

Written Public Input to Statewide Comprehensive Plan Submitted to the Office of Mental Health

June–September 2011

CENTRAL NEW YORK

Dr. Bharati Desai
Hudson River Psychiatric Center Medical Director

Please consider medical home model where patients can see a psychiatrist, internist, dentist, or podiatrist and get blood work done if needed. Having pharmacy on the premises will be even better. This will save money, give coordinated care and avoid many duplicated services for patients not following up. I strongly feel that after working in the Office of Mental Health (OMH) system for 31 years.

Mary Jane O'Connor
Parent, Family Tapestry Board Member

Five years ago in April, I spoke about the lack of psychiatric hospital beds for children in the Syracuse area because we personally experienced it with our daughter having to be treated out of town. Today the problem still lingers even more so because I'm speaking for hundreds of children and their families who have had to deal with this issue. Did you know that in 2009 over 200 children were sent out of town because there were no beds available here? Our own facility here at Hutchings has added a 30-bed child/adolescent psychiatric unit and it has been maxed out on several occasions.

I am on the board of "Family Tapestry" an advocacy group for families and children suffering from mental illness. We have been fortunate to have been invited to attend "Pediatric Mental Health Roundtable Meetings" with Dr. Mantosh Dewan at Golisano Children's Hospital (GCH), Comprehensive Psychiatric Emergency Program (CPEP), Hutchings, and Blue Cross Blue Shield to address the urgent need to have beds available locally for our sick children. Having a child with mental illness at home is stressful and disruptive enough but to have a child admitted to a psychiatric hospital far away is horrible and puts even more of a strain on families.

I know New York State is currently looking for better ways to expand on behavioral homes, treatment plans, etc., but the problem lies currently right from the start that children have to wait months for the initial diagnosis and then have to be treated out of town away sometimes hundreds of miles from their families. Initial diagnosis is crucial to recovery and treatment planning. Onondaga County was recently awarded 5-year Substance Abuse and Mental Health Services Administration (SAMSHA) Grant allowing us the opportunity to establish and streamline appropriate services needed once a diagnosis has been made.

Our children with mental illness desperately need to be treated **locally** just like children with physical illness currently do. They do not need costly operating rooms or the staffing that goes with it, nor do they need an expensive intensive care unit (ICU) and all those related costs. They need a friendly, peaceful, caring facility where they can be monitored while the proper medications are found and their families can be close by their side during this most difficult time aiding in their recovery. Hopefully, with the combination of Upstate and Community General Hospitals a space can be found for a 12-bed psychiatric ward for our children.

Please, please approve GCH the funding needed to provide **local** treatment to our children with mental illness.

Linda M. Wagner

I strongly encourage Dr. Hogan and others at New York State (NYS) OMH to read the book *Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America* by journalist Robert Whitaker. His review of research literature indicates that the psychiatric profession has taken the wrong approach to mental illness for many decades, resulting in a dramatic increase in the rate of long-term permanent disability among people with mental illness. NYS could and should be a leader in new approaches that reduce suffering and disability while increasing effective treatment and productive lives over the long term.



HUDSON RIVER

Wilma Alvarado-Little, MA

There are two areas where there is a need to better concentrate efforts. The first involves the provision of quality cultural and linguistic services. With approximately 29 percent of New Yorkers speaking a language other than English at home, it is imperative for these services to be part of the care plan. By providing a means of effective communication in an area that is challenging to navigate when the consumer and provider speak a common language, it would benefit the NYS OMH to develop strategies for the implementation and delivery of these services. In addition to the implementation of these services, there should also be a component to measure outcomes that could then determine the success of the use of these services along with an evaluation component to identify areas of challenge for the delivery of services.

The second area involves issues confronted by our youth when attempting to access services. Young adults who are in the mid to final years in high school or entering college do not have the resources to support these major life transitions. The lack of resources or direction complicates their ability to perform successfully in an academic setting, therefore compromising their ability for success.

It becomes an even more difficult journey if these young adults are individuals of color or children of immigrants who are under pressure to become "successful" as defined by the host society.

Jacki Brownstein, MPS
Mental Health America of Dutchess County

We are very concerned about the transitioning of our caseload of over 1,000 individuals in targeted case management (TCM) to health homes. Although we applaud the integration of physical and mental health services and the concept of a health home, we worry about the transition time table and the possibility that mental health behavioral care will become secondary to physical health treatment. Unfortunately, historically non clinical behavioral health care is not well understood and its provision has often been subsumed under the better understood medical model. Stronger regulations must be put in place to ensure that behavioral health organizations (BHOs) and health homes utilize the experience of TCM programs in the provision of services. Also, consumer choice must be protected under the State Plan.

Dr. Andrew Kirsch
Recovery Center, Rockland Psychiatric Center

1. Regional unified electronic medical record systems that can be accessed from various clinics.
2. Training in medical clinics about the work done in mental health clinics, including #3 below.
3. Recovery focused services including peer specialists running groups and assisting patients with wellness/health management; groups focusing on wellness, recovery and employment; more vocational specialists helping people at all phases of returning to work, including the pre contemplation and contemplation stages.

NAMI-FAMILYA of Rockland County

Overview: NAMI-FAMILYA recognizes the need for expanding and coordinating health and mental health services for Medicaid recipients in New York State. In Rock land County only a very limited number of health care providers accept Medicaid and only a handful of clinic services exist to serve the estimated 11 ,978* individuals with serious mental illness in our county who receive Medicaid. Some of the most serious gaps in services are in the areas of health specialties such as gynecology, urology, endocrinology, dental specialties (including exodontists, periodontists), audiology, cardiology, pain management, ophthalmology and optometry, etc. Mental health "homes," as we understand them, would provide needed health services for many of these individuals who are currently underserved or not currently receiving health services at all, and would refer those who need specialized services not available to appropriate providers, (*Based on estimated 20% of 59,874 Medicaid eligibles in Rockland County as of March 2010 from County of Rockland Budget & Management.)

Accessibility: Sufficient number and types of services are essential to ensure accessibility if we are to meet the needs of all Medicaid recipients. Health "homes" must be located in accessible areas.

Transportation is an essential component of health care for many Medicaid patients. In many communities public transportation either is non-existent, undependable and inadequate. If people on Medicaid can't get to a health home, they can't get health services. There also needs

to be provision for home health care for some patients who are severely disabled or homebound.

Quality of Care, Compensation of Clinicians, Oversight: One of the serious flaws in many currently existing managed care health services is the fact that physicians and other health professionals must see a large quantity of patients in order to pay high salaried administrators and frequently spend little time with each patient. Adequate compensation of physicians, physician assistants, and nurses must be a component of health "homes" in order to attract and keep well trained, competent, and caring "hands on" staff. Often "quotas" in number of patients required to be seen limit time and attention to individual patients. There also needs to be an oversight mechanism to ensure that services are adequately and efficiently provided, clinicians can devote time on an "as needed" basis to patients. Outcomes, perhaps, could be measured in terms of successful interventions, rather than number of patients seen.

Transition to Managed Care, Continuity of Care: We are concerned that the vulnerable populations we serve not experience constant shifts in health care providers and mental health clinicians. Continuity of care and the relationships developed between clinicians and consumers is particularly important for patients with psychiatric and psychological issues. Patients who have already established relationships with health and mental health providers who do accept Medicaid should be allowed to maintain those patient/doctor connections, which can be so important for recovery.

Flexibility and Choices for Patients: There needs to be some provision for choice of managed care network providers by patients, both for convenience of location and good relationship to clinicians. Randomly assigning patients to health homes will lead to dissatisfaction, failure to follow up on medical regimens, take medications, etc. Especially in behavioral health care, the relationship between the consumer and his therapist is a critical component of successful treatment and rehabilitation.

Multicultural sensitivity: In Rockland County, which has one of the most ethnically diverse populations in northeastern U.S., we are very sensitive to the varying cultural needs of individuals we serve. In setting up health homes, both the regional and the multicultural needs of the community should be addressed. Both health and mental health providers with varying language and cultural background are needed to serve the Medicaid population.

Care Coordination, Prevention: There needs to be mechanisms in place to educate people to the importance of health care, to help link people with psychiatric disorders to preventive health care and medical services, as well as behavioral health care, and to coordinate their health care services and their mental health care. Existing assertive community treatment (ACT) teams need to be expanded and can act as liaisons between health homes and the high risk consumers they serve. Trained peer coordinators can also be helpful in educating and linking individuals with psychiatric disorders to health services. We believe that professional expertise must be a part of all services provided to consumers

Support Staff sensitivity training: Receptionists (greeters), clerical and support staff should be trained, sensitive people who can recognize the humanity of all individuals, and treat them with respect and dignity. So often, we have witnessed staff in settings such as clinics, social services, etc. who treat people receiving entitlements in a demeaning, insensitive

manner. Staff members who come in contact with patients can contribute greatly to engage people, motivate them or, on the other hand, discourage their participation and cooperation.

Integration of Behavioral Health Care and Health Care: Although we recognize the importance of coordinating health care with behavioral health care, we also see the need to utilize trained professionals familiar with all aspects of mental illness. There already exist in many local areas mental health (including Rockland County) providers who have track records in successful treatment and rehabilitation of patients. We, therefore, feel that it is essential in providing contracts to behavioral health providers to utilize the expertise and experience of these providers. We believe a network of behavioral health providers makes sense with care coordinators to link and integrate health and mental health care.

Paige Pierce

Executive Director of Families Together in New York State

General Themes

- Families and youth must be full participants in planning of services on each level (state, local and family levels).
- No Wrong Door ... All children and their families must have timely, affordable access to appropriate services within their community. Services must be seamless and not dependent on payment models.
- Services must be cross-system and flexible to meet needs of family, child-centered, strength-based, family-focused, individualized, and culturally competent.
- Coordinated Children's Services Initiative (CCSI) is the model. It begins the Children's Plan and was developed with input from families, youth and providers. It reflects a cross-systems approach.

Medicaid Redesign, Behavioral Health Organizations (BHOs), Health Homes, Spending and Government Efficiency (SAGE) Commission

- We need a separate plan for children, based on the Children's Plan and CCSI.
- Kids BHO Work Group has prepared comprehensive recommendations that we support.
- The service models that are most flexible, able to deal with cross-system, and are most liked by families are family run, peer to peer family support, waiver and respite.
- New payment models need to respect independent nature of family run peer to peer, family support and find mechanisms that compensate these programs for their services. These services are as important as the traditional "medical" model services.
- We support peer-to-peer family run family support as a Medicaid billable service and we support requirements that contracts with peer services be required in contracts with BHOs and health homes.
 - We support credentialing of Family Support Specialists.

- Transparency and oversight are important and must include consumers in the oversight body.



LONG ISLAND

Marc Ducker

Consumer Link, Mental Health Association of Nassau County

Try to add or replace many segments of the service system with peers and peer-run services. Peers should be seamlessly integrated whenever possible, for example, transportation for nondangerous patients; emergency room intake process/support; on-ward support; crisis respite emergency room diversion; longer-term respite housing; assertive community treatment (ACT) teams; inpatient and outpatient individual support, case management, and support groups; peer mediation (housing disputes, etc.); peers in personalized recovery-oriented services, rehabilitation, and benefits counseling, etc.

Dr. John Kastan

Executive Director, Peninsula Counseling Center

While it's clear that reducing State Medicaid expenditures (and expenditures, in general) are at the core of many of the initiatives that are being given high priority by the MRT, I do believe that many of the individuals on the task forces are truly interested in improving the system of care for individuals on Medicaid. I do think there is a need for OMH, the Office of Alcoholism and Substance Abuse Services (OASAS), and the Department of Health (DOH) to articulate how the various initiatives being pursued fit together. To those of us in the field attempting to 1) keep up with the new initiatives and 2) maintain viability as providers, the more information we have the better in order to develop strategic approaches to continue to be able to serve the State's most vulnerable residents.

The sole focus on reform of the Medicaid system—the State's priority— without recognition that providers serve New Yorkers regardless of their payor status is problematic for providers. To dismiss the needs of non-Medicaid individuals as “not the State's problem,” is bad policy, bad politics, and bad public health. There needs to be in a statewide planning document recognition that the mental health of all New Yorkers is a priority and focus. To view OMH-licensed agencies as merely Medicaid providers is short-sighted and does not reflect the reality that such entities are the safety net for a whole host of individuals, and is part of our not-for-profit missions.

The effort to integrate physical and mental health is of course laudable. I hope that it is informed by the reality of care delivery on the ground, the economic incentives at work, the culture of medical specialty care, and the like. I believe it will take more than “care coordinators” to significantly change the interactions among consumers with multiple co-morbidities, primary care providers, specialists, and hospitals, and to achieve the kinds of behavioral changes needed to assure adherence to complex medical regimens, etc.

I am pleased that the State has recognized the unique needs of children and adolescents, and is developing a separate focus on children's services. I hope that there are sufficient resources provided to address the complex care coordination and assessment needs of children, as well as recognition of the dearth of child psychiatrists in the public-oriented system. While I understand the decision to eliminate the clinic plus program, I do hope that the focus on early identification, screening, assessment, and engagement is not lost. Despite the overall poor performance against unrealistic targets of the clinic plus program, there are, in fact, success among the cohort of clinic plus providers, and lessons learned that should not be lost.

I am troubled that there is no provision in the Medicaid regulations for mental health services for homebound individuals. Particularly in the face of changing demographics and the desire for aging at home, both to save dollars and improve quality of life, it seems short-sighted of CMS. Perhaps the State needs to take it upon itself to fund this service, which, if utilized correctly, can improve adherence, reduce emergency room and inpatient stays, and improve quality of life for those who cannot be expected to travel to a provider location.

Jeanne McGough

Outreach Coordinator, Mental Health Association of Nassau County

Please take into account the historical territoriality long known and unfortunately defended by the separate mental health and substance abuse service providers, which needs respectful and firm dismantling for a segue into co-locating behavioral services with physical health care. Peer supports should guide the development of health homes and other innovations in approaching overall recovery.

Vigorously recruit peers, including young people and their families, to help move New York closer to evidence based, person-centered, family focused care, based on the principles of recovery and resiliency that they practice daily.

Barbara Roth

President, Board of Visitors, Pilgrim Psychiatric Center

Given the fact that a large number of individuals occupying inpatient beds no longer need that level of intense care a new and innovative program has been developed. Restoring confidence and giving individuals the tools necessary to work toward their recovery has been extremely successful in the new Transitional Placement Program. Providing a less restrictive level of care coupled with developing strong community living skills results in enhancing the desire to work harder to reach all their recovery goals.

The fact that these transitional wards are unlocked and the residents are able to walk in and out freely affords the individuals the ability to make their own decisions and settle on the goals they wish to complete in order to fulfill their dream of returning to their community. Just the freedom (to go out in the fresh air and be able to walk around instills in each person the desire to continue on the path to complete freedom. Some of the skills and services needed to foster success are medication management, assertiveness, symptom management, vocational planning and peer support to mention a few.

For our staff the challenge of working on a new program requires many changes in their thinking. However knowing the dedication and deep commitment to those they serve they leave no stone unturned. Nothing is ever too much for them to tackle no matter how difficult the transition may be. Establishing workgroups to address the issues individuals may face living outside in their community are well defined and are reinforced during the day in an open ward. Changing their perspectives from inpatient to community based services is needed for them to meet with success.

Recognizing the changes necessary to be made on the part of the individuals and the staff as well to create a positive atmosphere; one can feel very optimistic about the future of those who will be able to regain a life that has been on hold for some time.



NEW YORK CITY

Robert Brassell, Jr.

Promptly conduct level-4-equivalent background checks on each and every homeless shelter “resident” within and without New York City (NYC) so as to at least know who and what you are dealing with.

Wendy Brennan, Director

National Alliance on Mental Illness of New York City (NAMI-NYC Metro)

New York State’s mental health system is undergoing an unprecedented transformation at a time of severe budget deficits and fiscal scarcity. Health care reform is a reality, at least for the present, through the Affordable Care Act (ACA), which holds the promise of expanding health care coverage for millions of Americans and includes a provision to establish health homes to more effectively coordinate the care of Medicaid recipients with chronic illnesses. At the same time, a new federal mental health parity law aims to improve access to mental health treatment for people with employer-based health insurance, while a Medicaid Redesign effort will change the way adults with serious mental illness and children with serious emotional disturbance on Medicaid receive services over the next two years.

The need to improve the current health care system is great, particularly for those impacted by mental illness. We are concerned, however, that some of these changes are being implemented at lightning speed—too quickly to produce the best outcomes.

The New York State mental health community, specifically children, youth and adults and their families who are impacted by mental illness directly, are extremely fortunate that Commissioner Hogan is providing leadership in this dynamic environment. He has a great capacity to understand the details of a complicated system, and the vision and passion to imagine what transformation at its best might look like.

I would like to focus my comments on the importance of peer-led mental health services and integrated health and mental health care as essential components to promote recovery.

Peer-led services: By November 2011, New York State expects to establish health homes, through a provision of the ACA that aims to improve care coordination for people with serious mental illness and to integrate delivery of their health and mental health services. We are very concerned about the speed of the health home implementation process and the lack of sufficient dedicated resources to ensure that health homes are able to provide quality recovery-oriented services. We are also concerned that the rhetoric about the importance of inserting consumers and families in treatment may not have a corresponding action. The current reality is that the mental health system rarely allows people with mental illness and their families to participate in treatment in a meaningful way. A dramatic change in culture will be required to make the rhetoric a reality, but culture is stubborn and very difficult to change.

To help facilitate real change, we reiterate our support for including peer-led support and education programs in health homes now and as part of the special needs plans when they are established in two years. When consumers and family members provide psycho-education to their peers, the stigma associated with participation decreases and the utilization of this essential information increases. Consumer-led education programs reduce stigma and isolation. They give individuals tools to understand and manage their illness more effectively, and they promote recovery. Family-led education and support help relatives to understand their loved one's illness and better care for themselves, and ultimately allow them to provide more support for their loved one.

Integrated care: One of the essential goals of the health home provision is to integrate health and mental health care. Integration is essential to eradicate stigma, improve outcomes, and promote wellness and recovery. In the mental health community, we continue to quote from the 1999 U.S. Surgeon General's report by saying that "there is no health without mental health." But the converse is also true: there is no mental health without good health.

To maximize integration, we recommend the following:

- Education about mental illness should be required for all primary care physicians and other health providers who are part of the health home network.
- Hospitals in health home networks should be required to train their medical staff to care for people with mental illness, providing information about psychotropic medications and how to appropriately interact with someone with mental illness. We have heard from our members that patients often do not receive their psychiatric medications when they are hospitalized for a physical health reason, which can trigger a relapse.
- One of the essential aims of the ACA is to improve access to medical information through electronic medical records. Access to accurate and complete information is essential for all quality health care treatment, but is particularly important for people with mental illness. We recommend as part of care coordination a provision to require that information about an individual's mental **and** physical health follows him/her from the community to the hospital and back. Hospitals in the health home networks should be required to train their psychiatric staff to address consumers' physical health needs, including providing appropriate medications in the hospital to address conditions such as heart disease and diabetes.

- Peer-led wellness programs must be an integral part of health home networks to address consumers' health needs and help them to set achievable wellness goals. People with mental illness are much more likely to address their physical health needs, including smoking cessation, weight reduction and exercise, with support from a peer. As an example, the health coaching program developed by the Department of Consumer Affairs at the New York City Department of Health and Mental Hygiene is a very effective model, one we have brought onsite to NAMI.

Finally, NAMI-NYC Metro has advocated strongly for establishing a Medicaid Redesign Team (MRT) subcommittee to address the needs of children with serious emotional disturbance and their families. We are pleased that children's health homes will not be implemented immediately. The needs of children and their families are different from those of adults, and we believe that more inter-agency planning is required to ensure the best outcomes for children with serious emotional disturbance. We cannot improve those outcomes, however, without taking into account the roles played by other child-serving systems, including education, child welfare, and juvenile justice, which are not funded by Medicaid dollars.

Through our family support programs, NAMI-NYC Metro annually serves more than 1,100 families with children under the age of 24, many of them referred through the Administration for Children's Services, New York City's child welfare agency. We have found that at least 15% of the parents we serve have serious mental illness themselves and need treatment. Health homes designed to treat adults with serious mental illness and future health homes established for children with serious emotional disturbance must make provisions to address parents' mental health needs. Finally, we believe that health homes for adults must include developmentally appropriate services for transition-age youth (18- to 24-year-olds).

Ms. R

The only person or entity that has the responsibility for and right to make decisions for my mind my body or my healthcare is **me**.

No one has the license to make decisions about my mind and body **for** me. Health homes should have responsibility to make services **available**.

ONE: Increased information access alone may provide (more economically) the improvements aimed for with the health homes model.

I believe that the regional health information organization (RHIO) efforts to allow doctors to access most computer records for their patients would solve many of the problems that health homes aim to solve. Most doctors want their patients to be as healthy as possible. And doctors already know they must work within a budget. And they try to avoid lawsuits. The health homes model doesn't change doctors' behavior. Many general practitioners did not go the medical school to become administrators.

Two: Problems with wording could lead to forced or coerced health and psychiatric care.

re-spon-si-ble adjective 1. answerable or accountable, as for something within one's power, control, or management (often followed by to or for)

(<http://dictionary.eference.com/browse/responsible> )

The words “responsible” and “accountable” may or may not imply control. By when contained in a legal or regulatory document there is no protection against one or another interpretation. After all, it makes sense that health homes cannot assure health or savings if patients refuse care, can they? Hence these words beg qualifications and/or footnotes whenever they appear. The footnote should read: “patients retain inalienable decision making rights over their minds bodies and care thereof.”

These words “accountable” “responsible” and “for” appear frequently in literature on health homes. Some samples:

<p>“That home then becomes accountable for all the individual’s care” </p>	<p>My comment: It can be argued that one cannot be held accountable without the ability to control.</p>
<p>“To achieve the goal to have an accountable entity managing behavioral health services and promoting the integration of medical and behavioral health services“ Proposal to redesign Medicaid Proposal No. 93 MRT No. 171.1</p>	<p>My comment: Accountable does not always give control. But a word with multiple meanings can lead to a future definition that would harm many people.</p>
<p>“In addition, consumers and caregivers will have the benefit of having a single entity that is responsible for assessing, implementing and monitoring plans of care.” Proposal to redesign Medicaid Proposal No. 90 MRT No. 54</p>	<p>My comment: Please add the clause, “in conjunction with the consumer’s wishes.”</p>
<p>“Health Homes must develop a care plan for each individual...” </p>	<p>My comment: The word “for” should read “with”: “for” insults.</p>
<p>“Develop a person-centered care plan for each individual...” </p>	<p>My comment: The fact that the author uses the word “for” shows their opinion of consumers.</p>
<p>Impacted Stakeholders: <ul style="list-style-type: none"> • Providers and administrators of services to Medicaid beneficiaries • Industry associations • Social community support and service providers. Proposal to redesign Medicaid Proposal Number: 89 MRT No. 57</p>	<p>My comment: Observe failure to include people receiving the services as stakeholders. This author demonstrated a lack of respect for people with serious mental illness and should therefore never make any decisions or design any programs for them.</p>

I believe that the people who put these words in the health home documents did **not** intend to impose control of people diagnosed with serious mental illnesses. They did not intend that health homes nor any other health insurance entity could retaliate or deny medical needs to or housing to anyone on the basis of their refusal of services or complaints. To assure their objective, kindly remove all words that give responsibility, accountability or other words implying this to all documentation about health homes.

Three: Some misconceptions that may have led to the wording. Some people have the impression that everyone diagnosed with a serious mental illness is less capable than everyone not so diagnosed.

Most people diagnosed with serious mental illness have the competence to make decisions for ourselves at least as wisely as the average citizen. Many of us have high IQs, common sense, experience and personality way above average. But even those of us who struggle in one or more ways have the human right to self-determination.

Moreover, every person in the world is an individual and should be perceived as such not as merely part of groups.

I think some innovators of health homes may have forgotten the above concepts.

Different language in accountable care organizations (ACOs). By contrast to health homes, discussions of [ACOs](#) (also part of the ACA) had phrases like “People with Medicare will have better control over their health care” and, “We envision that [successful ACOs will honor individual preferences](#) and will engage patients in shared decision making.” Why such a difference? The difference in terminology may come from the unfortunate opinions about people with mental illness that too many people who work in the mental health field have. By nature health homes see people with mental illness as a group rather than as individuals with the same variance in personalities, intelligence, and talent as the whole population. I wish OMH would demand that people whose jobs influence the lives of people with mental illness would have an enlightened point of view.

Four: Evaluating health homes

All health home evaluations should include patient evaluation based on patient values. The State evaluates based on the State’s priorities:

But the State’s goals of reducing “hospital readmission rates” may diverge from the goals of the patients. If people need to return to the hospital, health homes could deny that need in order to pass its own evaluations. If a health home denies a client’s request to return to an inpatient unit and someone hurts themselves, then this goal to reduce hospitalization **must** disappear. Conversely, if a person already hospitalized has their stay unjustifiably prolonged so as to perhaps diminish the chance of return that violated the right to freedom. The health home should not have these as goals. And, if the health home system does make a difference it will do so **naturally** without a need for stating these as a goal.

When health homes come up for evaluation, the benefits of improved information exchange should **not** count toward the benefits of health homes. Otherwise health homes may appear more useful than reality. All benefits of the RHIO should be attributed to the RHIO. (Wikipedia defined RHIO as “motivating and causing integration and information exchange among stakeholders that region’s revamped healthcare system.”)

What if the health home evaluation comes while receiving extra federal dollars and when those allocations finish the health home performs poorly?

What if these health homes do not provide us with better care?

How many years before patients can leave health homes to find better care?

If health homes provide poor service and little improvement, will they discontinue?

How easy and quick will the appeals process be? What may I appeal? What may I demand? What if I must wait a longer time for an appointment than those outside my health home?

Regarding consumer evaluations: Please remember that when a person with serious mental illness would like to complain his/her disability and a fear of retribution make this difficult. So you should never assume that few complaints mean few problems.

Five: Health home control over me

If health homes in fact receive the legal right to control my body and mind—they will decide my medications—both what I must take and what I may not have. In fact these homes might eventually argue that they have a right to control what we eat and my lifestyle choices. Patients could lose privacy so they can be monitored. If a patient does not follow the health homes directions they could lose their medical care and medications and even housing. You will basically be putting all of us under assertive community treatment (ACT) without having to go to a judge, despite our competence. In many ways health home will have broader control than ACT.

What you propose doing with health homes will make me feel like a criminal under house arrest. This is my body and my brain and the only person who has the right to make choices for it is **me**.

I am not stupid nor a baby nor do I lack common sense or lack motivation. No one has the moral right to disable me by taking away my autonomy. Maybe some people might choose this service for a limited time when they are very sick. This phrase, “the whole person,” often used benevolently, here means I will lose 100% of jurisdiction over my mind and body.

The health home might **not** go to extremes when first augmented, but it will have the legal right to if it is accountable.

Adverse reaction to repression: Ironically, of all the groups to try to control, a high percent of this population is significantly adverse to suppression, especially from staff with obviously lower IQs. Some may have a reaction leading to immediate hospitalization others will internalize their frustration increasing their depression or anxiety, decreasing their functioning and requiring more medication.

So, all implementations of health homes must guarantee that nothing in the laws/regulations/wording in any way gives the homes legal rights to any person, their body their health their lifestyle. Not can any law take a person’s responsibility for him/herself away and give it to any other person or entity, except by a judge on a person-by-person basis and only if he or she is indeed incompetent.

Six: If a health home is tied to one’s physical address

If a health home is tied to one’s physical address it will ghettoize people. Those of us in housing do not have control over where we live. My program moved me from one area of the City to another against my will. I take the subway all the way back to my old health care provider because it is infinitely better than my neighborhood options.

If I had been told when I moved that I would have to change my doctors I would have appealed on the grounds that it would damage my physical and mental health. Removing me from the therapy group I have participated in for nine years would not improve my mental health. Health homes should first “Do no harm.”

Seven: You won’t save money because health homes pay for decisions

Health home structure will require “decision makers.” When I make a decision about my healthcare I do not bill Medicaid for that decision. But health homes will take Medicaid money **away** from actual healthcare and use it to pay people to make decisions for me. And those decision makers can’t work without supervisors and managers and cost accountants and lawyers and computers and their own healthcare **all** for something that currently **costs** nothing. Health homes should only use 10% of their government money for all their administration.

And will they make better decisions? Better is an opinion. Heated debates take place over health and medical issues. People are so different—including culturally different—so how can sweeping decisions meet the best needs of all these people? And each person has the right to act in accordance with their own option. Just provide (unbiased) healthcare education, give them a budget and allow them to choose their priorities.

No one says people should have a right to the most expensive healthcare for free. But within what Medicaid can pay for exists room for a vast number of combinations. And patients should make those decisions, **not** a very expensive administrative decision committee.

Eight: Checks and balances

Currently, if I have a problem with my housing I can tell my psychotherapist who works for a different entity. And if I want to change psychiatrists I ask my housing agency for assistance. But if they belong to the same agency, where can I turn to for help? I could have a major imminent complaint about my care

Nine: Additional concerns

- I believe that the health homes will not provide quality care for disorders unrelated to mental illness, e.g., cancer, hip replacements, allergies, stroke, lupus, etc.
- How will I know whether the Medicaid “comparability” requirement waiver has allowed for fair care? How can I demand fair allocation?
- What if I must return to an inpatient mental hospital and I do not like the hospital my health home has?
- Can recipients choose between discretionary services?

No one has the license to take my rights away from me and give them to another person or entity without a judge.

Marguerite Harder, LCSW-R

The plan should include regulations and financing, to facilitate existing agencies in developing and providing services to high-needs individuals. Recognition of programs that provide services to a majority of high utilizers, as determined by the severity or complexity of

their illness, should be provided financial supports. This could be achieved by including flexible dollars to allow targeted financing to support the utilization level of high-needs individuals.

Jayette Lansbury

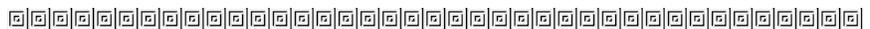
- We need to have more family involvement allowed at the forensic facilities.
- We need to move the patients through forensic facilities more quickly for those that are stabilized!!!
- We need more transparency at forensic facilities.
- The forensic facilities should be family friendly.
- More visitation days are needed in forensic facilities.

Edward Ross

Suggestion: Increase the amount of benzodiazapines that can be prescribed to a patient at a time. Presently, our psychiatrists say that they are limited by NYS to providing only a 30-day supply. This means that they must see the patient and bill Medicaid for monthly visits—even if there is no medical necessity for such frequency, for stable patients assessed as at minimum abuse potential. Other states allow prescribers to provide greater amounts than New York, a two- or three-month supply.

Benjamin Sher, MA, LMSW
Director of Training & Staff Development for Institute for Community Living

I think it crucial to prepare the workforce as much as possible for the many changes that are coming for the behavioral health system. We need to especially focus on case managers, whose roles will really change in a health home and BHO environment. At least at our agency, these are often staff with the least amount of formal training who will now be asked to coordinate care for persons with serious and mental illness. I think OMH should conduct a competency analysis and survey study as part of its next plan.



WESTERN NEW YORK

Karen Albanesi

Intensive Case Manager in Niagara County

I find that when you are dealing with youth you cannot make a family whole without including the caregivers. Many of our families lack parenting skills, or had babies at very young ages and do not have the life experience of having a stable family life to nurture children. We see from the get-go what goes on in the family structure and find it ironic that our services do not include linking families to parenting classes and the like. We have a Family Support Group within our agency and we could assist families by using service dollars, but we cannot access that service for the family in need as it is not in our regulations for case management. I hope you would address this issue in your planning.

Johanna Ambrose, Director

Compeer – New York State Region

Thirty-eight years ago, during an earlier time of change, a concept was born to help people who were inpatients reintegrate into their communities. This concept became known as Compeer, and introduced the simple idea of friendship into the complex mental health system.

The Compeer model incorporates the three elements of support—autonomy, relatedness, and competency. In implementing this model, we collaborate with many community partners. Caring, trained community volunteers are matched in one-to-one supportive friendship and mentoring relationships with adults in mental health recovery and youth with emotional challenges. The adaptability of the model allows Compeer to create programs serving youth with an incarcerated parent, the elderly, and a new one-to-one model program serving veterans, CompeerCorps, now operating in Utica, Rochester, and Buffalo with plans for more locations in New York.

Compeer programs are not only best-practices based, but evidence based. Our annual survey, filtered for the 21 community-based programs in NYS, reports by the numbers:

- Nearly 3,000 individuals, and their families, are served every year.
- Last year Compeer volunteers contributed nearly 85,000 hours in service. Because of this strong volunteer base, our services remain highly cost-effective -- \$1,275/match /year.
- Overall, respondents agree that the Compeer relationship has a 92 percent-plus impact on the client's life.

Additionally, Compeer programs are driven to positive outcomes, including:

- Independent living
- Positive change or stability in housing
- Positive change in employment status
- Greater engagement in community

- Improved resistance to drugs and alcohol
- Decreased need for crisis services

The real Compeer story, though, is not in the numbers. It is the story of personal success occurring in individual lives.

- The client who became a volunteer and says of the original match, “The friendship we shared was a life changing experience...that allowed me to evolve into the confident woman I am today.”
- Bonnie, a teacher, who mentored 10-year-old Kate, who now holds a bachelor of arts degree in sociology. Bonnie says, “Ours is a wonderful story of mutual growth...of two people meeting, and having their lives equally enriched.”
- The volunteer with diabetes and her friend with diabetes who support each other in illness management, such as diet and exercise regimens.

Compeer is a transformative model for engagement using natural supports in natural settings. It was relevant 38 years ago, it is relevant during this time of change, and it will continue to be relevant as long as people need the healing support of each other.

Lucille Sherlick

Behavioral, mental, physical health services housed in one space along with educational, vocational and social services would recognize that human health is multi-dimensional and the best approach is a holistic one where the needs of the whole person are addressed. We know that when people have work and feel productive their health improves and that when preventative services are readily available, the outcomes benefit the person, the community and the financial well-being of the State.

Tamre S. Waite, Director, Schuyler County Office for the Aging Community Input from Schuyler County

1. Medicaid redesign must not leave those most vulnerable without services!!
2. Rural Counties do not have multiple providers, and ancillary programs are also scarce, so the loss of a program due to funding cuts will lead to individuals not served.
3. People with serious mental illness in rural areas already lack options for treatment, and a portion goes without any treatment.
4. Transportation problems are significant and lead to no shows, cancellations, and drop outs. Even with public transit issues, individuals may not be able to independently navigate the system and may not have the supports available for assistance.
5. Local governments have had to cut back and curtail support of mental health treatment over the last three years. This has led to individuals going to the hospital,

- and emergency rooms for care at a crisis level and sometimes even prior to a crisis thus driving up costs of treatment.
6. Further cuts to local services will reduce the endangered safety net and lead to increased use of higher level services, and the criminal justice system.
 7. Lack of mandate relief reduces the local funding available for people with mental illness, developmental disabilities, and substance abuse disorder.
 8. Integration of primary and behavioral healthcare requires careful consideration regarding the rural community environment and culture.
 9. Care management design must consider the assets available in the rural community and the deficits.
 10. Administrative and fiscal issues related to integration must be developed and allow for success in the rural community.
 11. Support for peer worker development in the rural community needs to be encouraged and supported.
 12. The ability to share information, especially treatment plans, and progress documentation within an integrated care system is paramount.
 13. Serious effort to balance the medical model with one of a relapse recovery is essential if the Medical Home is to be successful.
 14. The holistic approach to the person in need is something the behavioral health system can bring to the medical table that is much needed in the rural setting.
 15. The funding, capacity and competency to do assessments and deliver care in a person's home is a key to building and strengthening individual resiliency.
 16. Evidence-based care is a laudable goal that should remain in the forefront; however, the rural community does not have the kinds of talent, training and array of evidence-based practices necessary given the full range of needs. Support must be provided in this area to bring the right treatment to bear.