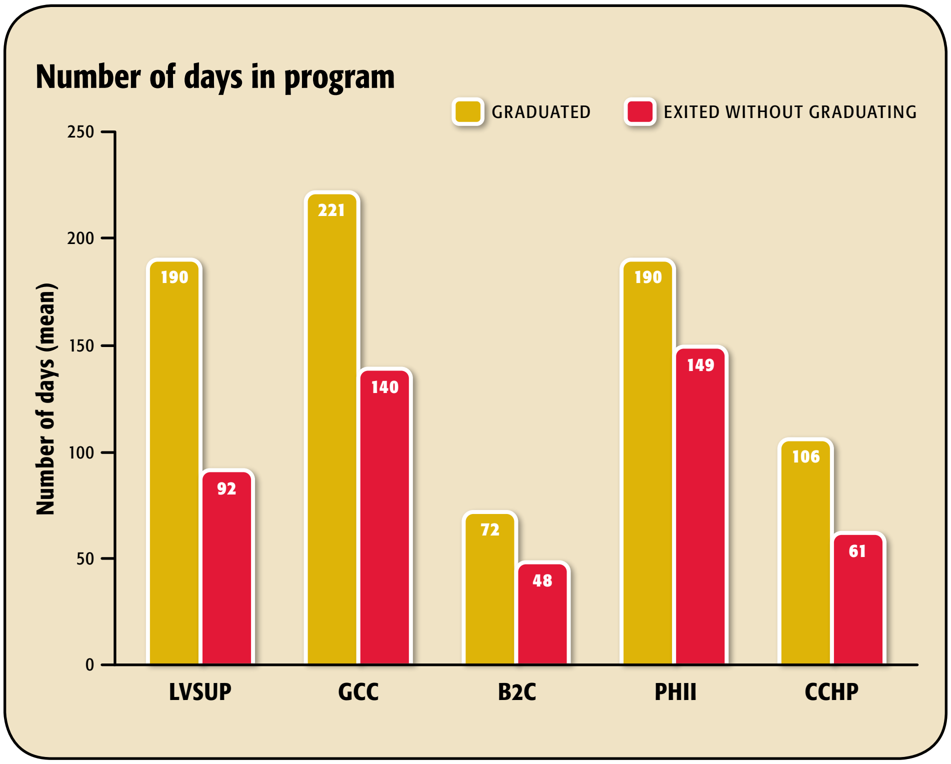
[5] Of the 1068, 49 were still enrolled when the grant expired on June 30, 2015, and continued to receive care. These 49 were excluded from all the charts shown in this report.

to better health. Goals often evolved as patients developed greater confidence and could range from staying sober, finding secure housing and learning to manage finances to taking cooking classes, starting an exercise routine or merely building friendships to combat loneliness.

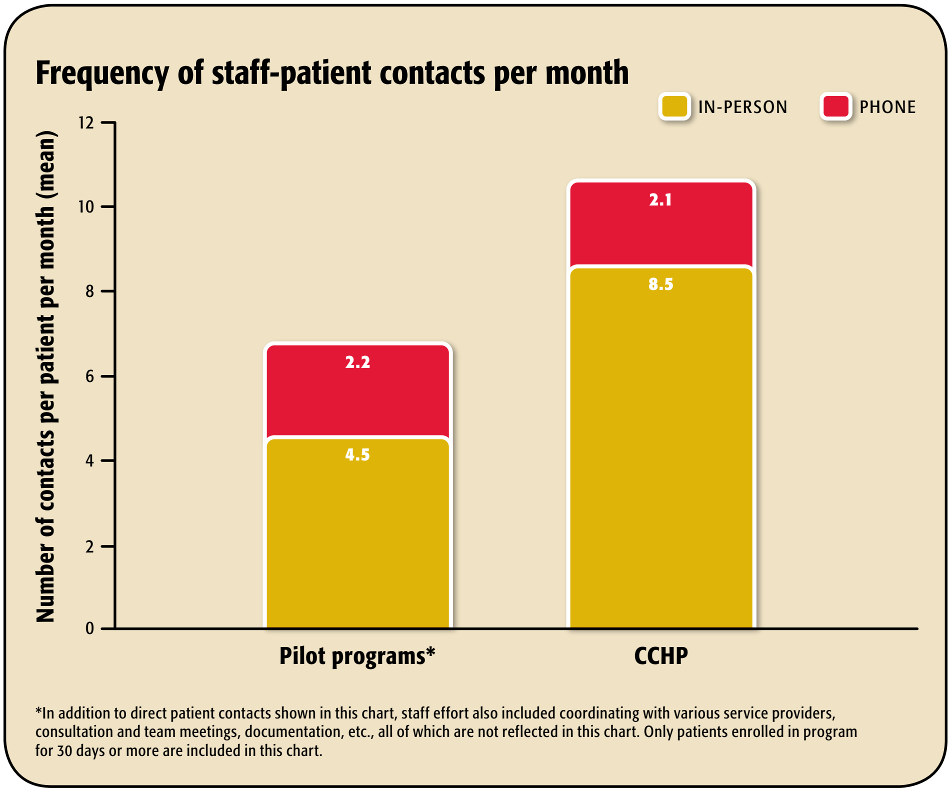
Camden's model calls for two to three months of intervention, but only Aurora adhered to a 60-day, eight-visit minimum care plan, and even that program held onto some patients longer than the original plan. On average, participants who graduated were in the programs three to six months; they typically had at least two weekly team encounters or received 1.3 hours of service. Of those served, nearly 700 graduated or transitioned to other programs. Team members made valiant attempts to re-engage patients who lost interest or simply fell off the radar, but sometimes efforts failed or patients disappeared. "Even if patients weren't ready for us to move them to graduation, there was a value in the coordination of care and in showing them, 'You are not forgotten,'" noted Cristina Ramirez, a Truman social worker.

To wean patients off reliance on their teams, the sites adopted a "step-down" process and checklist for graduation; however, patient care plans were so individualized and goals so varied that there was no clear, standardized way to determine "success." Staff found that some patients simply needed more time to stabilize. San Diego's PHII kept one patient in care for nearly a year, supporting her through the effects of lupus, rheumatoid arthritis and hip replacement complications. "I wasn't comfortable discharging her until she was healed," remarked Montrula Donaldson, the program's nurse case manager.

Sometimes, just when team members thought a patient had met his/her goals, implemented changes to improve his/her health and learned how to navigate the health highway, a setback would occur or the patient would suddenly become

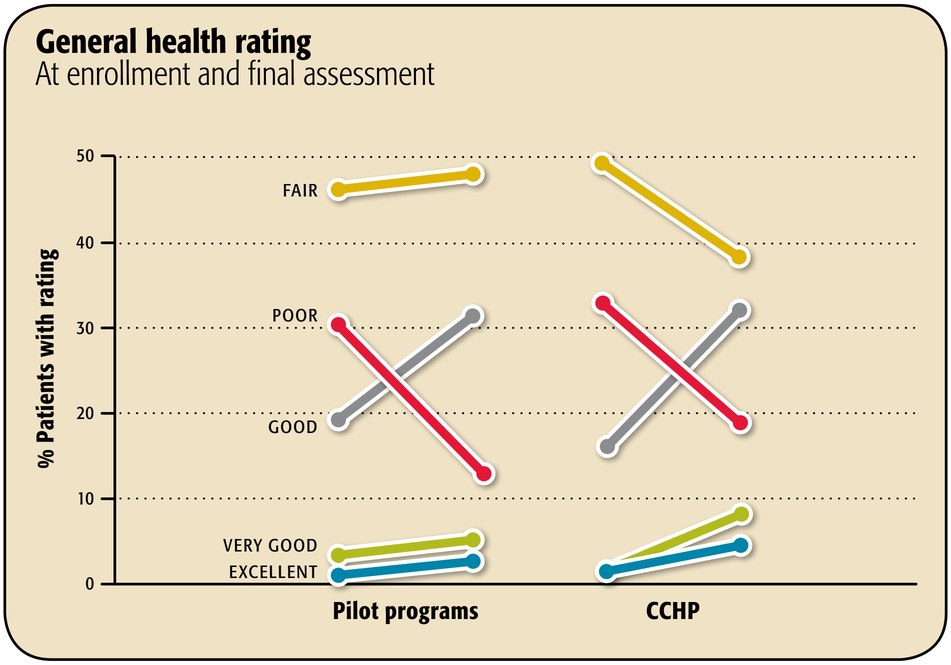


Number of days in program



Frequency of staff-patient contacts per month

*In addition to direct patient contacts shown in this chart, staff effort also included coordinating with various service providers, consultation and team meetings, documentation, etc., all of which are not reflected in this chart. Only patients enrolled in program for 30 days or more are included in this chart.


General health rating
At enrollment and final assessment

anxious and frightened about services being cut off. That is why Truman staff refused to set time limits on participation. "We don't think in terms of months," Cristina Ramirez said. "We're living in a broken system. We're just realistic."

As time went on, however, staff at all the sites grew more adept at recognizing when a patient had progressed and was ready to graduate. Teams made certain patients were prepared to manage their health care on their own, knew how to communicate with health professionals and had established ties with community resources for the future. Some patients continued behavioral care therapy, while others moved into different care coordination programs or long-term care facilities. The interventions all aimed to get enrollees connected with a primary care provider or at least have a medical home where they could go instead of the ED.

Each site had its own way of "letting go." Big celebrations, like the one in Aurora, were *not* the norm, but teams did make an effort to acknowledge the patients' achievements. In Allentown, team members preferred to use the word "commencement" instead of "graduation" to emphasize that patients leaving the super-utilizer program were beginning a new, healthier phase of their lives. Gathering at the patient's home or sometimes at a restaurant, the team would present the departing individual with a special certificate and take a group photo.

Truman also gave its graduates certificates and recognition at a small party; San Diego experimented with a big send-off, but it was so time-consuming to plan that the team switched to individual farewells. In addition to the health equipment and health-related knick knacks supplied during the intervention, Bridges to Care gave its graduates wristband flash drives that stored their medical information. Staff, or volunteers, at the various sites followed up with graduates monthly for at least the next three months to see how the former patients were faring and to recommend other providers or programs if needed.

"It's hard to change people's ways," said Rene Ramirez, an Aurora health coach. "We provide them with everything, but we say, 'It's up to you.'"

The Patients' Experiences

Health care today has been evolving from a system that centers on physicians and their treatment of disease to one that revolves around patients collaborating with physicians in treatment decisions. It is a departure from the age-old approach where "doctors know best" to the concept that patients are best at judging whether the delivered care is responsive to their needs and whether the outcomes are satisfactory.

The four super-utilizer programs were designed to be patient-centered and to deliver coordinated care. The site teams not only inquired about enrollees' diagnoses and medical histories, but were intent on hearing what was important to patients—what *patients* wanted to achieve to improve their health. In the relationships between patients and team members, there were striking revelations: Some patients said it was the first time any health provider had shown true empathy, interest and concern for the "person" named in the medical record.

Because the intervention targeted individuals with high hospital and ED utilization, it was important to track health outcomes to determine whether changes in health had occurred. The sites administered the Centers for Disease Control and Prevention (CDC) Healthy Days Measure, a tool that assesses perceived physical and mental health over time, and it indicated a general trend toward health improvement across all four sites. At enrollment, 77 percent of program participants reported their health was "fair or poor"; among participants who graduated, the proportion reporting "fair or poor" health dropped to 57 percent. Those reporting "poor" health declined from 29 percent to 11 percent, and the segment reporting "very good or excellent" health doubled from 4 percent to 8 percent.

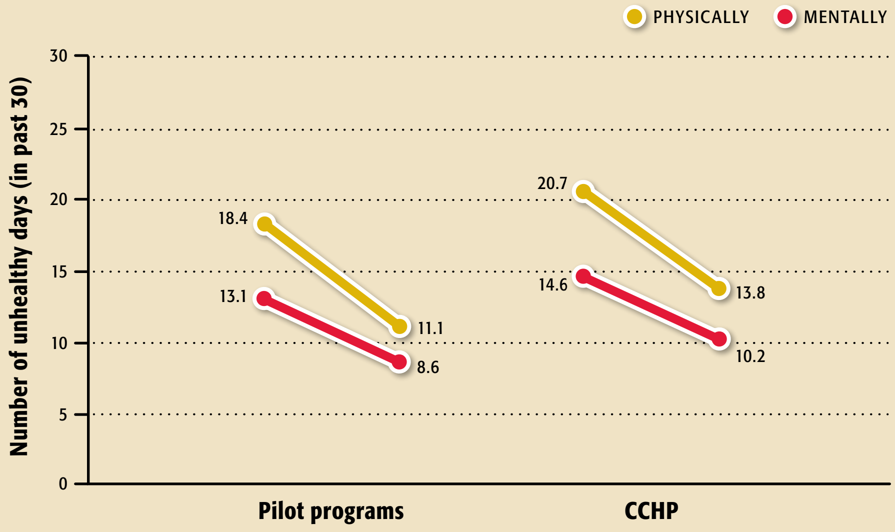
Improvements also were seen in the participants' reporting of the number of days in the past month feeling physically or mentally unhealthy. From the time of enrollment to exiting the program, participants noted an average drop of five to seven unhealthy days in a month. Findings showed these improvements typically occurred in the first month and lasted throughout the intervention.

As already noted, deterring unnecessary ED visits and hospital stays was a major objective, so emphasis was placed on securing patients a medical home or regular primary care provider (PCP). Individuals in Bridges to Care were able to receive primary care at an MCPN clinic; the other three sites also had providers available. For people already with PCPs, staff focused on enhancing those relationships and ensuring providers understood the patients' complex needs. The intervention encouraged patients to rely on their PCPs for ongoing care and problems. The teams' patient-centered care was so well-received that some graduates opted to remain with the providers involved in the intervention.

"Erin takes the time to ask me questions and find out what's bothering me," noted Amy, a former Bridges to Care enrollee who traveled from the west side of Denver to Aurora, on the east side, so nurse practitioner Erin Loskutoff could continue to monitor her lung disease and diabetes. "I just adore her!"

Days (in prior 30) feeling mentally unhealthy

At enrollment and last assessment



Reflections

The super-utilizer project demonstrated in fewer than three years the benefits of a care delivery model that is patient-centered, well-coordinated and collaborative. As with any new approach, there were hurdles to overcome and teams at the four sites experienced many challenges, not only due to the complexity of the patients, but also to the still-fragmented, competitive and often rigid nature of the health care system. The following describes some of the lessons learned.

DATA SHARING AND LINKAGES

In 2010, the Camden Coalition of Healthcare Providers established the Camden Health Information Exchange, a data-sharing infrastructure that gives participating providers and organizations in the Camden area secure access to medical information. Created to improve Camden's delivery of care, the data-sharing effort promotes coordinated care and reduces expensive duplication of services. Included in the exchanges are hospitals, medical practices, laboratory and radiology groups, social services agencies and other health care providers and organizations.

Such sharing of clinical information is a continuous challenge in the health care world and it took the Camden program years to set up the exchange; with a relatively short time span to launch the super-utilizer intervention, the four program sites had varied and limited experiences with data sharing. Before the demonstration project, clinical staff at the University of Colorado Hospital in Aurora had done its own informal "hot spotting" to try to prevent hospital readmissions for certain high-need patients. Doctors there were familiar with MCPN and its quality reputation and thus were open to working with the organization when it received the HCIA funding. However, all involved said it took considerable legwork and relationship-building to situate MCPN personnel inside the emergency department and allow them access to patient information.

Because the arrangement only existed with University Hospital, it remained difficult to obtain medical information for Bridges to Care enrollees who might have gone to other area hospitals for services. Still, most agreed that this partnership was a promising step. Dr. Roberta Capp, an assistant professor in the Department of Emergency Medicine at the University of Colorado School of Medicine, said the cooperative effort helped to eliminate barriers and de-fragment the system for both patients *and* providers. "We've created a huge opportunity for coordination of care," she noted.

In Kansas City, where the super-utilizer program was embedded in the hospital, the Guided Chronic Care team had access to the medical center's database and records, but that information was not part of a larger data-sharing community. The Allentown and San Diego programs were not privy to any formal data-sharing system, though their staffs nurtured relationships with hospitals, social service organizations and other groups for patient and service referrals. Over time, the LVSUP proved its effectiveness in managing super utilizers and two separate hospital networks allowed the agency to retrieve hospital data on patients enrolled in the program.

The San Diego team was particularly successful in its joint efforts with health care practitioners, case managers and health insurance representatives. They held weekly conference calls, in which they shared information about individual patients' medical and social circumstances. During the course of the project, the PHII created strong ties with three health plans. "Our program is getting recognition and health plans are seeing we can save them money with their most costly patients," Hood said.

To develop trust, identify shared interests and ease competitive tension, the program directors stressed the importance of reaching out early and often to a wide range of stakeholders: Medicaid and other state officials, local governments, hospitals, health plans, provider groups, community services and other care-management programs. To make the most efficient use of time and resources, staff advised honing in on organizations that share a similar vision.

TEAMS

The heart and humanity that the teams brought to patient care were central to the interventions. However, hiring for the multidisciplinary teams ran into some snags early on, as programs found that some people were not suited to the home visit model and others simply were not the right fit. It took time to establish a rhythm and team culture that were comfortable for all. Staff agreed that having unified, passionate teams comprised of strong personalities was both an asset and a challenge. Because staff cared so deeply about their patients, emotions could run high—especially since perspectives on care varied. "The RNs want to fix things right away, but a social worker sees things differently," noted Gaugh, the Truman psychologist.

By the second year, the programs hit their stride and team members learned to work together creatively and to respect and embrace the diversity each brought to the group. Hood, of San Diego's PHII, attributed much of his program's success with patients to the dedication and cohesiveness of his team; he noted that the PHII team members scored high on a Rutgers survey gauging employee satisfaction.

"It's not about the politics," said Montrula Donaldson, the PHII nurse manager. "It's all about helping the patients."

SUSTAINING THE PROGRAMS

Right from the start, staff at the four sites knew that in addition to developing and implementing their interventions, they would be exploring strategies for maintaining the super-utilizer programs after the federal grant expired in June 2015. By the third year, the sites had made considerable progress toward sustaining their programs, but still faced uncertainty in funding streams due to the ever-changing health care climate. While the programs could document improvements in patients' lives and demonstrate benefits of the intervention, they often fell short in producing solid statistics on cost savings to secure commitments from potential funders. Worries about the future lowered morale among the teams, and two sites experienced staff attrition in the project's last two years. Despite the unpredictability, dedicated staff kept the programs functioning at full capacity and forged ahead with efforts to obtain financial and community support.

Two sites succeeded in attaining the resources to continue – and even grow — their super-utilizer programs: MCPN in Aurora and the MultiCultural IPA in San Diego. In Colorado, MCPN has expanded its Bridges to Care program to include partnerships with two more area hospitals. The agency received four grants – two from nonprofit organizations and another two from health care foundations—and now has community health workers engaging eligible patients at three hospitals.

By the time the HCIA grant ended, Bridges to Care had enrolled nearly 500 patients (and "touched" many more). In the subsequent nine months, staff recruited several hundred more. The teams have remained intact and continue to conduct home visits and to integrate behavioral health care, a service that has proved to be one of the program's major assets, noted Heather Logan, who still oversees the intervention. Some changes have been instituted: MCPN altered the time frame for working with super-utilizer patients. During the course of the three-year project, the Bridges to Care teams stuck closely to the 60-day limit recommended by the Camden group. MCPN has since moved to a tiered model of care—30 days, 60 days and 90 days—that is more tailored to patient needs. Logan said the enhanced system allows patients who can be stabilized quickly to graduate earlier and receive follow-up care from a primary care provider; it offers a longer period of home visits and services for more fragile individuals.

MCPN's own analysis, performed with University Hospital, found that Medicaid patients enrolled in the Bridges to Care demonstration netted $13 million in hospital cost savings. To line up more consistent revenue for the program, MCPN and its partners have focused advocacy on state policymakers, urging them to authorize reimbursement for health care services provided through the super-utilizer model. Logan is confident the action will be approved. "We really believe in it, and our leadership believes in it," she said of Bridges to Care.

The MultiCultural IPA in San Diego is seeing similar promise with its super-utilizer program. The organization has broadened its patient referral base through contracts with its own physicians, another IPA and a local hospital. It ended the intervention in June 2015 with more than 150 patients and has steadily enrolled more; Rodney Hood, president of the MultiCultural IPA, hopes that talks with local insurance plans will lead to additional contracts and thus more patients.

The PHII team has added a clinical specialist and remains as committed as ever to the super-utilizer intervention. The program has received several grants and financial backing from the foundation created by the MultiCultural IPA's physician members. One grant has allowed the PHII to beef up its volunteer component. A new volunteer coordinator has targeted his recruiting toward students from the University of California, San Diego, who are going into the health professions and are interested in working with the underserved. The volunteers are trained to serve as patient advocates and are included as members of the care team. They not only assist with office duties and calls to patients, but provide additional home visits to enrollees requesting more companionship and support. Hood said the MultiCultural IPA also has adopted the PHII home visit approach for a special grant-funded initiative aimed at reducing heart attacks and strokes among African-American patients through better blood pressure control.

Like Aurora, the San Diego staff has modified the duration of care, but less formally. The PHII never followed a strict time table for patients in the super-utilizer program and has further liberalized its policy. Hood said some patients are admitted earlier—before they meet the criteria set for the original demonstration—while others with little social support may stay in the program for six months or even longer. Hood and his team believe it makes more sense financially to hold onto unstable patients. "It was unrealistic to think that we'd be able to turn these people around," Hood said. "It may be cost-effective in the long run to keep them in the program."

The NHCLV in Allentown, Pa., and the Truman Medical Centers in Kansas City were less successful in procuring the funding and assistance necessary to keep their super-utilizer programs viable. In Kansas City, the Truman teams have disbanded and most of the clinical and support staff have transitioned to different projects or left the organization. Others are taking what they learned from the Guided Chronic Care program and applying it in new ways: the intervention's social worker has moved to Truman's Home Health program to work directly with its super-utilizer patients, while two former team members – the project director and a licensed practical nurse– are investigating how to assimilate aspects of the demonstration into other practice areas at Truman.

Allentown's NHCLV, which is a relatively small organization, has managed to hold onto half its super-utilizer team – a nurse and community health worker, who still make home visits and receive some backup from the center's social worker. The duo basically serves super utilizers from NHCLV's patient population and others being followed from the original demonstration. Longer term, however, the intervention is in jeopardy, said medical director Abby Letcher. A contract with a Medicaid managed care organization (MCO) was due to expire and plans to sign with several other MCOs never materialized. Likewise, a hospital system that had considered partnering with NHCLV reneged on the arrangement.

Still, participating in the HCIA project, working closely with super utilizers and seeing the positive changes in people's lives had a dramatic impact on the health professionals involved, Letcher noted. NHCLV staff have made a commitment to trauma-informed care and thus are reminded daily of the intervention's legacy.

"It's informed a lot of our clinical practices," Letcher said, referring to the super-utilizer project. "It was life changing for some of us—and I'm not exaggerating."

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