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Testimony Before the NYS Legislative Joint Fiscal Committees

Mental Hygiene Budget Hearing February 14, 2012

Presented by

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On Behalf of NYAPRS Members and
The NYAPRS Public Policy Committee
Co-Chairs: Ray Schwartz, Carla Rabinowitz

NYAPRS Board of Directors
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The New York Association of Psychiatric Rehabilitation Services represents a statewide partnership of tens of thousands of New Yorkers who use and/or provide community mental health services and who are dedicated to improving services and social conditions for people with psychiatric disabilities by promoting their recovery, rehabilitation and rights.

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I'd like to thank the chairs and members of the mental hygiene and finance committees for this opportunity to present to you the concerns of the thousands of New Yorkers represented by the New York Association of Psychiatric Rehabilitation Services. NYAPRS is a unique statewide partnership of New Yorkers with psychiatric disabilities and the community mental health professionals who support them in over 100 community-based mental health agencies from every corner of the state.

I'm Harvey Rosenthal, NYAPRS Executive Director. The following testimony that I will present incorporates the direct input of many hundreds of NYAPRS members who gathered at local forums that were conducted this past fall and winter in localities across the state including Watertown, Buffalo, Rochester, Syracuse, Owego, White Plains, Newburgh, Lake Placid, Amityville and Brooklyn.

You may have seen our members out in great evidence last Tuesday. Throughout that day, the Capitol was filled with over 800 spirited mental health self and system advocates who came to urge their state legislators and Administration officials to advance policies promoting their recovery, rehabilitation and rights. I've attached some examples of media coverage of those efforts below.

State mental health policy is a very personal matter for our NYAPRS community. Many of our members, our board members, our staff and I all share a common personal journey of recovery from a psychiatric disability. We believe this strengthens our ability to speak to you on behalf of the thousands of New Yorkers with psychiatric disabilities and their supporters that we represent.

Our community greets this year's Executive budget and MRT proposals with the following reactions and recommendations.

First off, I'd like to extend our great thanks to the Administration and the Department of Health for extending to us a number of important opportunities to be heard on a broad range of issues associated with the Medicaid Redesign Team's considerations.

This process gave me the honor to serve as a member of the Medicaid Redesign Team and on the MRT's Behavioral Health and Affordable Housing Work Groups, along with sub groups on pharmacy, health homes and peer run services.

I also want to extend our community's great thanks to Governor Cuomo, who in his State of the State message emphasized his commitment to see that "people with disabilities have (the) right to receive care in the most integrated setting appropriate to their needs," committing our state to "provide access to affordable and accessible housing, and promote employment of persons with disabilities."

Serve New Yorkers with Psychiatric Disabilities in the Most Integrated Community Setting

Background

NYAPRS members are passionately committed to advancing policies that ensure that people with psychiatric and other disabilities are fully afforded their rights to live and work in the most integrated community setting, in keeping with the Americans with Disabilities Act and the Supreme Court's Olmstead decision. Accordingly, we strongly support the following:

Housing

NYAPRS members view affordable community based housing as an essential human need that is strongly tied to good health and reduced institutional costs.

Accordingly, NYAPRS members strongly support Executive budget proposals to:

- create a Supported Housing Reinvestment fund from Medicaid savings from hospital and nursing home closures or bed de-certifications to expand supportive housing and related services, explicitly including peer support and employment services.
- 3-year commitments to create 1,000 supported housing units for residents of nursing homes (\$10 million this year) and 3,400 beds for the NY-NY III program.
- In addition, NYS should establish a 10% set-aside program for high-need individuals with disabilities.

Bringing Justice to Adult Home Residents and State Hospital Residents

A federal court found NYS in violation of Olmstead and the ADA in the segregation of 4,300 NYC residents with psychiatric disabilities in adult homes, which it considered "segregated institutional settings that impede integration in the community and foster learned helplessness." The state has appealed that ruling. NYAPRS strongly feels that NYS must no longer delay meeting its responsibility to provide the supports necessary to help adult home residents with psychiatric disabilities to move into the community. Accordingly, we strongly support the Executive budget proposal to fund:

- 5,100 supported housing beds over the next 3 years to deal with "emerging needs", including \$16.8 million for adult home residents named in the lawsuit.

Expand Employment Options and Services

NYAPRS members strongly support the Governor's and OMH's proposal to

- expand the Ticket to Work program to boost federal employment funding incentives and reimbursements for services that successfully help New Yorkers with disabilities to return to the work force.
- support individuals to move from segregated outmoded sheltered workshops to employment focused Personalized Recovery Oriented Services.

Develop a NYS Olmstead Plan

NYAPRS members enthusiastically welcome Governor Cuomo's commitment to

- "develop an Olmstead Implementation Plan that will guide the transition of individuals from institutional to community-based care, provide access to affordable and accessible housing, and promote employment of persons with disabilities". Such a plan must set measurable targets and dates by which public dollars and people with disabilities are supported to move from segregated to identified most integrated settings.
- re-energize and re-focus the state's Most Integrated Setting Coordinating Council.

Reinvest Savings from State Hospital Downsizing Person-Centered State Hospital Discharge Planning

Background

Too many hospitals for too much money: New York State currently operates 27 state psychiatric hospitals (almost 7 times the national average), houses fewer individuals per campus than other similar states (most states house similar amounts in 5-7 facilities) and topped the nation in cost (our \$1.2 billion comes in at more than the combined total of other top states Pennsylvania and New Jersey).

Olmstead Requirements: In this year's state of the state address, Governor Cuomo emphasized the state's commitment to "develop an Olmstead

Implementation Plan that will guide the transition of individuals from institutional to community-based care, provide access to affordable and accessible housing, and promote employment of persons with disabilities". Such a plan must set measurable targets and dates by which public dollars and people with disabilities are supported to move from segregated facilities, like state psychiatric centers and adult homes, to identified most integrated settings.

Reinvestment: In 1994, the NYS Legislature passed the Community Reinvestment Act which authorized the closure of 5 state hospitals and reinvested a portion of the savings into creating an estimated \$200 million of community recovery services. In succeeding years, the legislature has suspended the requirement to reinvest savings from closing additional hospital wards and used those funds for deficit reduction.

In 2007, the state closed Middletown Psychiatric Center and reinvested about \$7 million into boosting services in the surrounding counties.

In 2011, the state authorized the closure of Hudson River Psychiatric Center and has committed several million dollars to surrounding county mental health systems.

In the proposed 2012-3 budget, the state proposes to close Kingsboro PC and several more wards without a definitive reinvestment formula.

Recommendations: **The NYS Legislature should restore the original Community Reinvestment Act's formula and requirement to reinvest a portion of savings from state hospital downsizing/closure to boost local community recovery services. This requires eliminating the 'notwithstanding' language in the Executive proposal.**

Person-Centered State Hospital Discharge Planning

Background: NYAPRS members share strong concerns about the pace and the quality and continuity of transitional and community care afforded to residents of closing state hospital facilities and wards.

Recommendations: NYAPRS members strongly believe recovery in the community should be expected and offered to all, including those we have traditionally institutionalized in the largest and costliest state hospital system in the country. To ensure that proposed closures and downsizing of that system are done properly, we call for a process that ensures:

- Person-driven community recovery and service plans with sufficient time to put individualized supports in place prior to discharge
- Substantive use of peer supports, including peer bridgers, warm lines, crisis respite programs
- A transition team from each community being affected by the closure will meet to design a strategic plan in preparation for the closure
- Behavioral Health Organizations and Health Homes will be active members in the transition and will prioritize services for individuals
- Tracking of post-discharge Medicaid and non-Medicaid reimbursable services and recovery outcomes as outlined in the discharge plan

Reinvest Medicaid Inpatient and ER Savings to Expand Housing, Peer Support and Employment Services

Governor Cuomo's 2012-3 budget continues to substantively re-shape our health and mental healthcare systems in ways that are intended to improve care

coordination and integration and maximize alternatives to Medicaid hospital and emergency room care through the use of Behavioral Health Organizations, health homes and, starting next year, the integration of service dollars and services for New Yorkers with serious mental health and substance use conditions from the current fee for service carve out into a fully capitated Medicaid managed care program.

While NYAPRS members strongly support these approaches, we believe that they will succeed *only* if the state dramatically expands the amount and array of **community wellness, prevention and support systems** on which New Yorkers with serious medical and behavioral health conditions will rely.

Otherwise, we will only be repeating the deinstitutionalization failures of the past where we closed the door to hospitals and ERs **without** placing sufficient services and supports in the community.

SIMPLY IMPROVING PEOPLES' CONNECTION TO MEDICAL SERVICES AND MEDICATIONS WILL NOT BE ENOUGH!

There is substantial data showing that addressing **housing and economic instability and social isolation are needed and can produce striking results in reducing avoidable relapse rates and costly ER and hospital visits.**

- A 2002 University of Pennsylvania study found **supported housing** produced an average of **\$16,282 in savings** from reduced use of hospitals, ERs, shelters et al.
- A 2010 study by OptumHealth found that **peer bridger hospital-to-community support services** reduced Medicaid hospital days by **73%** in Tennessee, **44.1%** in Wisconsin
- A May 2006 Mathematica study found that **working** Medicaid beneficiaries dropped their Medicaid dollar utilization by **40%**

NYAPRS members strongly agree with the findings of the Governor's Medicaid Redesign Team, which concluded that "*savings from better managed behavioral and physical health care should be reinvested to the extent possible for improved outcomes and reduced health costs. Reinvestment should prioritize non-clinical support services, such as housing, peer, employment, and family services.*"

This would build on successful models that moved public mental health services to managed care and required plans to reinvest savings into community like neighboring Pennsylvania, where one plan created \$60 million of supported housing.

Accordingly, we urge the Legislature to:

- **Expand the 'Supportive Housing Development Reinvestment Program' and extend discretionary reinvestment authority to OMH to include local peer support and employment services.**
- **Ensure that, as New York heads for 2013 implementation of fully capitated Medicaid managed care systems, all proposals and contracts are written to explicitly require reinvestment of state and plan savings into local housing, peer support and employment services.**

Support for Other Reinvestment Initiatives

NYAPRS members also strongly support a range of innovative initiatives in the Executive Budget proposal including:

- Innovative 'First Break' Initiatives which will reverse past service responses to those first experiencing psychosis, moving from expectations of life-long

incapacity and patienthood to ones of recovery, self management and a full independent integrated life in the community.

- Information Technology (IT) enhancement grants for mental health providers to support capacity development for transition to a managed care environment.
- mobile rehabilitation and crisis teams,
- a training program to help primary care physicians improve early identification of children with behavioral health needs
- reforms in the Sex Offender Management and Treatment Act (SOMTA)

Protect Consumer Rights & Choices in New Medicaid Initiatives

This year's budget incorporates an unprecedented number of groundbreaking changes and reforms to our healthcare and social support systems that, while they may ultimately improve care, can limit beneficiaries' choices and privacy protections. Examples include:

- assigning Medicaid beneficiaries to the new health home networks of care but giving them the opportunity to "opt out,"
- requiring individuals to enroll in Medicaid managed plans that will limit choice of services and providers and
- sharing patient information broadly through the use of electronic records.

At the same time, health homes might give people new opportunities to review the effectiveness and appeal of their current providers and treatments and to more actively direct their care...if they get the information and support they need.

The NYS Legislature can ensure that New York best protects the health and rights of Medicaid beneficiaries by engaging in **strong monitoring functions to see that the Department of Health:**

- **Education:** Adequately provides a widely available array of culturally and linguistically competent and understandable educational materials and strategies, in keeping with recommendations by the MRT's Health Disparities Work Group.
- **Oversight:** Conducts strong oversight over Medicaid managed care plan administration of new components
- **Appeals:** Sufficiently educates enrollees about plan grievance and appeals processes
- **Assistance:** Boosts the amount and use of enrollment brokers, hence our strong support for the \$3 million allocation in the Executive Budget proposal
- **Self Direction:** Ensures that advance directives are prominently displayed in new electronic healthcare record systems

Ensuring Access to Previously Protected Classes of Medications

Many in our community take years to find out which medication works best for them, at what dosage and for how long.

Accordingly, our community has long fought policies that have sought to deny or limit access to those particular medications and/or forced people to fail on other ones that have failed us before simply because they were on the state's or a plan's formulary.

These choices don't belong to budget makers, bureaucrats or plan officials...they belong as part of the personal relationship between prescriber and person served.

That's why we were so worried when the Legislature removed longtime "prescriber prevails" protections for 'protected classes' of mental health, AIDS, seizure and organ transplant meds. And that's why we were initially pleased when the Health Department, in apparent recognition of our community's concerns, announced that 19 out of 20 plans were going to allow Medicaid beneficiaries to stay on those drugs...even if they weren't on their formularies.

Insufficient Beneficiary Education

Our hope turned to worry when the Department of Health's and managed care plans' letters to Medicaid beneficiaries about the drug carve-in were hard for many to understand and failed to explicitly mention the grandfathering of mental health and other drugs.

Beneficiaries Being Denied, Delayed

Throughout our regional forums and highlighted at last week's Legislative Day, we have regularly heard concerns about the lack of adequate consumer education and increased details of delays in getting approval to stay on 'grandfathered' medications...and now outright denials. Here are some details:

- An Owego nurse practitioner has shared with us documented evidence of numerous denials of patient efforts to stay on the anti-depressant Pristiq
- A Long Island psychiatrist reporting that a local plan would only approve a 15 day supply at a time of the antipsychotic zyprexa, which would require him to see her twice a month, a 'waste of resources' and that other plans were taking too long to respond to a continuation of clozaril, leaving the beneficiary down to their last 2 pills as the companies were 'still working on it.'
- A NYC psychiatrist who has complained of being inundated with unnecessary and time consuming 'paperwork burdens' just to get his patient continued on grandfathered medications.

We urge the State Legislature to actively pursue the following remedies:

- ***Restore prescriber prevails protections for Medicaid managed care medications for vulnerable groups like ours that used to be guaranteed in fee for service. This will assure that plan promises to ensure crucial continuity of care for our community is a promise that is kept***
- ***Ensure that the Health Department:***
 - ***step up its oversight over plan performance and assure the promised automatic grandfathering of these medications, without costly delays that waste prescriber time and jeopardize beneficiary's health.***
 - ***redouble its efforts to educate beneficiaries about these patient protections.***
 - ***publicly publish data demonstrating the numbers of beneficiaries who experienced uninterrupted, undelayed continuity of care in receiving their 'grandfathered' medications.***

Alternatives to Involuntary Outpatient Commitment

Once again, the NYAPRS community continues to strongly oppose Kendra's Law's highly controversial involuntary outpatient commitment program that:

- relies on coercion whose effectiveness has yet to be scientifically validated,
- is used primarily in New York City and Long Island in contrast to almost every other county,

- continues to be disproportionately (66%) used for communities of color and that
- now involves considerably more effort and costly time by local and court officials in the wake of last year's NYS Court of Appeals ruling that sharing medical records of individuals under consideration for a Kendra's Law order is a violation of their HIPPA privacy rights, unless their approval or a court order is obtained.

Instead, NYAPRS points to the state's strong commitment to:

- favor the expanded use of modern, state of the art voluntary outreach and engagement approaches,
- maximize the use of peer run services, and
- to advance more coordinated and integrated and effective care approaches that are being promoted by the state's new Behavioral Health Organization and Health Home initiatives.

In fact, included in the Medicaid Redesign Team's recommendations to the Governor is an expectation of decreased use of involuntary court orders as a measure of these programs' effectiveness.

Finally, NYAPRS members strongly favor non-medical "alternative treatments" like acupuncture, reiki, shiatsu, meditation, yoga and nutritional supplements. We will be strongly advocating for the funding of these approaches in the more flexible capitated managed care environment of the future.

Thank you for this opportunity to share our community's concerns and recommendations.

Saying 'Yes' to a Normal Life

Mental Health Advocates Say Housing, Jobs Needed to Help their Recovery

by Andrew Carden Legislative Gazette February 06, 2012

Hundreds of New Yorkers with psychiatric disabilities rallied in Albany last week to urge Gov. Andrew Cuomo and state legislators to reinvest savings from planned psychiatric facility downsizing into housing, employment and peer support.

The New York Association of Psychiatric Rehabilitation Services, a statewide partnership of tens of thousands of New Yorkers who use or provide community mental health services, began its 14th Annual Legislative Day with a two-hour event in the Kitty Carlisle Hart Theatre at The Egg. ...Among the major initiatives continued under it are health homes and managed care expansion, aimed at overhauling health and behavior health care systems to improve outcomes by decreasing the use of hospitals and emergency rooms.

"If we're going to lower the money in hospitals, it must be reinvested in housing, peer support and employment for the residents," said Rosenthal. "We're on board with the governor's support for health homes, so long as the residents have more control over their care. These people need a house and a job."

Rosenthal offered praise to the governor and the New York State Department of Health, though reiterated there is more work to be done.

"The governor is holding the system to be more accountable, trying to give people more control over their health care and working to close institutions," said Rosenthal. "There are a lot of good people in the Health Department, but they have much more oversight to do."

....There are, Rosenthal said, about 80,000 people in New York state with psychiatric disabilities. Many suffering from mental illness, Rosenthal said, are often told by their health providers they will never work, get married or own a home.

"We're here to say 'yes' to a normal life for the 80,000," said Rosenthal. "You're here to tell your legislators you want a job, want to get married, want to own a home and want to have rights." Rosenthal polled the audience on how many are currently employed. While a mere handful raised their

hands, the vast majority raised their hands upon asked whether they want to work. ...Issac Brown, CEO of Baltic Street, AEH, Inc., which works to support recovery efforts among the mentally ill, seconded the need to renovate empty buildings for individuals transitioning out of institutions. Brown, who now owns a home in New Jersey, was himself once in support housing. "Twenty years ago, I was someone wandering the streets who couldn't put two and two together," said Brown. "I know how difficult it is to be homeless and without the necessary medication."

<http://www.legislativegazette.com/Articles-c-2012-02-06-81288.113122-Saying-yes-to-a-normal-life.html#222>

Mental-Health Advocates Want "Reinvestment" In Housing, Supports

By Cara Matthews Gannett News Service January 31, 2012

Hundreds of people with mental illness and advocates for the mental-health system were at the Capitol today to lobby for the state to invest more money in housing, peer support and employment opportunities. They participated in the New York Association of Psychiatric Rehabilitation Services' 14th annual Legislative Day.

According to NYAPRS, Gov. Andrew Cuomo's budget would continue the state's overhaul of its health and mental-health systems in ways that are intended to continue consolidating and closing Office of Mental Health psychiatric hospitals, improve coordination of care and help avoid Medicaid hospitalizations and emergency-room visits. To achieve these goals, the state has been expanding managed care, establishing health homes and using behavioral health organizations. New York has 27 state psychiatric hospitals, about seven times the national average.

The organization said the state needs to do more than improve access to medical services and medications. It wants the state to "reinvest" the savings in community wellness, prevention and support systems. Research has shown that housing and economic stability and a community support system can reduce relapse rates and costly hospital visits, NYAPRS said in a statement.

...Josue Hernandez, 32, of the Bronx said people with mental illness have a lot to offer, but they need more help finding jobs and housing and getting peer support after they are discharged from hospitals. He participates in a psychosocial club in the Bronx called the Boulevard Clubhouse, which provides placement in transitional jobs, advocacy and referrals and social programs. He finished a transitional-employment program and is now looking for a permanent position.

"My situation now, I'm dealing with finding a job after finishing my program. And it's been a little hard," he said.

He and his wife, Margaret, got married last July. They both belong to the Boulevard Club.

"They think that because I get disability and I work part time, they think I have enough to support the both of us. So until he gets a job, a lot of things are a stretch," said Margaret Hernandez, 33.

Taxpayers spend more when someone is in a state psychiatric hospital than if they live in the community, said Christian Florio, a generalist/case manager at the Boulevard Clubhouse. "It actually costs less if you reinvest the money back into the community," he said.

<http://polhudson.lohudblogs.com/2012/01/31/mental-health-advocates-want-reinvestment-in-housing-supports/>

