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Key Findings from the New York State Health Foundation-Commissioned Report:

Lessons Learned from HIV Prevention and Care: Implications for the Development of Health Homes

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New York State (NYS), the mental health system is at a generational crossroads. With the Affordable Care Act and mental health parity laws, millions more individuals are now eligible for care. At the same time, costs for the care of those with the most complex needs and circumstances are expected to exponentially rise without policy and provider-level interventions. One such intervention, NYS Medicaid Redesign, has given rise to the inclusion of health homes in the NYS plan.

Health Homes are not to be confused with Patient Centered Medical Homes, another new program model that is transforming the organization and delivery of primary medical care. A Health Home is a care management model where a care navigator/care manager coordinates all services among various providers and facilitates communication among an individual's care providers.

Health Homes models hold the promise of improving the quality of care for those struggling with complex physical and mental health challenges, while simultaneously containing costs. However, informing the implementation of Health Homes could be greatly enhanced by drawing upon lessons learned from previous attempts at care coordination, particularly from the recent development and design efforts of HIV care systems.

The McSilver Institute for Poverty Policy and Research at New York University Silver School of Social Work in collaboration with the New York State Health Foundation produced a report summarizing lessons learned from HIV case management models and offering recommendations for the development of Health Homes in New York State with a specific focus on patients with serious mental illness (SMI).

In order to understand the evolution of the HIV system of care and glean general design principles that could be adapted to Health Home development, the McSilver Institute undertook a robust review of the New York State HIV Care System, which included a comprehensive literature review and expert key informant interviews. The McSilver Institute reviewed over 100 research publications about potentially relevant features of the HIV Care System. In addition, twelve expert informants were identified: government policymakers, academic HIV researchers, HIV providers, and consumers. All had critical perspectives to offer from their particular vantage point of developing, studying, and/or having received services from the NYS HIV Care System. These prominent New



Yorkers provided first-hand accounts of the development of the HIV system of care. Their practical experience, as well as existing governmental reports and academic literature, has informed the discussion of the issues that are the focus of the report.

Although several of the recommendations are specifically applied to NYS, many are broadly applicable to states across the country implementing Health Homes models.

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Backdrop: The Transformation of the HIV Care System

Only three decades ago, health care providers and policy makers in New York State, nationally and worldwide were forced to respond to a serious public health threat—human immunodeficiency virus (HIV), a virus that destroys the body's CD4 immune cells, which help fight disease. Untreated, HIV progresses to Acquired Immune Deficiency Syndrome (AIDS), resulting in almost certain death at the start of the epidemic. Development of highly active antiretroviral therapy (HAART) in the mid-1990s enabled individuals with an HIV diagnosis to live longer by suppressing the HIV virus from progressing into full-blown AIDS.¹ Consequently, mortality rates decreased and HIV no longer was considered a terminal illness, but a chronic health condition.²

An increased survival rate among persons living with HIV and AIDS (PLWHA) brought about a new set of treatment challenges for HIV care providers who were then faced with the growing prevalence of chronic health conditions, such as hypertension³ and diabetes,⁴ as well as the co-occurrence of mental illness and chemical dependency among PLWHA.⁵ Untreated behavioral health disorders started undermining providers' ability to engage PLWHA in life-saving treatment. Other commonly identified barriers to care were the stigma associated with a HIV diagnosis, poor knowledge about HIV care, mistrust of health care providers and the health care system overall, housing and food instability, transportation and child



care difficulties, lack of insurance coverage or uncertainty about insurance benefits, and competing concerns related to comorbid conditions.⁶

To address the changing and complex care needs of PLWHA, the HIV Care System had to completely reorient its mission, goals, and services, responding by piloting a number of innovative chronic care interventions. HIV providers offered, for example, some of the first integrated care and medical home models for people with poly-morbidities. Large provider groups and provider consortia created systems of comprehensive care based on a holistic approach in which primary, specialty (e.g., infectious disease), and behavioral health care were coordinated, drawing on social service supports and care coordination, as needed.⁷ Professional, peer and community case management and support service initiatives helped PLWHA navigate the care system, address homelessness and food insecurity, and provide behavioral interventions to engage and retain individuals in care. All of these issues are congruent with concerns faced by people with serious mental illness (SMI), many of whom have comorbid substance use disorders in addition to multiple medical disorders, including HIV.

The HIV Care System benefited from a funding model that supports a coordinated, comprehensive service delivery model. The Ryan White CARE Act (RWCA) had a large influence on HIV care by facilitating the creation of a comprehensive care system to respond to the complex needs of patients.⁸ This funding allowed for integrated, person-centered care with intensive case management. Such a concentrated stream of funding has not been replicated, until recently. New York State received an unprecedented opportunity in 2014 with the approval of a Medicaid waiver of approximately \$8 billion allocated for medical and behavioral health services.9 These funds are being used to transform its siloed primary and behavioral health care funding systems. This added funding along with many of the elements of the HIV system of care that were and continue to be successful are also considered core to the Medicaid Health Home model. The aim of this report is to highlight how the HIV system of care approached these varying elements and assess how Medicaid Health Homes are building upon these principles, while offering some recommendations for strengthening their ability to do so.

Summary of Lessons Learned

I. Auxiliary/Supportive Services

The NYS HIV Care System Experience

Treatment engagement, retention, and adherence are much more likely to be achieved with PLWHA who receive support services, such as housing assistance and adequate access to food. Acknowledging that care for PLWHA needs to be multifaceted to achieve desired healthcare outcomes and prevent transmission, the New York State AIDS Institute requires its funded providers to develop partnerships with community-based organizations to facilitate access to food, housing, social supports, and other resources. The type of services offered continually change to meet the evolving needs and demographic characteristics of PLWHA, but the core concrete resources are the following:

- > Housing
- > Food support
- > Language assistance
- > Transportation
- > Legal services

Auxiliary/Supportive Services: Implications for Health Homes

Ensuring the same array of services for the complex chronically ill patients engaged in the Health Home setting is a critical part of the care manager's job. In 2013, NYS began targeting some of the health care reinvestment funds into supportive housing for people enrolled in Health Homes. In talking to many lead Health Home agencies from across the State, however, a common theme is that many care managers are not completely familiar with housing resources and, more importantly, there is a severe housing shortage across the state.

Though the New York State Department of Health (NYSDOH) cannot immediately address the shortage of affordable housing, care management teams at both lead and downstream agencies (i.e., community-based organizations that have subcontracted with the lead entity to provide care coordination services) could certainly benefit from technical assistance that would strengthen their knowledge and ability to navigate the housing support system. For example, care managers might need better screening tools to identify patients in need of housing; they may also need a designated contact person, on-site or easily accessible, who can



help them access available housing. They might also benefit from training on eligibility and documentation requirements and the process of applying for housing. Public and private funders might also consider testing and evaluating a few models to better understand how to solve patients' housing needs through better service integration with Health Homes.

Similarly, many care managers face a learning curve when it comes to navigating other social support systems. Many care managers are used to working with clients in a familiar way; learning to navigate social support systems with which they may be unfamiliar is a process that could be facilitated with additional technical support and continuously updated resources. While the resources may be available, some technical assistance and support could help case managers to more effectively use these resources for their clients. One example is the availability of free legal services for low-income patients with serious and/or chronic illnesses who are experiencing life-threatening barriers, such as being denied access to private insurance, private insurance disputes regarding treatments and procedures, or denial of other benefits. To leverage and ensure better use of these services, New York Legal Assistance Group (NYLAG) established a LegalHealth division in 2001 to provide technical assistance to spread the availability of medical-legal services to low-income patients. LegalHealth also formed a coalition of lawyers, physicians, social workers, and other professionals to share ideas and best practices needed to move forward.

One way to connect lead Health Home agencies with information about resources such as LegalHealth is through webinars or learning collaboratives. This practice has been a successful element of the Center for Health Care Strategies Learning Collaborative, in which established Health Home network leaders come together via in-person and web-based meetings to discuss and share best practices. Participating providers can then test out ideas and learn from their colleagues about what does and does not work.

II. Integrative Care and a "One-Stop Shop" Approach

The NYS HIV Care System Experience

Faced with a host of interrelated challenges (e.g., HIV, substance use, poverty, mental illness) that all needed to be addressed to engage and retain individuals in HIV treatment, RWCA-funded clinics developed the first models for comprehensive care offered in one location. These clinics specifically and effectively addressed

the fragmentation of care. The establishment of HIV specialty clinics (staffed with multidisciplinary teams that include a primary care provider, nurse, social worker, and pharmacist, these were the country's first patient-centered medical homes, or PCMHs) was one of the most important system restructuring outcomes for the RWCA¹⁰ programs.

In particular, offering all core services in one location (a "one-stop shop") is the most effective way to facilitate integrative care and ensure that individuals get the array of services they need. Service providers, administrators, and researchers who were interviewed for this report described this model as helpful in improving retention by addressing barriers to care.¹¹ Physically integrating services makes it much easier to coordinate care, since multiple types of providers are together in one location, often utilizing a centralized electronic health record (EHR) system. Having all or most types of providers that a PLWHA might need in the same place "helps with linkage and retention because we can just send someone down the hall," a pediatric provider reported.¹²

Integrative Care: Implications for Health Homes

Health Home services are meant to be integrative as well, though one-stop shop is more difficult because Health Homes include a vast network of organizations—hospitals, community providers, health plans, and supportive housing agencies. Since a Health Home is not a physically integrated care network, the network is better understood as a virtual Health Home.^{"13} Having a network of providers is helpful for integrating care, but is not sufficient. Providers within a Health Home network may be spread across different locales, which may present a barrier to engagement and retention efforts. Limiting the number of locations where clients must qo—and the distance between those locations—would potentially encourage more real-time introductions (commonly called "warm hand-offs") and easier patient referrals. Such limitations could be achieved through guidance issued to lead Health Home agencies. That guidance could take the form of organizing network members into more manageable geographic locations where possible so that people might have all of their providers clustered in or around that neighborhood.

Two key services that need to be more seamlessly integrated are behavioral health and primary care. Some work toward this end is occurring. For example, New York is home to several of the

Substance Abuse and Mental Health Services Administration's (SAMHSA) Primary and Behavioral Health Care Integration (PBHCI) programs. With this funding, grantees are attempting to imbed primary care risk assessment and services within the walls of their behavioral health sites. Recognizing the importance of early identification and treatment of chronic health conditions, the New York State Office of Mental Health (OMH) also created a Medicaid incentive program to encourage behavioral health agencies to offer physical health assessment, treatment, and monitoring so that primary, secondary, and tertiary prevention might more rapidly be available. Clinic incentives include the ability to bill for these physical health services plus a small increase in behavioral health reimbursement rates. On the primary care side, some FQHCs have both Article 28 and Article 31 licenses, but regulatory and administrative issues prove somewhat challenging and act as a disincentive to provide seamless primary and behavioral health care. A review of the existing barriers—including the longstanding culture of division between mental and physical health services—in these areas is an essential part of determining the changes that need to be implemented to promote integration. Some related regulatory and administrative changes might help advance the primary and behavioral health care systems' abilities to provide a more integrated array of physical and mental health services.

III. Uniform Standards and Centralized Data Systems

The NYS HIV Care System Experience

As the HIV Care System transitioned to a chronic care model in the 1990's, it became a pioneer in the health care sector for provider performance and patient outcome measurement, as well as record management. In conjunction with professional associations, the U.S. Department of Health and Human Services developed prevention, care, and treatment guidelines. The guidelines had corresponding quality measures to facilitate both provider-conducted internal reviews and funding agency-conducted external reviews of adherence to uniform, best practice standards of care.

The chart below summarizes the federal guidelines established for the HIV Care System and includes recommendations for related Medicaid Health Home guidelines.

Practice: Clearly measurable and common goals

HIV Care System Capability	Medicaid Health Home Recommendation
One common goal to unite providers: achiev- ing an undetectable viral load for an individual and increasing their CD4 count.	Health Homes should be required to report on numerous indicators of care quality and outcomes. In particular, networks could use health risk assessments to determine suitable prevention strategies.
	If the State could issue an aggregate dashboard of a handful of measures on an ongoing basis, that dashboard might serve as a unifying measure of progress. One measure to consid- er is the application of accepted treatment processes that meet HEDIS benchmarks.

Practice: Provider outcome profiling

HIV Care System Capability	Medicaid Health Home Recommendation
Data on organizations that are achieving better outcomes than typical through use of best practices, as well as poorly performing providers that are offering substandard care, informs periodic reallocation of HIV funding to the best performing providers. Moreover, funding agencies use the information gathered through the assessment process to improve system performance by disseminating best practices and setting system-wide quality improvement goals.	NYS DOH could publish this aggregate data at regular intervals to allow Health Home provid- ers to benchmark themselves alongside peers. NYS DOH should measure Health Homes against a standard set of quality benchmarks and publish those benchmarks.

Practice: Assessing diagnosis measures

HIV Care System Capability

The HIV system has detailed quantitative Health Homes can capture the same infordiagnostic measures for the disease that mation through their electronic health provide a uniform assessment framework for records and CMART (the Care Management cross-systems comparisons. Diagnostic screen- Assessment Reporting Tool), which should ing can identify people at risk (i.e., those with allow for integration of health and care plan an STD or who are IV drug users), those who information. Health Homes may need more are infected, where in the disease's progression technical assistance with electronic records the diagnosis has been made, and desired to move ahead in this area. treatment outcomes.

Medicaid Health Home Recommendation

Practice: Collecting interim data

HIV Care System Capability	Medicaid Health Home Recommendation
The HIV System routinely collects patient self-reports because measures of non-adher- ence have been shown to have high predictive validity. ¹⁴	Health Homes should have the ability to vali- date patient report data with claims data.

Practice: Consumer satisfaction

HIV Care System Capability	Medicaid Health Home Recommendation
Consumer satisfaction with services is a	NYS should begin to standardize the col-
key predictor of a person's engagement and retention in care. The NYS HIV Care System	lection of consumer satisfaction data along with consumer feedback in the field. The
incorporates consumer satisfaction as a critical	information collected could be used to improve
performance measure. The NYSDOH Bureau	the quality and types of services to be more
of HIV/AIDS conducted an annual Client	person-centered.
Satisfaction Survey.	

In addition to a strong focus on data collection and centralizing record management, streamlining quality management was also a useful and effective practice within the HIV Care System. The HIVQUAL (HQ) model began in 1992 as the NYS HIV Quality of Care Program, sponsored by the NYSDOH AIDS Institute and the HIV/AIDS Bureau of the US Health Resources and Services Administration (HRSA). HQ was created to improve the quality

of care for persons living with HIV/AIDS by building capacity and capability for HIV quality management (QM) throughout the United States. The model provides nationwide technical assistance, coaching (to facilitate quality improvement and cross-clinic collaborations within regional groups, as well as sharing of best practices) and mentoring to HIV service providing organizations. HQ also measures HIV clinical care quality and primary care quality based on 17 indicators (see Figure 1).¹⁵

Composite Quality of Care Scores

HIV care quality score

- 1. Clinical visits
- 2. CD4 counts
- 3. Viral load tests
- 4. Antiretroviral (ARV) prescription
- 5. ARV adherence assessment
- 6. *Pneumocystis jiroveci* prophylaxis (PCP)
- 7. Lipid screening among patients on ARV
- 8. HIV prevention education

Primary care quality score

- 1. Substance use screening
- 2. Tobacco use screening
- 3. Dental exam
- 4. Cervical cancer screening (in women)
- 5. Gonorrhea screening (in women)
- 6. Chlamydia screening (in women)
- 7. Syphilis screening (all patients)
- 8. Hapatitis C status known
- 9. Tuberculosis screening

All 17 Indicators = Total Quality Score

Figure 1. Components of the three constructed quality of care scores using HIVQUAL-US performance data: HIV care, primary care, and total quality scores. For more information: http://healthqual.org/hivqual-us

Participating programs send reports annually to HQ based on patient medical records, which ensures the high quality of the self-reported data. Based on the provider's annual data transmission, HQ generates an annual report to the provider on performance for the 17 quality indicators and its overall score. Agencies providing continuous annual reporting showed improvement in quality across client population and clinic types.¹⁶

Uniform Standards and Centralized Data Systems: Implications for Health Homes

NYS has set certain uniform quality measures for Health Homes, though the NYS quality measurement process only started up in a meaningful way in 2014. In addition, each Health Home has been asked to develop its own patient assessment instrument, care plan, and internal quality assurance metrics. Since 2012, best practices have been shared through a statewide Learning Collaborative, regular webinars and DOH written communications. Like the HIV Care System, which created a scientific and best practice-based framework to inform provider performance and patient outcomes, NYSDOH has put in place a statewide set of standards, reporting, and benchmarking mechanisms. Performance monitoring and outcome surveillance is more complicated within a Health Home model because of the presence of multiple diagnostic groups that lack a unitary measure. Medical co-morbidities may provide HEDIS standards of measurement and benchmarking; however, the metrics on the behavioral health side require considerable development.

IV. Critical Time Intervention

The NYS HIV Care System Experience

There is a short window of time for engaging new clients.¹⁷ For the HIV Care System, the Institute of Medicine, the National HIV/AIDS Strategy, and the US Department of Health and Human Services set system-wide goals specifying that treatment should commence within three months of diagnosis.¹⁸ Even so, one provider shared, "It's best to have same-day referrals. The fewer times a patient is rescheduled the better. Sometimes referring someone to another provider in-house involved simply walking them down the hall."¹⁹

The practice of a "warm hand-off," as the provider noted above mentioned, was more easily achieved at "one-stop shop" facilities. However, providers in HIV testing facilities without co-located services can provide important and effective linkages to services by making active referrals (that is, promptly scheduling appointments for clients, rather than giving a passive referral to a treatment provider with a name, phone number, and address). This active referral method increases the likelihood that an individual will keep his/her appointment.²⁰ An active method is more effective

because the interaction between the provider and consumer in linking them to treatment establishes rapport and trust and offers the opportunity for education and behavioral interventions to reduce high-risk behaviors.²¹ It bears repeating that geographic proximity of the treating facility to the "home" of the patient being referred is of major importance in establishing linkage and engagement.

Critical Time Intervention: Implications for Health Homes

Some Health Homes are already modeling this type of approach as they conduct outreach and engagement of patients, but some standardization of the allowable timeframe between first contact/ enrollment and linkage to services could be encouraged more globally. In addition, Medicaid Health Homes should be encouraged to employ timely referral of care rather than be silent on the issue. *The CHCS Learning Collaborative and webinars could pursue this topic and provide some guidance and assistance to Health Homes.*

V. Collaboration

The NYS HIV Care System Experience

Inter-professional collaboration is a way that may help improve quality of care and coordination of care, while reducing the use and prescription of excess services.²² The literature has shown that often the HIV team's collaboration rests on a shared understanding about what it takes to get and keep a PLWHA in treatment. In the HIV Care System, the team members each have a skill set that enables them collectively to address the entire gamut of individual needs, but individually would not be nearly as effective. In addition, EHRs are accessible to all team members, including peers and community workers, and are the most efficient way to share information.²³

Collaboration: Implications for Health Homes

Medicaid Health Homes realize the importance of electronic information-sharing and have more capabilities than when they started, especially with the emergence of regional health information organizations (RHIOs). Yet because the Medicaid Health Home model is based on an open rather than a closed system of care, seamless information-sharing is still a work in progress.

Many other lessons from the inter-professional collaboration that exists in the HIV system of care are easily translated to the Medicaid Health Home setting and could be communicated through the CHCS Learning Collaborative meetings and webinars. For example:

- EHRs accessible to all team members, including peers and community workers, are the most efficient way to share information.²⁴
- Case conferencing with providers across disciplines and programs facilitates care coordination when EHRs are not available or not quite thorough enough.²⁵
- Specific tools for medical and behavioral health screening should be standardized across the state to ensure quality across a diversely staffed program or network in which staff members possess a varying degree of skills and training. A university researcher gave an example of an integrated standardized screening tool that is directly embedded into the treatment adherence counseling encounter record: "Whoever is working with a patient may be able to assess potential problems, helping to streamline the process. This screening tool is helpful for lay counselors who don't know much about mental illness and substance abuse."²⁶
- Talking points to guide staff through patient discussions where cultural sensitivity and stigma might impede the counseling/ support process have been found to be very helpful. According to one provider, "We also give them a script to recommend follow up in language that normalizes [the consumer's] situation and the actions they need to take."27
- > Trust and open communication are important components of partnership in which the team works together to achieve

a common goal.²⁸ Because of their shared goal, it is important that team members recognize that they are to function interdependently, instead of autonomously.²⁹ The lead Medicaid Health Home agencies need to champion this level of interdependence.

Power should be distributed as equally as possible in order that all opinions may be considered, and no one individual (or set of individuals) dominates the team's decisions.³⁰ A review of research studies suggests the effectiveness of inter-professional collaboration in HIV care to improve patient outcomes; however, there is too much variability in methods and conceptualizations of inter-professional collaboration to assert its effectiveness.³¹ "Care coordination is better within the HIV care system than in other systems because of forced collaboration through the HIV Planning Council", one HIV researcher reported.³²

VI. Workforce Expansion

The NYS HIV Care System Experience

In addition to professional staff such as social workers and nurses, the HIV Care System uses a non-traditional workforce to aid in the provision of care coordination. Care team members include:

- > Community health workers (CHWs) are usually laypersons whose duties include case management, informal counseling, community advocacy and capacity building, providing health education, and coordinating care.³³ Along with nurses, CHWs have been shown to be just as effective as physicians or clinic counselors with respect to these tasks and thus may be good alternatives in under-resourced areas.³⁴
- > Patient navigators coordinate care by connecting individuals to resources and services that fulfill unmet needs.³⁵ Patient navigators perform a wide variety of functions, including care navigation, appointment coordination, counseling, and psychosocial support. The primary characteristic of patient navigators is their peer status to consumers. Their peer status allows patient navigators to develop rapport and establish trust with consumers more readily than traditional providers.³⁶
- > Peer workers are individuals who share a diagnosis with fellow consumers. These providers facilitate communication across care systems, help patients connect with appropriate services, and help them to better understand their diagnosis and care.³⁷ "The use of peers in an intervention program has been effective

in that individuals within the program are more likely to listen to someone who has similar experiences and struggles," reported an HIV researcher.³⁸

Workforce Expansion: Implications for Health Homes

While Medicaid Health Homes are also leveraging the non-traditional workforce to expand their capabilities, a 2014 ruling from CMS regarding reimbursement for these staff members was a game changer. CMS now allows reimbursement of a broader array of health professionals for preventive services as outlined in the ACA, including patient education, outreach, counseling, and self-management support (many of the activities provided by case managers). **Prompt action by states that haven't already acted to put the mechanisms and codes necessary for reimbursement into place could help dramatically improve the scope of services Health Homes can provide.**

Conclusion

Health Homes today face the same challenge that the HIV Care System tackled in the past 20 years—how to engage people with complex clinical treatment that will enable them to live longer, healthier lives. Health Homes also face new and more complex challenges. As a service delivery mechanism, Health Homes are intended to serve a more diverse population with heterogeneous needs and diagnostic categories, thereby making standardization of outcome measures complex.

Several different care models are likely needed for the diverse population being served by Health Homes. Health Homes are serving people who are housed and homeless, people who have serious mental illness with and without serious medical disorders, people who have serious health disorders with and without mental illness, and many other distinct cohorts. While people served by the HIV Care System all were HIV-infected, they had marked social, cultural, and behavioral differences, and the interventions that may be efficacious for one subset of the population are not necessarily effective for other subsets.³⁹

Despite efforts at the federal and state levels to reduce gaps in health care access and outcomes, racial/ethnic, gender, sexual orientation, socioeconomic, and disability disparities persist in the US health care system.^{40–41} Health Homes will need to be creative about opening up access to service networks for people who have long experienced disparities in using the health care system.

The HIV Care System has benefitted from a funding model that supports a coordinated, comprehensive service delivery model. The RWCA has had a large influence on HIV care by facilitating the creation of a comprehensive care system to respond to the complex needs of patients.⁴² The Health Home Program, on the other hand, requires contracting with a number of Medicaid Managed Care Plans. These plans will likely have autonomy to develop service delivery models and reimbursement structures to support care integration needed to achieve managed care outcomes.

Given this decentralized approach, some central organizing presence could help standardize best practices and enhance efficiency. A Center of Excellence similar to the New York State AIDS Institute, for example, could focus upon developing a best practice operations protocol, including tackling the question of decision support in collaborative care for a heterogeneous population. Best practices would consist of adaptation of many of the strategies proven effective for the HIV service system, as well as development of new strategies to accommodate the more complex Health Home mission. Such an effort would be scalable to the 35 Health Homes in operation across NYS, and the State could require managed care plan funders to give priority for consumer assignment to and perhaps enhanced funding to Health Homes that are successful in implementing these best practice protocols.

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