



STIGMA AND DISCRIMINATION:

Overcoming the Barriers to Care and Recovery

Numerous advances in the treatment of mental illness have been made during the past several decades. Every day, people are recovering and living meaningful and productive lives.

Yet, research says that society still holds negative stereotypes. There are plenty of positive stories about recovery for the news media to cover, yet they're quick to portray a gunman as "mentally unstable." School children bully the classmate who's "weird." Pedestrians ignore homeless people because they're "crazy."

U.S. Surgeon General David Satcher said in his landmark 1999 report that stigma is perhaps the biggest barrier to obtaining proper mental health care. Reports by the World Health Organization and the World Economic Forum indicate that mental illness is an enormous economic burden for nations – costs were estimated to be \$2.5 trillion in 2010 and are projected to be \$6 trillion by 2030. Nearly two-thirds of these costs were attributed to disability and loss of work. Yet, one of the reasons that nearly 60 percent of those with mental health issues are not receiving any form of care is the fear of being stigmatized.

Mental illness has a long history of being misunderstood. Believing that people with mental illness were either taken over by demons, morally flawed, or responsible for their own conditions, most societies over the ages either punished, banished, or confined them. American colonists branded them as possessed. And the mentally or physi-

cally disabled were often the earliest victims of history's genocides.

Today, discrimination is more subtle – such as denying job opportunities, housing, health insurance coverage, or custody of children. And it can be personal, through "social distancing" or by dismissing an individual's pain by telling them to "snap out of it, you're not really sick."

The New York State Office of Mental Health recognizes that people with mental illness are **people first** – thinking, feeling people with rich, personal histories and bright futures. Stigma has no place in our society today. We believe that by presenting the facts about mental illness, we can change attitudes.

In this edition, we'll discuss some of the efforts over the years to reduce stigma. We'll discuss how today we're developing and supporting programs that chip away at discriminatory policies and allow people recovering from mental illness to live full and productive lives in their own communities. We'll show how we're working to reduce the fear and cultural obstructions that lead some people to hide their mental illness or avoid seeking help all together, and how we're working to ensure that they're treated with the basic human dignity they deserve.

If you would like to share your own story about overcoming stigma and discrimination, please contact us at: omhnews@omh.ny.gov. OMH

The Fight for Change in New York

The fight for respect, dignity, and fairness for people with mental health needs has been a long one in New York State. But small steps taken more than a century ago have led to a movement that continues to grow to this day, shaping legislation that guarantees and protects consumer rights.

Patients Find Their Voice

One of the earliest efforts to dispel the stigma of mental illness was the publication of *The Opal*, a monthly newsletter that was produced from 1851 to 1860 by inpatients at the New York State Lunatic Asylum at Utica. Topics discussed through poems, essays, news articles, correspondence, and editorials included inpatients' experiences and views on restraints and seclusion, forced treatment, medications and alternatives, hope and recovery, and basic human rights.

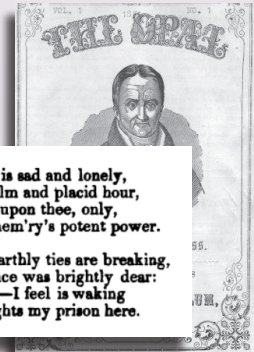
The "Queen of night" is beaming
On Mohawk's sparkling rills,
Her silvery light is streaming
O'er grand Oneida's hills.

Its rising mists are bathing
With dew their tow'ring heights,
The stars above are waving
Their countless golden lights.

My heart is sad and lonely,
This calm and placid hour,
It dwells upon thee, only,
With mem'ry's potent power.

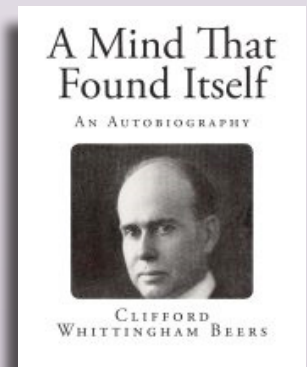
Though earthly ties are breaking,
That once was brightly dear:
A heaven—I feel is waking
That lights my prison here.

A poem from *The Opal*, a monthly newsletter published by inpatients.



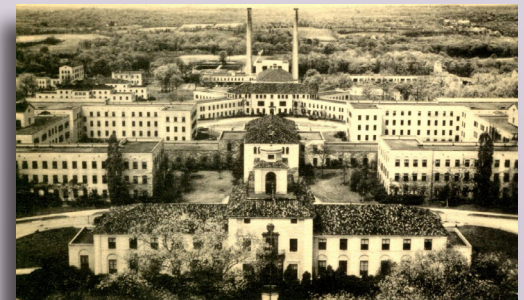
Then in 1908, New York City resident Clifford W. Beers, a former psychiatric patient, described his abusive experiences in public and private mental hospitals in his book *A Mind that Found Itself*. Followed the next year by founding the National Committee on Mental Hygiene – which is now known as Mental Health America – Beers helped inspire international efforts to challenge the stigma and change attitudes about mental illness.

Clifford Beers' groundbreaking autobiography.



Leading the Way in Rockland

During World War II, six patients from the Rockland State Hospital further changed society's perception of people with mental illness, forming one of nation's first self-support groups, "We Are Not Alone," to share stories, read, paint, and take part in social activities. After discharge, they continued to meet to provide each other with support and help others make the difficult transition back into the community. The organization later became Fountain House, but the founders' work in proving that successful recoveries are possible led to a better understanding of mental illness and to a reduction in stigma.



The old Rockland State Hospital

Even Heroes Need to Talk

The most successful anti-stigma campaign conducted by OMH didn't start out as one. Project Liberty was intended to respond to the traumatic stress experienced by metropolitan New York residents after the September 11, 2001, terrorist attack on the World Trade Center.

A needs assessment estimated that more than three million area residents were experiencing substantial emotional distress, and that more than 500,000 were experiencing symptoms that met diagnostic criteria for post-traumatic stress disorder. OMH worked with the federal government, the New York City Department of Health and Mental Hygiene, and local county health departments to aggressively push mental health therapy services out among the public, offering free, face-to-face crisis counseling and public education.

The name "Project Liberty" was chosen to give the three-month program its own identity. The team knew it was important to encourage people to take part and giving the program a traditional "mental health" name could have acted as a deterrent, because of the stigma that surrounds mental illness.



Project Liberty PowerPoint slide

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The slogans, including “Even Heroes Need to Talk,” “Feeling Anxious After 9/11 is Normal,” “New York Needs Us Strong,” and “Feel Free to Feel Better,” were non-judgmental and emphasized that stress is indeed a normal response to an abnormal situation. They urged people to seek support from those they trust and offered practical coping strategies.

The campaign made use of public-service posters in subway cars, bus shelters, bars, restaurants, and drug stores. Television, radio, and print advertisements featured handwritten messages from New Yorkers describing how they had been coping since the events. More than one million people were served by Project Liberty, receiving crisis counseling and education in their communities.

Parity Law Ensures Access to Coverage

The New York State Mental Health Parity Law, also known as “Timothy’s Law,” is a tool that New York State can use to fight against discrimination by insurance companies toward people with mental illness.

The law was named after a 12-year-old boy from Schenectady who had been diagnosed with behavioral disorders and depression. Their mental health benefits exhausted, his family was forced to relinquish full custody to make him eligible for Medicaid. Even after Timothy returned home, he was still limited by his parents’ medical insurance benefits. He took his own life in March 2001.

The law went into effect on January 1, 2007, to require most group health plans to cover adult and child mental health care as they would any other medical or surgical treatment. The law requires:

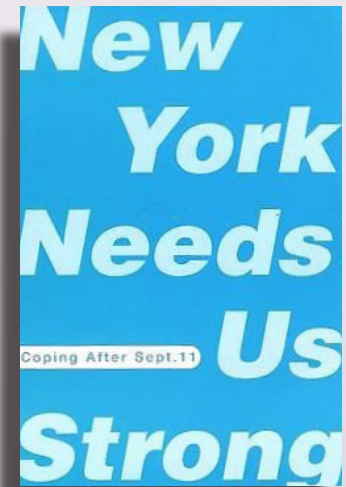
- Coverage each year for a minimum of 30 days of inpatient care, 20 visits of outpatient care, and at least 60 outpatient visits for substance use disorders, 20 of which can be for family members.
- Inpatient treatment for substance use disorder, including detoxification and rehabilitation.
- Out-of-Network coverage, deductibles and co-payments, and the utilization review process must also be calculated in the same manner as any medical surgical treatment.

Except for the “30/20 limitations,” there can be no limitations on treatment of mental illness unless the same limits apply to treatment of other medical conditions. Nor can the costs be higher. A May 2009 study by the New York State Insurance Department on the cost effectiveness of Timothy’s Law reported that the law had considerably increased mental health parity at a nominal cost to employers.

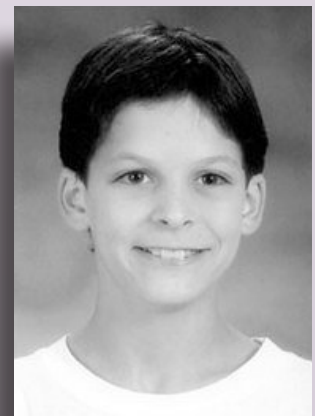
Funds to Fight Stigma

New York State taxpayers are now able to play a role in helping to end the stigma of mental illness as a result of the Mental Health Tax Check-Off Law, signed by Governor Cuomo in November 2015. The law created a tax check-off box in New York State tax forms for a fund dedicated specifically to the Mental Illness Anti-Stigma Fund.

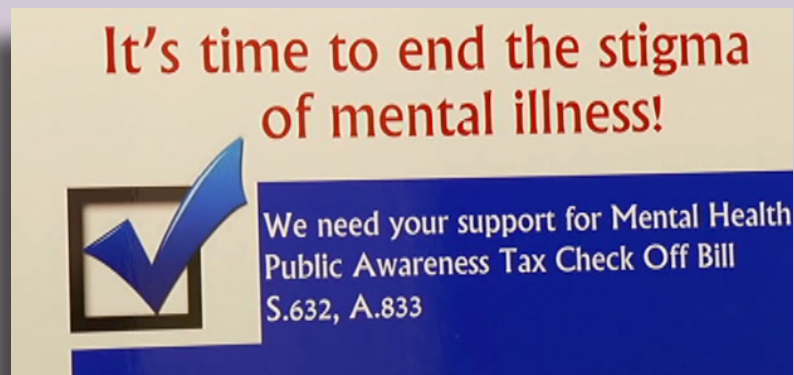
The legislation directs OMH to provide grants to organizations to conduct educational programs and services dedicated to eliminating the stigma attached to mental illness. The fund was supported by a grass roots effort of thousands of mental health clients, family members, friends, and advocates. ^{OMH}



Project Liberty brochure



Timothy O'Clair, for whom Timothy's Law was named.



Campaign poster for the Mental Health Tax Check-Off Law.

Stigma is One of Many Barriers to Access in Communities of Color

Although there is growing acceptance about mental illness and the necessity for early intervention, communities of color still experience considerable disparities in accessing mental health services. One of these challenges is the perception about mental health care.

A 1996 study commissioned by Mental Health America found that nearly two-thirds of African Americans surveyed believed that depression is a “personal weakness,” considerably higher than the national average across all demographics. The study found that African Americans were less likely to take an antidepressant for treatment of depression and cited denial, embarrassment or shame, lack of money or insurance, and fear as reasons to avoid treatment.

Social Determinants of Health

These attitudes about mental health care have been shaped by a history of adversity – including slavery, and exclusion from educational, health, social, and economic resources.

“In order to preserve their existence, African American communities developed a long history of resiliency,” said Nadia Allen, Executive Director of the Mental Health Association in Orange County, Inc., Chair of the Cultural Equity Taskforce in Orange County, and a practitioner with more than 30 years’ experience in human services. “Due to the never-ending oppression, from one generation to the next, they have had to learn how to survive, in spite of the adverse conditions.”

“We can’t talk about population health without understanding and addressing the social determinants of health,” Allen added. “We don’t like to talk about race and racism, but economic and racial inequality are real and palpable.”

There is a strong link between socioeconomic status and mental illness. Individuals who experience impoverished conditions, have been incarcerated, are homeless, or have substance abuse problems are at much higher risk for poor mental health.

In the event that these individuals seek treatment, they are less likely to access it due to lack of health insurance or underinsurance and lack of African American mental health professionals, who are more likely to be culturally competent and sensitive.

African Americans of all ages are underrepresented in outpatient treatment but over-represented in inpatient treatment. Few African American children receive treatment in privately funded psychiatric hospitals, but many receive treatment in publicly funded residential treatment centers for emotionally disturbed youth.

Health disparities disproportionately affect groups of people who have systemically experienced greater social and economic obstacles. Such negative treatment can lead to a mistrust of authorities, particularly law enforcement. Illicit drug use is frequently associated with self-medication among people with mental illnesses. African Americans account for 14% of regular drug users, but 37% of drug arrests.

Need for Deeper Understanding

“In order to decrease the stigma and eliminate health care disparities, our work must be performed while looking through the lens of social justice,” Allen said. “We must be culturally humble, we must see the whole person, we must ask them about their story, we must develop an understanding of the history of their race and how it impacts them today, we must see their color, we must question our assumptions, we must recognize and own our white privilege.”

“If we don’t strive to do it all, we will continue to oppress the African American communities, and they will remain invisible and underserved or not served at all.” ^{omh}

“We can’t talk about population health without understanding and addressing the social determinants of health.”

– *Nadia Allen, Executive Director of the Mental Health Association in Orange County, Inc., Chair of the Cultural Equity Taskforce in Orange County*

Assessing & Addressing Mental Health Needs of Youth

Children’s social emotional health is an integral part of their overall health and well-being. How children feel emotionally influences the success of their relationships with family, school and friends.

Research has shown that social and emotional health of children and adolescents – how they experience and express feelings, interact with others, build and sustain positive relationships, and manage challenging situations – affects their success in school and in life. Yet too frequently, due to the stigma associated with mental health, children’s mental health needs are missed until they are already experiencing behavioral problems.



Early Recognition and Screening

OMH has been working to support children’s mental health and to counter stigma through its Early Recognition and Screening (ERS) initiative. The program supports development of cooperative relationships with local primary care practices, schools, and other community-based programs to promote early identification through universal social emotional screening and linkage to resources and services.

“It’s of vital urgency that we address the mental health needs of children early,” said Kathryn Provencher, Mental Health Program Specialist and ERS Program Lead. “It’s natural to measure your child’s height, weight, vision and hearing. It’s just as important to measure other ways children are growing.”

ERS grew out of OMH’s 2007 Child and Family Clinic-Plus initiative. A major shift in policy and focus, the Clinic-Plus program adopted a public-health approach to the early identification of child mental health problems through screening in community locations. Although the mission of the Clinic-Plus program was widely supported, providers encountered a variety of difficulties that impeded their capacity to consistently meet their screening goals. The most significant was that of stigma. Before a child could be screened, the providers needed to obtain parental consent. The idea of associating their children with a mental health program elicited fear and suspicion in even the most open-minded of parents.

One recommendation that emerged from this experience was to carry on, but in a different manner, by funding full-time early recognition specialists to conduct community outreach, engage children and their families, obtain active parental consent, and carry out a community-wide plan for early identification. This new model enabled providers to overcome prior challenges.

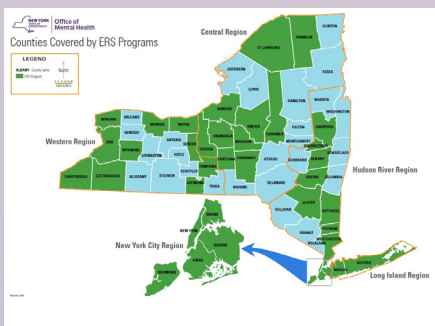
Since ERS started as a separate program in 2012, 37 providers throughout the state have received funds from OMH to hire full-time early recognition specialists. “Programs are tailored to meet each community’s specific needs and resources,” Provencher said. “With parental consent, specialists conduct free and confidential social and emotional screening in schools, health centers, or other locations in communities to check that youths up to age 21 are on the right track for healthy development.”

A major part of this initiative is to engage in education and social marketing activities to decrease the stigma that often prevents youth and families from seeking support by improving the public’s understanding of social emotional wellness. ERS programs provide informational presentations, use social media, participate in health and wellness fairs, and collaborate with other prevention efforts in the community.

ERS specialists evaluate the screens and provide individual follow-up with families when a screen is positive. Families of children who are identified as needing support are given referral information to agencies that can provide further assessment and treatment. ERS specialists have been key in helping families connect with resources, and with behavioral health clinics if needed, before major problems develop.

ERS programs have been active in promoting national Children’s Mental Health Awareness Week in May each year. In 2015, several of the ERS programs worked with OMH to create printed materials promoting screening

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Counties participating in the Early Recognition Screening program.

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and children's mental health for use during the event and throughout the year. As of the fall of 2015, the programs have provided screenings to 170,615 youths throughout the state. The work of ERS programs has been instrumental in helping their partners, such as schools, identify needs and move toward initiating new services that will be beneficial for children and families.

Community Outreach on Staten Island

The Staten Island Mental Health Society is using several methods to increase emotional health screening in that community. "For the past three years we've been working on incorporating screening into annual physicals at local pediatric practices," said Jane DiFortuna, Early Recognition Specialist for the society. The screenings help to identify early emotional and behavioral problems from infancy to age 21.

They provide a Pediatric Symptom Checklist (PSC) for parents that takes less than 10 minutes to complete. Once children reach age 11, they can take it for themselves. A PSC for preschoolers came out last year. PSCs are also being included in registration packets for local Head Start programs.



From right, Staten Island Mental Health Society ERS team members Jane DiFortuna and Vicki Gambale, and Mobile Integrated Health Team member Marigrace Guce.

If a screening is positive, appropriate referrals are made to get them help. "In each of our community programs, we want to be aware of problems and do a screening before these problems become disorders," DiFortuna said.

They are now reaching out to local day-care workers by planning a community Family Fun and Learn Day. "Daycare workers are often overlooked as a source of information," DiFortuna said. "But they spend several hours each day with our children, observing their behavior." The event will offer information on what to look for and who to contact for referral. "We'll help them learn about how to interpret emotional health signs and then how to follow-up with children through play therapy," she added.

They currently provide screenings at the College of Staten Island and plans are in the works to extend outreach to local junior high schools through professional staff training days and parent-teacher association meetings. "It's important that we, as a society treat mental illness as a medical disorder," DiFortuna said. "There are physical changes in the brain, and people with mental illness must be treated with the same respect and empathy as people with physical illness."

Teens Speaking to Teens in Cortland

Another program, Family Counseling Services of Cortland, sent teens ages 16 to 18 who are recovering from their own struggles to speak at area schools. "Many of them went through some rough times – such as legal trouble, substance abuse, and attempting suicide," said Sue Marks, Director of School Based Programs and ERS. "It started out as a suicide prevention program, but it turned out that the teens had a lot to say. They wanted to offer messages of hope and support. They wanted to help get rid of the stigma by letting other kids know it's okay to seek help."

It took about a year to establish the program while the teens refined their stories, and grew more comfortable about themselves and with speaking in public. They also met with administrators at several schools to get them on board. They thought it would be important to speak to kids at the junior-high level in order to reach them early. They also thought it would be important to keep groups small so that they could have direct conversations.

"They did beautifully," Marks said. "They really got through to the kids because they were open and honest. Audiences knew that they were speaking with someone who understood what they were going through, because they'd had the same experiences. In them, they saw hope and inspiration that they can get through this."



Judging by the feedback after the program's first year, it's been a success. Almost 400 junior and senior high students listened to the stories in health classes, and local schools are asking them to come back. In a post-session survey, there was a 15% decrease in feelings of fear of a classmate with a mental health condition and a 17% increase in asking a classmate if they want to talk about their condition.

Comments written after the presentations indicated the positive impact they had on the students. One student wrote: "I thought it was informative and definitely gave me a different view on mental health conditions." A second wrote: "It made me find out I am not alone." And a third wrote: "I think the stories were inspirational. I now will never give up." OMH

Social Media: “Deleting” Stigma Online

YOUTH POWER!, a statewide network of young people who have been labeled and are seeking change, is making extensive use of social media to spread its message of hope and acceptance.

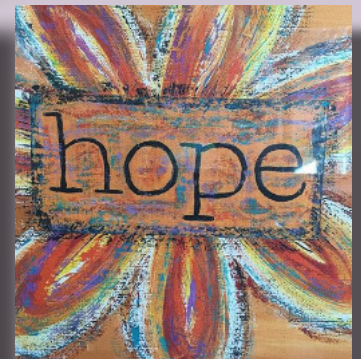
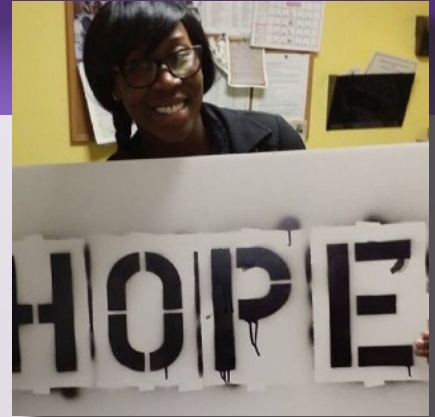
“The idea came about in 2010, when a group of us from the Long Island region were having a conversation about how we could help to spread hope,” said Regional Youth Partner Desiree Moore. “We all had lost hope at one time or another and then regained it, and we wanted to share our stories.”

The group had visited area psychiatric hospitals and received tremendous feedback. So they looked into how they could take it a step further.

They started a page on Instagram; which has grown to more than 500 images of hope, created and posted by young people themselves.

Moore said this idea has been expanded to greeting cards. “Most greeting cards usually say ‘Get Well,’ but our people aren’t sick. We decided we wanted to make cards that would offer encouragement.”

Below are a few heartwarming examples from the Instagram page. You can see the rest for yourself at <https://www.instagram.com/ypspreadshope/> or visit the YOUTH POWER! website at www.youthpowerny.org/hope/ to learn more. OMH



Advocates: Changing Attitudes Through Education

Mental health advocacy organizations in New York State are using the power of knowledge to change attitudes about mental illness. By working through community outreach programs, speaking with providers, or addressing sensitive issues directly with lawmakers, they're working to make sure the voices of mental health consumers are heard.

At the Community Level

For the past two years, the New York State Conference of Local Mental Hygiene Directors (CLMHD) has conducted a Youth Mental Health First Aid (YMHFA) train-the-trainer program to increase knowledge about mental health topics, reduce stigma, and improve responses toward teens with mental health challenges.



Katherine Alonge-Coons

“Symptoms of mental illness can be difficult to detect,” said Katherine Alonge-Coons, Commissioner of Rensselaer County Department of Mental Health and Chair of the CLMHD Children and Families Committee. “Friends and family of someone in crisis may not know how to direct them to help.” The course is designed for adults who regularly interact with adolescents. Participants come from throughout the state, and include professionals in the mental health or related field, such as community services board staff, school nurses, or counselors from private organizations.

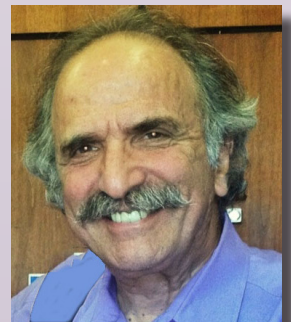
Since the program began, 59 individuals have become certified YMHFA instructors. Follow-up research has indicated that the course is helping to improve knowledge about mental health topics, reduce stigma, and increase first-aid actions toward teens with mental health challenges. The Conference is planning another session for Fall 2016, hoping to train up to 30 more individuals.

“This goes a lot further than emergency intervention,” Alonge-Coons said. “It really helps people understand the shroud of fear and misjudgment facing individuals and families who experience mental illnesses and addiction.”

Facts, Not Fear

Misconceptions about mental illness have been at the center of the recent controversy over gun control.

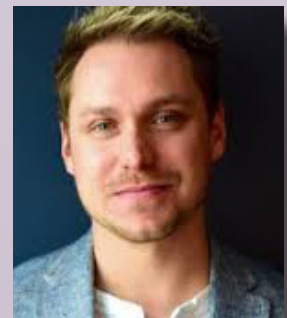
“Those with mental health conditions share the same grief and horror that strikes other Americans,” said Harvey Rosenthal, Executive Director of the New York Association of Psychiatric Rehabilitation Services (NYAPRS), “but they can feel singled out, due to the mental illness tags that are pinned on killers.”



Harvey Rosenthal

In response, NYAPRS has been conducting a campaign focusing on “facts not fear,” citing recent research indicating that people with mental illnesses are no more violent than the general public, and are actually more likely to be victims.

“People with the most disabling conditions can substantially recover when offered the right mix of engaging and effective services,” said Tom Templeton, NYAPRS Public Policy Specialist. Templeton added that NYAPRS promotes legislation and policies to protect the rights of people with mental health conditions, including fair housing, community reinvestment, and expanding managed care programs to provide more peer counseling and other forms of assistance to people who can live safely outside of institutions.



Tom Templeton

NYAPRS also joined with other advocacy organizations to protest the airing of an episode of a popular television comedy that used an “insane asylum” theme and stereotypes of people living with mental illness as a vehicle for humor. “The fight against stigma involves all of these efforts,” Templeton, added. ^{OMH}