From siloed systems to ecosystem

The evolution of the Camden Coalition's complex care model

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Authors' note

While discussions about the social determinants of health are featuring more prominently in the nation's current health policy conversation, many organizations, like the Camden Coalition, have been working for years to understand and address this intersection. In 2016, we created the National Center for Complex Health and Social Needs as a way to build a field that addresses what we have come to call complex care. The field has yet to discover the full set of solutions that bridges the gaps between medicine, behavioral health, public health, and social services to guarantee better health and well-being, but recent discussions about "social determinants" provide new pathways of hope and inquiry. In the spirit of reflection and continuous learning, we thought it was timely to share the story of the Camden Coalition's 15-plus years developing a care model that is centered around both health and social complexity. In this piece, we describe the phases of our model as we addressed challenges and tested new solutions. We hope it encourages others to start, continue, persist, or expand this work. For more information about the Camden Coalition, visit www.camdenhealth.org.

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Background

In 2002, before the Affordable Care Act and healthcare buzz words like "value-based care," "bundled payments," and "social determinants of health," Dr. Jeffrey Brenner, a family physician in Camden, New Jersey, brought together an informal breakfast group of like-minded clinicians to imagine a better healthcare system.

Healthcare hotspotting is the use of data to identify and engage patients who are outliers in the healthcare system—usually in terms of cost or utilization. The process reveals patterns within data that point to areas of system failure where individuals' needs are not being adequately addressed.

This informal group grew into a citywide coalition of hospitals, primary care and social service providers, and community representatives, eventually calling itself the Camden Coalition of Healthcare Providers. Clinical observation and data analysis guided our work together, giving rise to the practice of "healthcare hotspotting." We learned that the highest-need patients had the most frequent emergency room (ED) visits and hospital admissions. And as is common across the country, our internal analysis showed that one percent of patients represented 30 percent of hospital costs in Camden. Further analyses found that many of these patients not only habitually frequented the ED and hospital inpatient wards for what were considered easily treatable conditions, but were also often seeking care for advanced issues that could have been prevented if diagnosed and treated earlier.

In 2007, this early work of coalition-building and data analysis evolved into a pilot care intervention, which we now call the Camden Core Model, funded by the Robert Wood Johnson Foundation through their New Jersey Health Initiatives. Since then, we have worked with thousands of people from the Camden region struggling with chronic health issues, addiction, mental health challenges, poverty, unemployment, housing instability, child welfare issues, and criminal justice system involvement. Alongside pathbreakers building programs for home visitation, care management, and hospital-to-home transitions[1-3], we focus solely on serving people facing the most complex medical and social challenges using an approach we call complex care.

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Our work on the ground over the past 12 years has given the Camden Coalition a deep understanding of the challenges and barriers that make success difficult, especially around the burdens of discrimination and inequity that were in place long before many of our patients were born. With that in mind, we have continually innovated, moving into new models of care and refining our approach and theory of change based on that experience.

The healthcare field is now discussing social determinants of health, the underlying conditions that affect health, differently than it did back when the Camden breakfast group started meeting. Given this, we thought it would be useful to reflect on how our approach has evolved in light of the significant challenges we have encountered serving our clients in Camden, and the opportunities presented by this emerging conversation.

We are quite sure that we have yet to discover the full set of solutions that bridge the gaps between medicine, behavioral health, public health, and social services to guarantee better health and well-being. But there are many pathways of hope and much to be learned. The story of the Camden Core Model's evolution is testament to our willingness to iterate and change based on what we learn. We have broken our story into four phases, which are described here.

Complex care addresses the needs of people who experience a combination of medical, behavioral health, and social challenges that result in extreme patterns of healthcare utilization and cost.

Complex care works at the personal and systemic levels, coordinating care for individuals while reshaping ecosystems of services and healthcare. It is person-centered, equitable, cross-sector, team-based, and data-driven.

Phase 1: Directly providing healthcare and building citywide partnerships (2007–2011)

In its earliest form, the Camden Coalition's care model was a partnership between a nurse practitioner, a social worker, and a part-time community health worker.

We called this partnership our "Care Team." Through home and community-based visits, the Care Team directly provided prescribing and treatment for individuals experiencing frequent emergency department or inpatient utilization. The Care Team's broader goal was to figure out what was driving patients' emergency department and inpatient utilization and, when appropriate, redirect patients to primary care and specialists. The Camden Coalition's work during this time was featured in a 2011 New Yorker article by Atul Gawande, which brought national attention to our intervention and healthcare hotspotting.[4]

Refining and strengthening the Care Team structure and role

Providing home-based care allowed us to more directly meet our patients' healthcare needs. However, because patients were receiving a type of concierge home-based service through our nurse practitioner, they did not want to visit providers' offices. We realized that we were creating a new silo by duplicating services that were available through a more stable relationship with primary care practices or appropriate specialists. Thus, we decided to move from a prescribing-treating relationship to a more coordinating and supportive role that worked alongside office-based primary care providers. We substituted the nurse practitioner with a registered nurse to lead the Care Team since prescribing was no longer part of our model.

Becoming more data-driven through the Camden Coalition HIE

At that time, we were also identifying patients almost exclusively through referrals, in part through the connections we made as part of our citywide Camden Care Management Meetings. While the referral process was useful in developing very strong partnerships, it did not consistently identify the patients who were incurring high utilization and high healthcare costs, which was the patient population we wanted to serve.

We also believed duplicative services and higher costs were at least partially related to hospital and other outpatient providers'

inability to view clinical information about the care that their patients were receiving from other facilities. Therefore, we established the Camden Coalition Health Information Exchange (Camden Coalition HIE), a web-based portal directly integrating real-time alerts and patient medical information, such as admission and discharge information, labs, and radiology reports from the city's major hospitals. By raising awareness of the need to see data from other providers and building relationships with regional health systems, we established the Camden Coalition HIE as a centralized patient data repository for care providers in Camden.

We quickly realized that the utilization data housed in the HIE, if analyzed with patient complexity in mind, offered a powerful alternative to word-of-mouth patient referrals. Using utilization as a proxy for high healthcare costs allowed us to conduct healthcare hotspotting more efficiently. The Camden Coalition HIE has become central to our ability to identify patients in real-time who need more intensive care management.

Phase 2: Using healthcare hotspotting to find patients and adjusting the model to suit patient needs (2012–2013)

The second phase of our care management work continued to focus on home and community visits.

Our ultimate goal was to reduce hospital admissions by supporting the patient in finding ways to best manage their health conditions, engage in preventive care, and develop a stable relationship with primary or specialty care. We sought to appropriately navigate patients away from the hospital and address psychosocial factors.

Refining the healthcare hotspotting process

In this second phase, we refined our healthcare hotspotting process and began to strategically use Camden Coalition HIE data to institute a triage methodology. This real-time patient identification was a unique component of our approach at the time, given that most other approaches used retrospective claims data to identify patients.

Camden Coalition staff reviewed all admissions at local hospitals to find patients who, based on our experience, were more likely to be in need of the kind of care management that the Camden Coalition offered. We started using the criteria of high hospital usage coupled with social and medical complexity. Specifically, we sought to mitigate hospital use by delivering care management only to patients who presented with both medical and social complexity, including two or more chronic conditions and two or more additional barriers that might include: polypharmacy; lack of social support; housing instability; active drug use; physical disabilities; language barriers; and mental health conditions. At this point in time, some referred to these patients as "super utilizers" or "frequent flyers."

During this period, we became much more effective at identifying patients who might benefit from care management and navigation services and excluding patients that we knew would not benefit from our intervention. Our exclusion criteria became patients living in a nursing home or assisted living facility, since these patients receive all of their care at their facility; individuals experiencing dementia or Alzheimer's because patients with these conditions do not have the capacity to care for themselves or participate fully in the intervention; and those receiving intensive care management services from another agency. We also excluded

patients with certain diagnoses such as cancer because the diagnosis itself would drive most of the patient's hospital visits. This daily triage process continues today at the Camden Coalition.

Using the Health Care Innovation Award to test changes to our approach

These were the early days of getting ready for Affordable Care Act implementation, and our experience was that most primary care offices were not set up to support the patients that we brought to them. Although most clinicians we interacted with were committed to caring for our population of clients, they were operating in practices that did not have the care management or social work support needed to address their patients' level of medical and social complexity. In addition, the financial model for primary care still left clinicians with very little time for patients. Treating complex medical needs was difficult to do in a single appointment, and addressing social needs in that same appointment was nearly impossible. The financial model of primary care continues to be a major challenge for our patients and their hard-working clinicians.

Amidst the buzz of "healthcare homes" and the promise of new resources for primary care, we sought to develop a strategy to navigate patients to a permanent relationship with primary or specialty care and graduate patients from our intervention after some of their most immediate social needs were addressed. We received support through a Health Care Innovation Award from the Center for Medicare and Medicaid Innovation (CMMI) to test a shorter-term intervention, modified to last an average of 90 days and scaled to serve up to 800 people in a 3-year period. We wanted to limit the number of weeks that our Care Team engaged with patients because longer engagements did not seem to increase the likelihood of creating stable connections to primary and specialty care. Our Care Team made it clear to patients that this was a short-term intervention designed to help them meet their goals and was not a permanent care management model. The premise of the short-term intervention was that navigating back to health care was an important aspect of meeting our patients' needs.

The Health Care Innovation Award also allowed us to expand our staffing. We created a second care team so we could serve more patients and better attend to their needs. Each Care Team included an RN or LPN paired with a community health worker. The two teams were supported by a social worker and housing specialist who provided their expertise as needs arose. The RNs and LPNs were responsible for engaging patients while they were in the hospital, and the full care team served patients after discharge.

We sought to navigate patients to a permanent relationship with primary or specialty care.

Phase 3: Expanding the intervention and broadly sharing our knowledge (2014–2017)

In 2014, the Care Teams continued to conduct home and community visits and accompany patients to other meetings related to the management of health and social needs.

Care Team members went with patients to their meetings and appointments for primary care; helped with applications for public benefits like food stamps; and provided referrals to social service and housing agencies. They also arranged medication delivery in partnership with local pharmacies, and coordinated care among providers.

Adding a staff psychologist

Because of our patients' mental health needs, we partnered with Rutgers University Behavioral Health Care to add a psychologist to our staff. The psychologist evaluated and coordinated care for patients with significant mental health and addiction issues and gave advice to Care Team members for patients with less significant behavioral needs. The psychologist also provided formal training for Care Team staff and community partners.

Forming a hospital bedside enrollment and engagement team

Until this point, we primarily focused on working with patients after hospital discharge and within the primary care setting. This meant that there were missed opportunities to begin relationship building and goal setting while individuals were still admitted to the hospital, as opposed to waiting until patients were discharged. We decided to add two staff members who were solely focused on working with patients while they were in the hospital. These staff enrolled patients into our model or met with patients who were already enrolled but had re-admitted. While this added a layer of complexity because it meant that our hospital-based team would need to hand off the patient to our community-based team, it increased our ability to enroll patients and build relationships within the local hospitals. It also allowed our community teams to focus on attending home visits and accompanying patients to services within the community. In the end, the change allowed us to become more efficient, gain expertise about how to engage patients in different settings, and strengthen our partnerships with local health system staff.

Building a Housing First program

As our Care Teams continued their community work with an expanded emphasis on social supports, housing surfaced as a major, if not the most significant, barrier to health and stability for our clients. Our data analysis showed that homeless patients had worse outcomes and were less likely to graduate from our program. But wait lists for housing were long and shelter beds were scarce. Simply navigating homeless patients to social services was not helpful, since the services our patients needed were unavailable and the primary care providers we were connecting our clients to were unable to address their housing problems. To fill the gap, in 2015 the Camden Coalition launched a Housing First program, a national model aimed at ending homelessness. A Housing First approach meant that we could help our patients stabilize their housing situations by moving them into permanent housing and providing support services without preconditions such as sobriety or mandated treatment. By mid-2015, the Camden Coalition had received 50 vouchers from the state of New Jersey, which provide market rate payments for housing for up to 15 years. We housed our first patient in November 2015, and by the end of 2017, 39 patients had been housed through Housing First.

Unit availability and landlord willingness to take on these tenants were — and still are — the major limitations in our ability to get patients into permanent housing. Furthermore, we found that legal issues often complicated the use of housing vouchers, and many of our patients were dealing with court matters related to issues such as unpaid child support and other municipal fines and fees that, although civil in nature, could result in jail time. The prevalence of legal barriers in the patient population led us to another insight: the need to clear up legal matters that were excluding people from housing and other benefits. As a result, we began exploring how to build a Medical-Legal Partnership at the Camden Coalition.

Connecting patients to primary care after hospital discharge

Our Care Teams also observed that patients were having trouble being seen by a primary care provider within a week of hospital discharge. Despite the Affordable Care Act's financial incentives available for primary care, most practices in the City of Camden had limited bandwidth for significant organizational change and almost none had enough social work support. Drawing on what we learned serving our patients, we launched the 7-Day Pledge in 2014, a collaborative approach to insuring primary care follow up appointments within seven days of hospital discharge. We knew that the primary care providers' existing workflows were not structured to provide appointments within just a few days, so we worked alongside them to co-design a new process that would ensure the availability of timely

> Patients who saw a primary care provider within seven days had fewer hospital readmissions than patients with less timely or no follow-up.

follow-appointments. The 7-Day Pledge became our signature clinical redesign initiative, allowing us to strengthen our relationships with primary care providers throughout the Camden area. The results of this program were published in January 2019 in JAMA Network Open.[5] We found that patients attending a primary care follow-up appointment as part of the 7-Day Pledge had fewer 30- and 90-day readmissions compared to patients with less timely or no primary care follow-up.

Codifying and sharing lessons and knowledge from our work

After almost ten years of working on the frontlines of healthcare delivery with the most complex patients, we began to synthesize key lessons from our care management and coalition-building work.

Partnering with researchers to conduct a randomized controlled trial

As we refined our approach, we wanted to learn more about how our model could affect patient outcomes. Simultaneously, the Camden Coalition was becoming increasingly seen as an innovator in care management, which led other organizations to become interested in our work. Given that the evidence base for care management interventions did not focus on people with complex needs and there were few randomized controlled trials testing care management interventions for the population we serve, we partnered with researchers from MIT's Abdul Latif Jameel Poverty Action Lab in 2014 to investigate the impact that the Camden Core Model has on patients' readmission rates. We anticipate sharing the study results when they are available.

Camden Coalition's 16 care domains

The **Camden Coalition's 16 care domains** are the areas in which we work on behalf of our patients. Patients set their own goals as part of the Camden Core Model, and we use the care domains to help organize the work that needs to be done. The care domains are:

- Addiction
- Advocacy and activism
- Benefits and entitlements
- Education and employment connection
- Family, personal, and peer support
- Food and nutrition support
- Health maintenance, management, and promotion
- Housing and environment
- Identification support
- Legal assistance
- Medication and medical supplies
- Mental health support
- Provider relationship building
- Reproductive health
- Transportation support
- Patient-specific wildcard (i.e., patients' unique needs that do not fit neatly into any of the other categories)

Developing the COACH framework for patient engagement

We learned that our patients seemed to do better when they developed what we call "authentic healing relationships" with our Care Team — a secure, genuine, and continuous partnership between the Care Team Member and the patient. Our knowledge of the techniques and practices that worked best with patients, including authentic healing relationships, evolved into what we now call COACH. This five-part framework trains staff to problem-solve with patients to effectively manage their chronic health conditions and reduce preventable hospital admissions. Once the Care Teams were routinely practicing COACH, we worked with researchers from PolicyLab at the Children's Hospital of Philadelphia to develop a COACH manual that outlines the approach and standardizes how we use it with our patients.

Solidifying our care planning approach and launching My Resource Pal

During this time, we also developed a care planning toolkit which captured, synthesized, and documented Care Team members' individual knowledge around how to implement our 16 care domains. This process allowed us to standardize the methods and resources that staff use over the course of the Camden Core Model and develop a comprehensive resource library of all services available in the Camden region. Once we completed the toolkit, we were able to ensure continuity and institutional knowledge. We also wanted to share this knowledge, and our framework for care planning, with the broader Camden community. We then partnered with Aunt Bertha, a public benefit company, that has built a comprehensive, user-friendly, online social services database to host our knowledge of area resources categorized using our 16 care domains on the website My Resource Pal (formerly My Camden Resources). The site is free and accessible for both individuals looking for services as well as providers looking to help connect clients to services. Providers and individuals can enter their ZIP code and find an up-to-date list of services providing food, health, housing, transportation, employment, and more. We train our partners to use the site to connect their patients to resources.

COACH stands for:
- **C**onnect tasks with vision and priorities
- **O**bserve the normal routine
- **A**ssume a coaching style
- **C**reate a backwards plan
- **H**ighlight progress with data

Creating the National Center for Complex Health and Social Needs

Finally, we launched the National Center for Complex Health and Social Needs (the National Center) as an initiative of the Camden Coalition in 2016 to share our experience in Camden with the emerging field of complex care and highlight the latest complex care innovations and breakthroughs from other communities across the country. The National Center serves as a professional home for individuals and organizations caring for people with complex health and social needs, uniting and amplifying their efforts to improve care nationwide. Each year, the National Center hosts Putting Care at the Center, a conference for innovators and advocates for healthcare delivery reform to create a shared agenda for the emerging field of complex care.

Phase 4: Creating an ecosystem for complex care (2018–2019)

Armed with a deep understanding of the extent of our patients' needs and the significant limitations of our current systems to address them, we have turned our attention to creating ecosystems for complex care, both in the Camden region and nationally.

This has meant changes to our Care Teams, a growing focus on regional and national partnerships, and an expanded dialogue about the inability of our current systems and structures to address the needs that we observe in Camden and around the country.

Starting a Medical-Legal Partnership

After several years of planning, we were able to launch a Medical-Legal Partnership with Rutgers Law School in 2018 to support our Care Teams and their clients. A consulting attorney joined the Camden Coalition's nurses, social workers, and community health workers to resolve legal needs that can undermine patients' health and well-being. To date, our consulting attorney has worked on legal matters for 41 patients, obtaining both reductions in fines and access to benefits. At this point, we cannot imagine addressing our patients' needs without access to an attorney working alongside our Care Team.

Establishing Regional Health Hubs to better serve our patients

Over the course of our model's evolution, other care management programs have also emerged in Camden and the surrounding region. We are also now thinking about how our program may need to evolve even further to meet patients' needs — given the realities of a healthcare system that has not changed as much as we hoped and a social service system whose investments have not kept pace with the population's needs. Since 2007, we have seen the health care field respond to a call for expanded care management and home visiting models, but very little of it is done collaboratively. In Camden, we continue to hold monthly care management meetings which bring together 40 to 50 people each month who are navigating patients with chronic health issues, and

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other social needs. These meetings are vital to our region's ability to share resources, and collaborate around patient needs. And yet, we feel the field needs a more sophisticated approach to care management that connects high-touch, high-stakes navigation, such as navigation from the emergency department for a patient with medical and social complexity, with longer term navigation support that crosses sectors.

To further this approach, the Coalition has worked with state-level partners to establish the organization as one of four Regional Health Hubs in New Jersey to leverage our care management experience to serve individuals in the broader Camden region through navigation, convening, and data sharing. Over the past 12 years, our social sector partners have not been able to make the same investments in data and infrastructure that has been possible in healthcare. Through our Regional Health Hub, we hope to make the Camden Coalition HIE more widely available, and learn even more about our care management approach's impact on patients.

Strengthening the field of complex care

Through our National Center, we continue to highlight the fact that complex care works at the systemic level by creating ecosystems — local networks of organizations that collaborate to serve individuals with complex health and social needs. Through these efforts, complex care needs to address the root causes of poor health that defy existing boundaries among sectors, fields, and professions. The most expensive and challenging populations for the current healthcare system will remain underserved until there is a unified effort — rather than small, incremental steps — to improve care for people with complex health and social needs, and question the limitations of the existing models of care. Complex care programs may be housed in many settings, ranging from health care clinics and health plans to community-based organizations and social service agencies. Because of the broad set of stakeholders providing complex care, there is risk of further fragmentation of services, which makes ecosystem development an even more critical goal. Our focus in Camden is on ensuring that we build systems that propel us toward this goal.

The complex care ecosystem

From: The Blueprint for Complex Care (2018)

Looking ahead

While we are continuing our core case management with individuals with both medical and social complexity, we are also looking for new ways to holistically address complex needs.

We know that our original idea that we could navigate and piece together services that require a patient to move from provider to provider, each with their own eligibility requirements and service gaps, is not the way forward. In other words, short-term help navigating back to healthcare is not the answer. It is one part of the puzzle, but health systems cannot solve these problems on their own and may not even be the best "home" for many patients with certain types of medical and social complexity. Instead, systems and models of care have to be built around patients' complex needs. The Camden Coalition is testing this theory in a variety of ways. For example, we are embarking on a pilot to more closely link social services to our HIE and, by harnessing the data-sharing power of this effort, institute joint care planning activities alongside providers to serve our patients even better.

The Camden Core Model has gone through many phases. As we considered our successes and challenges, we made changes to our staffing, engagement practices, data infrastructure, and more. This is the hallmark of any learning organization — the willingness and ability to continuously iterate on a process in order to make it better. We look forward to sharing more of this story with the field as we continue to refine how we serve our patients.

Short-term help navigating back to healthcare is not the answer. Systems and models of care must be built around patients' complex needs.

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About the Camden Coalition

We are a multidisciplinary nonprofit working to improve care for people with complex health and social needs in Camden, NJ, and across the country. The Camden Coalition works to advance the field of complex care by implementing person-centered programs and piloting new models that address chronic illness and social barriers to health and wellbeing. Supported by a robust data infrastructure, cross-sector convening, and shared learning, our community-based programs deliver better care to the most vulnerable individuals in Camden and regionally.

Through our National Center for Complex Health and Social Needs (National Center), the Camden Coalition's local work also informs our goal of building the field of complex care across the country. Launched in 2016, the National Center exists to inspire people to join the complex care community, connect complex care practitioners with each other, and support the field with tools and resources that move the field of complex care forward.