

Building Health Homes for Kids:

New York's Reforms for Children on Medicaid Finally Take Shape



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Children's Health Homes: Hope Meets Reality

On the top floor of a squat, dull-brick public housing development, close enough to the north shore of Staten Island that, if the windows were lower and less stingy, he might see the glassy condos of lower Manhattan gleaming across the Narrows, a 10-year-old named Troy* shares two crowded bedrooms with his parents and seven younger siblings.

When he takes his medication, Troy is a sturdy kid with a goofy sense of humor, passing grades, and a reasonably agreeable attitude toward the pack of noisy co-claimants to everything he holds dear, from his Xbox to his mother's much-divided attention.

When he doesn't take his medication, things go badly. Last year, after his dad lost a job and then the family's apartment, Troy moved far from the neurologist who had been treating his dual diagnoses of ADHD and oppositional defiant disorder. He started getting in trouble at home and school, until one afternoon he stabbed a younger brother in the ribs with a pencil, ran away, and ended up in a psychiatric hospital for two weeks.

While he was there, he became part of one of the most ambitious health care reforms currently underway in the country. Since 2011, when Governor Andrew Cuomo first took office, New York has been working to overhaul its Medicaid program—a \$64 billion-a-year enterprise that currently serves almost one-third of the state's residents. The goal is to reverse a decades-long track record of mediocre health care outcomes, achieved at spectacular cost: When the Medicaid redesign project launched, [the state ranked](#) second-highest in the nation for per-enrollee Medicaid spending, but 21st for overall health system quality and dead last for avoidable hospital use and expense.

Troy's particular convergence of circumstances—the combination of a mental health disorder and chaotic life circumstances that sometimes get in the way of accessing care—put him directly in the path of New York's Medicaid reform, which rests on the premise that complex, intractable health problems can't be solved by focusing on medical care alone.

In fact, reformers posit, the way to simultaneously rein in costs *and* get better outcomes for vulnerable patients is to impact a much wider array of circumstances that contribute to poor health: a mental illness that stops a patient from showing up for doctors' appointments, for example; or a moldy apartment that exacerbates asthma; or a food desert that increases an entire neighborhood's risk of diabetes.

The big-picture ambition is to keep kids out not only of hospitals, but also foster care, homeless shelters, the justice system, and, ultimately, adult psychiatric institutions.

In order to help bridge these concerns—traditionally the purview of separate social-service realms and divergent funding streams—the State created a program called Health Homes, designed to offer a kind of broad-spectrum care management for Medicaid recipients with especially complicated needs. Health Homes care managers work with clients intensively and up-close, often in their homes,

* Not his real name.

helping them to navigate what can be a baffling maze of doctor's appointments, special-education evaluations, drug treatment programs, housing specialists, food stamp applications, and so on—all in the name of keeping them out of emergency departments and hospital beds.

"Health care is tremendously siloed and fractured and opaque to most families and patients dealing with multiple chronic and behavioral health conditions," says Greg Allen, a director in the Office of Health Insurance Programs at the New York State Department of Health (DOH). Health Homes attempt to impose order on the chaos.

New York's Health Homes program rolled out first for adults, in 2012. After several delays, the State launched the Health Homes Serving Children program in December 2016, opening services to kids from birth to age 21. Children qualify for Health Homes if they have multiple and chronic physical conditions (diabetes and asthma, for example) but the program is largely geared toward kids with mental health conditions, such as a diagnosis of serious emotional disturbance or a history of severe and repeated trauma.

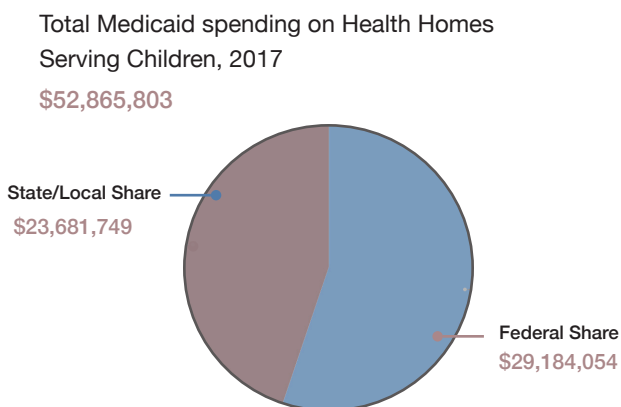
Each Health Home is run by a central administrative agency, which is responsible for putting together a network of care management agencies. The Health Home provides trainings, collects data, assesses quality, and bills the State Medicaid program. The care management agencies hire frontline staff, recruit enrollees, and conduct the day-to-day work with families.

Statewide, there are 16 Health Homes designated to serve children, most of which are led by large hospital systems that added a small number of kids to their pre-existing adult Health Homes programs.

The vast majority of enrolled children, however, are clustered in just two, children-only Health Homes, both of which formed as member-owned coalitions of social-service agencies that work with vulnerable kids. In total, children's Health Homes served close to 18,000 members in 2017, at a cost of nearly \$53 million (\$24 million of which came from State and local Medicaid funds; the rest from the federal government).

The State's bet is that Health Homes can grow much larger, eventually providing an inexpensive mechanism to reach a vast number of children: In 2013, while planning the program, DOH

Medicaid Spending on Children's Health Homes



Source: New York State Department of Health

Children, Age 0-21, Enrolled in Health Homes

Total children served, 2017

New York State 17,834

Point-in-time enrollment, March 2018

New York State 15,178

• New York City 6,431

Cumulative enrollment, December 2016 - March 2018

New York State 20,957

• New York City 9,126

How do Health Homes Work?

New York State Medicaid Program

Reimburses Health Homes at a per-member-per-month rate, ranging from \$240-\$800, depending on the child's assessed acuity level.



Health Homes

Statewide, there are 16 Health Homes designated to serve children. Most are led by hospitals that also run Health Homes programs for adults, but the significant majority of enrolled children are clustered in Health Homes formed by coalitions of community-based organizations. As the lead entity, the Health Home is responsible for administration, including collecting data, reporting outcomes metrics to the State, and distributing funds to care management agencies.



Care Management Agencies

Each Health Home convenes a network of care management agencies—usually community-based, social service organizations—which do the frontline care management work with members.

estimated that nearly 174,000 children and adolescents on Medicaid were potentially eligible for services. Long term—in the furthest reaches of the Health Homes vision—the hope is that community-based care management will steer kids into care that helps forestall magnitudes of compounded suffering (not to mention taxpayer spending) caused by inadequately treated health problems. The big-picture ambition is to keep kids out not only of hospitals, but also foster care, homeless shelters, the justice system, and, ultimately, adult psychiatric institutions.

However, a year and a half since New York State Health Homes first started working with children, many providers are struggling just to keep their services running. In part because of operational

fumbles, enrollment is a small fraction of what was anticipated. Since Health Homes are reimbursed per child, under-enrollment means that some programs aren't covering their own overhead costs, much less spending staff time on the kinds of outreach efforts that might bring in more kids.

The program is also hobbled by a lack of investment in the technology needed to track clients' medical appointments and records—a fact that especially hurts Health Homes run by social-service agencies, which, unlike hospitals, haven't already spent millions of dollars on health information technology systems. And providers say the assessments used to determine the scope of each child's needs—and also the rates at which Health Homes are reimbursed by the State—are flawed, with the result that care

managers face pressure to increase caseloads and dilute the attention they're able to give to each child.

Beyond its operational problems, the children's Health Homes program finds itself in an existential debate over its role in New York's bigger-picture Medicaid redesign plan. After [some false starts](#), the State has committed to moving forward with its strategy to re-engineer children's behavioral health care services—a system that's notorious for funding problems, months-long waitlists, and chronic shortages of staff and capacity.

In 2019, in addition to moving behavioral health services for most children on Medicaid under the control of managed-care insurance companies, New York will expand eligibility for an array of community-based behavioral health services, making them, for the first time, entitlements for kids on Medicaid.

Some advocates for children with behavioral health needs say the State's reform plan doesn't put nearly enough resources into expanding community-based and clinical services, and that the money spent on Health Homes would be better invested directly into therapists or day-treatment slots. How much value can be added by a care manager, after all, where there's not enough care to manage?

State officials, on the other hand, say that children's Health Homes will be essential to the larger reform. As part of the transition, some 6,000 children will likely shift from more limited, pre-existing care-management programs into children's Health Homes (a move that will alleviate a piece, but far from all, of the program's enrollment problem). Health Home care managers will then be responsible for identifying the neediest kids and steering them into re-engineered behavioral health services. Health Home proponents hope that the program can grow into a model for the rest of the country,

showing the power of community-based care management to integrate medical care into a bigger, broader understanding of health.

What's clear, to people inside the world of children's Health Homes, is that, in order for the program to play a meaningful role in reform—to have a chance at real impact for vulnerable kids—it will need more support and attention than it has received so far.

"The State has created a system with the potential to change the trajectory of children's and families' medical and behavioral health care," says Jodi Saitowitz, the CEO of a children's Health Home called The Collaborative for Children and Families (CCF). "But they keep adding obstacles and barriers."

An Ounce of Prevention – And a Ton of Detective Work

The Health Homes model is a lesser-known progeny of the 2010 Affordable Care Act, which, in addition to encouraging states to expand their Medicaid rolls, called on them to improve their generally dismal outcomes for Medicaid enrollees with behavioral health disorders.

People with severe mental illness are [two to three times more likely](#) to have chronic physical health problems than the general population and—in part because of inconsistent medical care—[die an average of 25 years younger](#). Psychotropic medications can exacerbate serious physical illnesses, such as diabetes, yet the various payment structures embedded in most Medicaid programs, including New York's, have traditionally ensured that physical and mental health providers share very little information about their patients. A doctor prescribing meds for schizophrenia, for example, might have no way to know whether the patient is also getting his or her blood sugar monitored.

While these problems are most visible among adults, they often take root in childhood. The State Office of Mental Health estimates that one in 10 children in New York has a serious emotional disturbance. There is little disagreement that good, early intervention can prevent life-long harm, but there's also little in the way of a coherent system to identify high-risk kids and steer them into care. In practice, children's behavioral health care is as fragmented as that of adults, often kicking in only when a child is in crisis.

With Health Homes, Medicaid reformers saw a way to skew the system toward prevention. In one of the most innovative pieces of the program's design, Health Homes do not limit eligibility to children who have formal mental health diagnoses, but also accept kids who've experienced significant trauma, such as prolonged abuse or neglect. The goal is to catch children as early as possible and get them into comprehensive care that might change the course of their lives.

Formally, the primary job of a Health Home is to create a coherent plan of care: With the family's permission, a care manager works with all the service providers in a child's life—from pulmonologist to therapist to probation officer—to develop an integrated strategy to address medical, behavioral, social, and practical needs. That strategy is codified in a shared document, designed to impose a measure of coordination—to ensure, for example, that every provider is working with the same list of diagnoses; that doctors don't repeat endless screenings for developmental delays or depression or substance abuse; that a patient isn't prescribed contraindicated medication.

In practice, much of a care manager's job happens around the edges and between the cracks of the care plan, navigating the tangled bureaucracies of health care and social services.

In one of the most innovative pieces of the program's design, Health Homes do not limit eligibility to children who have formal mental health diagnoses, but also accept kids who've experienced significant trauma, such as ongoing abuse or neglect.

The initial task of collecting consent forms can require days of detective work, says Carissa Molinary, a Health Home care manager with the Jewish Board of Family and Children's Services.

"A lot of clients don't know their doctor's name," Molinary says. "They'll say, 'you know, the big building on Bay Street.' So then I'm on a duck hunt. I can't call and say 'Do you see this client?' because the office doesn't have permission to talk to me. But I can't get permission without knowing the doctor's name."

Molinary is the care manager who ended up working with Troy, the 10-year-old from Staten Island. While Troy was still in the hospital, Molinary helped to identify a new constellation of providers for him, including a psychiatrist to manage medication and a therapist specializing in children. After his discharge, she visited him regularly at home, which is where she became the person to discover that he'd stopped taking his medication again—due to precisely the kind of problem that a care manager is trained to

consider and a doctor is not: His mother doesn't read, and she'd either forgotten or hadn't been told to give Troy his medication with food. Taken alone, it made his stomach hurt.

Now, Molinary checks in with Troy's mom about his treatment every week. She found an afterschool soccer program that helps him burn off the excess energy that can turn into trouble at home, and she put him on a waiting list for more intensive services, including a respite care program that would get him one-on-one attention, out of the house, twice a week. "He has so much potential," Molinary says. "With the right interventions now, it could make a huge difference in what happens to his life."

To be effective, care managers require an unusual combination of skills. They must be able

to win families' trust, hearing information that might not come out anywhere else. (Is there enough food in the fridge? Is a child taking his insulin every day? Does he hate his therapist?) And they must exercise the tenacity to overcome bureaucratic problems that can derail a child's care. Care managers make and reschedule appointments. They arrange transportation, collect medical records, rectify clerical mistakes, and fight for services that have been erroneously denied. They spend many, many hours on hold.

Because nearly a quarter of the kids enrolled in Health Homes are also in foster care, care managers might be the only provider to stick with a child as she moves between homes. They are also, often, the only bridge between families, health care providers, and schools. They tell guidance counselors when a child is having a

Who is Eligible for Children's Health Homes?

The Health Homes Serving Children program is open to children on Medicaid from birth to age 21.

Children may be eligible for services if they have:

- two or more chronic health conditions, such as asthma, diabetes, and substance use disorder; or
- a single qualifying condition, such as HIV/AIDS, serious emotional disturbance, or complex trauma.

To be eligible for the program, a child must also be unlikely to receive adequate care without care management. The program's "appropriateness criteria" include:

- risk for an adverse event, such as death, disability, inpatient or nursing home admission, mandated preventive services, or out of home placement;
- presence of inadequate social/family/housing support, or serious disruptions in family relationships;
- inadequate connectivity with health care system;
- does not adhere to treatments or has difficulty managing medications;
- recent release from incarceration, placement, detention, or psychiatric hospitalization;
- deficits in activities of daily living, learning or cognition.

Based on a review of Medicaid billing data, DOH estimated in 2013 that approximately 174,000 children in the State were eligible for Health Homes services.

crisis at home, and intervene when kids aren't getting appropriate special education services. They convince principals that therapy will work better than a suspension.

"You become a lawyer, you become a nurse, you become a secretary," Molinary says.

Care managers are not medical or mental health clinicians but, ideally, they develop enough clinical knowledge to recognize that a child should be assessed for something like autism or developmental delays. And they do plenty of informal counseling, especially with teenagers who refuse to see therapists, or who don't tell their therapist what's really happening in their lives.

"Some young females, maybe they're hitting puberty and they don't have a mom," Molinary says. "You teach them, this is what you do. You buy them products and explain how to use them. You talk to them about maybe it's time to start wearing a bra."

The success of Health Homes rests on the presumption that it will be possible to grow a workforce of care managers with the wide range of skills the program demands. Candidates "have to be pretty bold and tough, going out and knocking on doors and finding people," says Meggan Schilkie, a consultant who advises Health Homes statewide. "You've got to be savvy enough to talk to people in juvenile justice and foster care and the school systems. And smart enough to engage with families, to make them want to talk to you. Most people don't want extra people in their business."

"On top of that," Schilkie says, "we ask them to do it all for peanuts."

Typical pay for a care manager is about \$40,000 per year. The State mandates that care managers who work with the highest-acuity children must have either a bachelor's degree plus two years

Care managers make and reschedule appointments. They arrange transportation, collect medical records, rectify clerical mistakes, and fight for services that have been erroneously denied. They spend many, many hours on hold.

of relevant experience, or a master's degree plus one year in the field. New hires receive a long list of trainings in topics like trauma, child development, and assessment skills.

When Health Homes for children first rolled out, many care management agencies recruited staff directly from child welfare programs, but those hires often left within a few months, overwhelmed by the relentless hustle of the Health Homes program. A common solution, at this phase of the program, is to hire aspiring social workers with the minimum required experience, and to invest in intensive training and supervision. As with other government-contracted service programs, however, many programs find that turnover is high and fast, since people with experience can find better-paying jobs at hospitals or working directly for City or State agencies.

Ideally, in a fully realized Health Home program, care managers should pay for themselves many times over, by preventing crises that require emergency care. New York's Health Homes for adults have, in fact, begun to show some cost-saving outcomes among their clients, including

a drop in spending related to inpatient stays and preventable hospital readmissions. But for children, it's too soon to measure impact, says Lana Earle, a deputy director at DOH.

Shaky Financial Foundations

When they were planning the Health Homes Serving Children model, State officials expected that the program would be something of an extension of its counterpart for adults. The adult Health Homes program had experienced its own bumpy and contentious rollout but, by the start of the children's program, its providers had already invested in the infrastructure and technology to run the program's basic operations. Existing Health Homes, it was expected, would sign up the eligible children of adults they had already enrolled, as well as recruiting child-serving organizations into their networks of care management agencies.

By the time children's services were authorized, however, the leaders of many of those child-serving organizations were wary—not just of adult Health Homes, but of the power dynamics built into the State's strategy to overhaul Medicaid.

One of the explicit promises of New York's Medicaid redesign was that the big players of the health care world—the multibillion-dollar hospitals and insurance companies, many of which have spent the past decade consolidating their heft in order to bargain with other, even bigger players—would work with the smaller, community-based organizations whose mission is to engage with what health care reformers call the “social determinants” of health. They would be incentivized and rewarded for collaborating with a neighborhood asthma-education group, for example, or a housing specialist, or food pantry, in the interest of developing a broader, more holistic approach to health and wellbeing.

“Reform is really driven by the big health care agencies. The hospitals, the insurance companies, they have so many more dollars. It's difficult for us to speak the same language.”

In reality, merging these worlds has been difficult and contentious. It is a common complaint, among community-based organizations, that the vast bulk of power and money involved in Medicaid redesign has been filtered through large hospital systems, with little tangible benefit to social-service organizations that have spent countless (and costly) hours scrambling to keep up with the changing parameters and timelines of reform.

“In theory, there's a recognition about the significance of the social determinants of health,” says Alan Mucatel, the CEO of the social service agency Rising Ground (formerly Leake & Watts). But reform is “really driven by the big health care agencies. The hospitals, the insurance companies, they have so many more dollars. It's difficult for us speak the same language.”

With children's Health Homes, social service agencies saw an opportunity. Rather than joining pre-established Health Homes as care managers, two large coalitions of community-based organizations came together to form their own. In New York City, Rising Ground joined with more than 20 other nonprofits, including the

Health Homes Designated to Serve Children, with Enrollment

| Health Home | Enrolled Members March 2018 | Total Enrollment December 2016 to March 2018 |
|--|--|---|
| Children’s Health Home of Upstate New York | 4,619 | 6,490 |
| Collaborative for Children and Families | 4,405 | 6,371 |
| Coordinated Behavioral Care | 1,869 | 2,669 |
| Children’s Health Home of Western New York | 1,192 | 1,364 |
| Encompass Health Home | 745 | 973 |
| Hudson River Healthcare | 779 | 1,021 |
| Central New York Health Home Network | 300 | 323 |
| Adirondack Health Institute | 244 | 385 |
| Mount Sinai Health Home Serving Children | 242 | 383 |
| Community Care Management Partners | 201 | 240 |
| Montefiore Medical Center | 183 | 215 |
| North Shore University Hospital | 110 | 118 |
| Niagara Falls Memorial Medical Center | 98 | 289 |
| St. Mary’s Healthcare | 99 | 143 |
| Institute for Family Health | 52 | 52 |
| Greater Rochester Health Home Network | 39 | 54 |

Source: New York State Department of Health

majority of the City’s child welfare providers, to form The Collaborative for Children and Families, which had 4,400 enrolled children in March 2018. (Mucatel serves as CCF’s board chair.)

Outside the City, a similar coalition of organizations created the Children’s Health Home of Upstate New York, or CHHUNY, which had 4,600 enrolled kids. Between them, CCF and CHHUNY served 60 percent of the 15,000 children enrolled in Health Homes statewide in March 2018.

Providers say the new Health Homes model makes sense. Child-centered social-service organizations have access to vulnerable kids who are likely to be eligible for Health Home services. And they have the expertise relevant to community-based care management—to go into a client’s home, to take stock of his or her problems, and to do whatever hand-holding and hoop-jumping is necessary to solve them.

What they don’t have, providers say, is the financial means to run programs at a loss. Based on the eligibility projections released by DOH in

2013, member-owned Health Homes and care management agencies believed they'd easily enroll enough kids to cover their overhead and staffing costs. "We invested a lot of money up-front, with the anticipation that we would have the volume," says Jodi Saitowitz of CCF. "We were expecting more than 30,000 kids. I'm struggling to get 5,000." (See "Enrollment: Challenges" pp. 12.)

The Health Homes program's money problems filter down to care management agencies. "The financials don't work," says Caryn Ashare, who runs the care management program at Catholic Guardian Services, which serves approximately 350 enrolled children. "We are a big program, relative to others. I recently redid our budget and raised our average caseload size. We still do not have enough money for administrative costs, and we are going to run a structural deficit for the foreseeable future. It's a big money loser for us."

In the current State budget, DOH has allocated \$2 million in "readiness funds," to be distributed among four Health Homes that work primarily or exclusively with kids. Depending on how the money is structured and distributed, it may be matched by federal dollars to make a total of \$4 million. But Health Homes administrators say it won't be enough to fill the holes in their budgets.

Compounding the problem of under-enrollment, Health Home providers say there's a misunderstanding of the time and labor it takes to walk into the lives of families who are stressed and strapped and often transient. "The dollar signs attached to services do not sustain what the State is asking people to do," Schilkie says. "You might have an assessment tool that's supposed to take 20 minutes—but not if you have a mom with a 2- and 6-year-old and they're going to be evicted next month. It doesn't take 20 minutes to have that conversation."

One of the explicit promises of New York's Medicaid redesign was that the big players of the health care world—the multibillion-dollar hospitals and insurance companies—would work with smaller, community-based organizations whose mission is to address social determinants of health.

For many people in the field, the sense that children's Health Homes are undervalued—that the work of community-based care managers is misunderstood and inadequately reimbursed—corroborates their persistent concerns about the State's Medicaid redesign: that lip service is paid to the value of community-based organizations but dollars don't follow; that children are pushed to the back of the line.

In theory, kids with behavioral health needs should be a primary target of a reform that prioritizes prevention. In reality, advocates say that children's needs struggle to compete against those of adults, who offer far greater potential for short-term savings. Children's suffering accumulates over the long-term. The payoff for serving them better is diffuse and deferred.

"If you follow the money," says Alan Mucatel, "it's not going in that direction. It never has. We know that if we don't address kids' problems, it's going to cost us, whether it's homelessness or behavioral health issues or medical needs. These issues will manifest in 15 or 20 years." §

Challenges & Policy Recommendations

The Health Homes Serving Children program is the first major, concrete initiative to come from New York State’s efforts to re-engineer behavioral health care for children on Medicaid. Its success—including its ultimate potential to benefit vulnerable kids—is dependent on the larger reform. Care management cannot, by itself, make up for a lack of services to manage, or for instability and financial stress across the field.

In order to effect meaningful change for children, the State must make substantial investments in a full range of behavioral health care: community-based strategies to identify high-risk children and intervene early; clinical and wraparound services that keep kids out of institutions; as well as excellent facilities for children in extreme crisis. Outcomes must be conceived and measured over the long-term, with the payoff coming as children grow into healthier adults, better prepared to fulfill their own potential.

In the meantime, and in response to the specific implementation challenges faced by Health Homes and care management agencies serving children, we offer the following policy recommendations to the New York State Department of Health (DOH). Recommendations were developed in collaboration with experts in the field, including administrative and frontline providers of Health Homes care management, as well as advocates for the children and families the program is designed to serve.

Enrollment

Challenges

Health Homes and their care management agencies serving children cannot thrive without more support to build enrollment.

In planning the program, the State estimated that—based on their Medicaid billing records—close to 174,000 children were potentially eligible for Health Home services. Unlike adult Health Homes, which were given long lists of potential clients and instructed to track them down, the assumption was that children would come in through organic networks of providers—that the State’s web of foster care agencies, preventive service programs, and pediatric clinics would generate enough referrals to make the programs viable. Over time, the hope was that referral networks would grow, reaching places like school guidance offices and homeless shelters.

“In working with stakeholders, folks agreed that a list wasn’t the right way to go,” says Lana Earle of DOH. “We heard from providers: ‘We know where these kids are.’”

In fact, enrolling kids has been Health Homes’ biggest challenge. In March 2018, just over 15,000 members were enrolled in the Health Homes Serving Children program. More than 9,000 of those children were distributed between just two Health Homes: The Collaborative for Children and Families (CCF) in New York City and the Children’s Health Home of Upstate New York (CHHUNY), both of which serve children exclusively.

A significant percentage of children in the program were already enrolled in some other program at a care management agency—child-welfare preventive services, for example, or a pediatric mental health clinic. While children

in these programs are, inarguably, appropriate recipients of Health Home services, the program should also reach kids who have not already come to the attention of such providers.

Many Health Homes administrators believe that the most promising solution to the enrollment problem is to embed care management into places like hospitals and pediatric health clinics—either by having a care manager on site to meet with families when they come in for medical appointments, or by developing close enough relationships that clinic staff will think to call a care manager when they encounter a family with complicated needs.

“Families often trust their pediatric clinic. I may not know what a Health Home is, but if the doctor or nurse where I take my kids says ‘I think this is a good idea,’ that’s convincing.” says Amanda Semidey, the vice president for care coordination services at a Health Home called Coordinated Behavioral Care, which serves close to 1,900 children in New York City and runs the State’s third-largest children’s Health Home.

The problem, Semidey says, is that it takes months of labor to get partnerships set up—and none of that labor is funded. “There’s a very high level of project management. You’re showing up at meetings, schlepping to Brooklyn to talk to pediatric doctors. It can take eight weeks to get to a place where general counsels have looked at MOUs and boards have given approval. And three months out, there’s yet to be a referral.”

The value of partnerships is illustrated by the care management program at New Alternatives for Children (NAC)—an exception to the enrollment problem. NAC runs child-welfare programs

for medically fragile children. Because the agency has strong relationships with medical providers who see children with complicated needs, it's had no trouble getting referrals for kids who qualify for Health Homes care management, says Wendy Geringer, NAC's chief officer of Medicaid redesign, research and evaluation. For NAC's care management program, "There's more demand than capacity," Geringer says.

Enrollment

Recommendations

DOH should fund Health Homes enrollment activities, at least until the program has achieved stability. Enrollment strategies include supporting children's Health Homes and their care management agencies to develop partnerships and, in cases where it makes sense, to embed care management services at hospitals, clinics, and other institutions in contact with vulnerable children. Without a sufficient increase in enrollment, care management agencies will not be able to sustain the staffing and infrastructure necessary to make this service viable in the long run.

DOH should also consider allowing Health Homes that exclusively serve children to adopt a family model, serving other members of clients' households as appropriate. This will make the program more effective at helping kids and families, as well as alleviating some of the challenges with enrollment. In developing this approach, DOH should establish protocols to protect each client's privacy, with particular consideration of the needs of adolescents.

Assessments

Challenges

Once a child is enrolled in a Health Home, her care management agency has 30 days to conduct an assessment designed to ascertain the severity of her situation. Her score—high acuity, medium, or low—determines almost everything about what kind of help she'll get: how often she'll see her care manager; that care manager's credentials and caseload; how much the Health Home is reimbursed for serving the child.

The idea is to build necessary flexibility into the system, but **Health Homes and care management agencies say that kids regularly score at lower acuity levels than their life circumstances seem to call for**, with the result that care managers spend significant time working with ostensibly low-acuity children who, in fact, have very urgent needs.

In 2017, close to 6,300 of the total 17,900 children served in Health Homes (approximately 35 percent) were reimbursed as high-acuity, according to data from DOH.

There's debate over the cause of the perceived mismatch between needs and acuity score. The acuity assessment, which is a version of a national model called Child and Adolescent Needs and Strengths (CANS), considers dozens of aspects of a child's life, including the trauma she's experienced, how she's doing in school and in her family, and the capacity of her caregiver.

That information is compiled into a standardized template, but providers say that it may be filtered differently—and sometimes incorrectly—through the subjective perceptions of care managers. While the CANS assessment is designed for non-clinicians, it takes a certain level of clinical knowledge to understand

what life events to consider under the various domains, says Jodi Saitowitz, the CEO of The Collaborative for Children and Families.

"I'm concerned that care managers are going through the motions to complete the assessment and are not clinically skilled enough to be able to score the child and family correctly," Saitowitz says. "If a kid was suspended from school for fighting in the last 30 days, why is the care manager rating them zero for risk behaviors?"

Frontline care management staff report that they don't find the online CANS training to be effective or efficient, and that the test to qualify as a CANS assessor doesn't reflect their work in the real world. As one care manager put it, "I have never met a social worker who didn't hate the CANS."

Other Health Homes staff say that the problem doesn't necessarily lie in the assessors or the assessment, but the fact the CANS is typically conducted so soon after a care manager meets a family, who may not be interested in disclosing all their problems to a person who has not yet won their trust. "Since we have such a short window," said a supervisor at another care management agency, "we often don't learn about all of the complexities of the family, caregiver, and the child. So those children that appear to have a strong caregiver are initially rated as low acuity."

Then a crisis happens, and it becomes clear that a supposedly low-acuity kid has very intensive needs.

The difference in reimbursement rates is significant, ranging from \$800 per month for high-acuity children to \$240 for low-acuity kids.

The difference in recommended caseloads is also large: DOH says that a care manager should work with just 12 high-acuity kids at a given time, but can take on as many as 40 kids who score as low-acuity.

Unless a care manager learns new clinical information or a child experiences a major life event, such as getting adopted or admitted to a psychiatric hospital, the CANS can't be re-administered until six months after the first assessment. In the intervening time, care management agencies have to make hard decisions about how much time to spend with children in crisis.

If a child is, in fact, high-need, it's inappropriate or worse to pair her with a care manager whose caseload is 40 kids, says Renee Jones, a director of care management services at the Jewish Board for Children and Family Services. "If you think about 20 weekdays in a month, with a caseload of 40, that's two families a day. It's not a best practice to give [care managers] more than they can handle and cause harm to families. Someone will fall through the cracks."

DOH officials report that care management agencies are almost universally staying within their recommended caseloads. And Lana Earle, a deputy director in the DOH Office of Health Insurance Programs, points out that the perceived discrepancy between need and acuity score may be explained, in part, by the fact that a significant percentage of kids currently enrolled in children's Health Homes came directly from a previous, more limited care management program. "A lot of those kids have been served for a long time," she says. "It's a good thing they were scoring low on the [CANS] algorithm. It makes sense."

DOH has launched a training institute for the CANS assessment, and is now requiring care managers and their supervisors to attend in-person trainings. "Our sense is that folks

need more training around how to fill out and complete the CANS," Earle says. It would be premature to conclude that the algorithm itself is wrong, she adds. "There could be other layers. We need the benefit of time to look at that data."

Assessments Recommendations

DOH should give careful consideration to reports from frontline care managers that the acuity assessments used in Health Homes Serving Children frequently do not reflect the severity of children's circumstances and needs.

As DOH moves forward with its initiative to better train care managers in conducting the assessments, it should explore the possibility that problems may lie in the assessment itself, in addition to user error.

DOH should also ensure that care managers have the flexibility to reassess children whenever appropriate—and that they understand the full range of circumstances under which a reassessment is permitted. This will allow care managers to better provide appropriate services, at the intensity level a child needs, without taking needed time and attention away from other children and families.

Complex Trauma

Challenges

New York State's Health Homes Serving Children program is the first in the nation to include not only children who have more traditional mental health diagnoses, but also kids who fall under a category called "complex trauma"—meaning a child has been exposed to multiple traumatic events and suffers ongoing consequences, such as neurodevelopmental problems or difficulty forming relationships.

To many advocates for kids with behavioral health needs, the complex trauma designation was a major win, creating the potential for Health Homes to reach younger children—including babies and toddlers—and to steer kids into services before they end up in the kind of crisis that results in a more standard behavioral health diagnosis.

But now, a year and a half after the rollout of Health Home services for children, many providers and advocates describe complex trauma as the program's greatest disappointment. State-wide, just 12 percent of the children currently enrolled in Health Homes came in with a complex trauma designation, according to data from DOH.

The challenge is that there's no easy or pre-worn path for children to be designated as having complex trauma. For the purposes of Health Homes, the State adopted an assessment originally developed by the National Complex Trauma Association. It must be conducted by a licensed social worker, psychologist, or psychiatrist.

But kids who aren't already patients of a mental health clinic—in other words, many of the children whom complex trauma was expected

to cover—are unlikely to have access to one of those professionals. Even for children who are already in the child welfare system, there's no clear, straightforward system to get the assessment conducted and reimbursed.

"New York was the first state in the country to lead the way to enroll children with complex trauma by creating eligibility criteria, a process, and assessment tool," says Phyllis Silver, a former deputy director of the New York State Office of Public Health and the current executive director of the health care consultancy Partnership for Quality Care. "However, the State did not create a mechanism to pay for this new evaluation."

State officials make the case that complex trauma is, in fact, a specific condition that should not be applied to children too broadly. "We don't want to label every kid out there to say they have complex trauma," says Colette Poulin, the program director for children's Health Homes at DOH.

"We want to match the diagnosis with proper treatment," Poulin says, and to "be cautious that we don't just label children and find out later that they have some other kind of mental health diagnosis that was overlooked."

Health Home providers, on the other hand, describe the failure to make fuller use of the complex trauma category as an exasperating missed opportunity: It prevents them from working with children who stand to benefit from intervention, and it exacerbates the problem of low enrollment. It also represents a missed opportunity to maximize federal Health Home funding: Because children with complex trauma are deemed a new Health Homes population, their services will be

Complex Trauma Recommendations

reimbursed by the federal government at a rate of 90 percent until December 2018.

The care management program at Catholic Guardian Services has developed a promising workaround for kids who are in foster care, says Caryn Ashare, the program's director. First, a child's foster care case planner conducts a modified version of the complex trauma assessment, then passes on the information to a licensed clinician, who is paid under the agency's per-diem reimbursement for foster kids. The clinician can then do the formal assessment without seeing a child face to face.

"It's very successful for kids in foster care," Ashare says. Close to 80 percent of the children in Catholic Guardian's care management program came in under the complex trauma criteria. It's one of the reasons that the program, which serves about 350 Health Home kids, is larger than most.

But the strategy is far from perfect. Even with the expedited workaround, reviewing complex trauma assessments eats into the limited time of clinical providers who work with kids in foster care. And it doesn't solve any problems for children in preventive service programs, or who might come into the program via community referrals. Because Catholic Guardian is a relatively large organization with a fundraising department, they're able to cover some of those assessments with private dollars, but that's not a scalable solution. "It's another thing that's unfunded," Ashare says.

DOH must facilitate evaluations of children for complex trauma. This will help expand services to a population in need, boost enrollment among care management agencies, and enable the children's Health Homes program to more effectively serve its role in preventing serious behavioral health problems.

Technology

Challenges

Health information technology is central to the function of Health Homes, which are tasked with facilitating communication among the multiple medical, behavioral health, and social-service providers in a child's life, in addition to interfacing with regional and State health information platforms and insurance companies that work with Medicaid.

At least in theory, the State's health care system is moving toward a world of integrated, electronic records, in which all of these entities seamlessly share information that would—ideally—make care management more efficient and effective.

In reality, integrating electronic health records is slow, cumbersome, and very expensive. In the past several years, the State has distributed many millions of dollars to help hospital networks build better information technology. **Smaller, community-based organizations say they have been left behind. Most have neither the funds to invest in the development of complex technology, nor the technical expertise to use existing systems to their full capacity.**

"Each Health Home may use different electronic health platforms," says Saitowitz of CCF. "They are all required to talk to the State's platforms. There are systems for referrals, for quality assurance reporting, for billing. You'd need a brilliant developer to code it all for you. Which you can do if you get millions of dollars, but we did not."

The difficulties spill onto care management agencies, especially if they attempt to work with more than one Health Home and must navigate multiple IT platforms, comply with various sets of administrative and reporting processes, and fulfill different training and compliance requirements. "It would be a nightmare for a case manager to remember to do half their caseload in one system, half in another," says Renee Jones from the Jewish Board care management program.

Technology

Recommendations

DOH should consider how to bend the Health Homes Serving Children program toward useful standardization, reviewing best IT practices and effective systems, and making them available to Health Homes and care management agencies across the program.

The State must support children's Health Homes to build and improve their information technology systems. This is especially vital for Health Homes administered by coalitions of smaller, community-based organizations, which urgently need investment and training to offer effective care management services and to participate successfully in broader health care reform.

Transparency and Access for Families

Challenges

Families of children with behavioral health needs commonly find themselves contending with an opaque and difficult system. Caregivers often don't know where to turn when things go wrong—when an insurance claim is denied, for example, or they have a complaint against a provider.

“There’s nowhere for parents to go when they run into problems,” says Amber Decker, a certified family peer advocate who consults with families struggling to navigate services.

The Health Homes Serving Children program is designed, in part, to make the system clearer, helping families understand the services to which their children are entitled and offering a means of recourse if a child is not getting appropriate care. In order to serve that purpose, the program must, itself, be fully transparent to members and their families. Care management agencies must be assessed for how effectively they integrate families’ meaningful participation in the development of children’s care plans. And families must fully understand the implications of the consent forms they sign when enrolling in the program.

Ultimately, Health Homes Serving Children will be most successful if its leaders solicit and act on regular feedback from members and their families. Too often, “providers assume they know what families want without asking them to be part of the conversation,” Decker says.

Transparency and Access for Families

Recommendations

DOH should solicit regular feedback from Health Homes Serving Children members and their families, including through surveys conducted by an entity other than care management agencies. DOH should also ensure that the families of children in Health Homes are fully informed about how to participate in stakeholder meetings where policy decisions are made. The department should consider creating a family steering or advisory committee, in order to hear from families about what’s working in the Health Homes Serving Children model and what’s not.

DOH should ensure that children’s Health Homes have reliable and timely mechanisms to respond to complaints from families of children enrolled in the program, and to families’ requests for health and other records collected or distributed by care managers.

Administrative Requirements

Challenges

Frontline staff at care management agencies say they spend a dispiriting amount of time on **burdensome, duplicative record-keeping and reporting**. Such complaints are often dismissed as an inevitable part of social service work, but ineffectively streamlined administrative tasks can take valuable time away from providing services.

Duplicative tasks also contribute to burnout among staff, who do emotionally taxing work, and who already spend time navigating inefficient bureaucracies on behalf of their clients.

Administrative Requirements Recommendations

DOH should work with children's Health Homes to review and simplify administrative requirements. As the State supports Health Homes to build technology and infrastructure, it should incentivize standardization wherever possible and useful. Streamlining and standardizing administrative tasks will make it easier for care management agencies to work with multiple Health Homes and facilitate greater enrollment. It will also improve morale among care managers, allowing them to spend more time on clients' needs and potentially boosting staff retention.

Conclusion

The Health Homes Serving Children program offers a meaningful promise: In its mission and design, it embodies the integrated, person-centered approach to health and wellbeing that the State has made an explicit goal of its project to redesign health care for people on Medicaid.

While it is too early to measure concrete outcomes, this report finds that the program struggles with several operational obstacles to achieving its goals. The significant majority of enrolled children are being served in Health Homes run by community-based organizations, which need far greater support to—at the least—remain solvent until the Health Homes program becomes more stable.

Fully realized, the Health Homes Serving Children program has the potential to pay for itself several times over, helping vulnerable kids to access better, more appropriate care and—in the long run—to live healthier, more successful lives.



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