BEFORE THE NEW YORK STATE SENATE
STANDING COMMITTEE ON MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES

PUBLIC HEARING

TO EXAMINE SUPPORTS AND SERVICES FOR INDIVIDUALS AND FAMILIES DEALING WITH MENTAL ILLNESS IN NEW YORK STATE

Rockland Community College, RCC 3214
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PRESIDING:

Senator David Carlucci
Chair

PRESENT:

Assemblywoman Ellen Jaffee
Member of the Assembly Mental Health Committee

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SENATOR CARLUCCI: Good morning.

I want to welcome everyone to our hearing on mental-health support and services in New York State.

And, I'm Senator David Carlucci. I chair the Committee on Mental Health and Developmental Disabilities.

And, I want to thank everyone for coming here.

The idea here today is, we'll hear a broad range of issues, all dealing with mental-health supports and services in New York State.

The idea is to get it on the record so that we have a blueprint, that we have an agenda, going into the next legislative session, that we can really address the issues at hand.

We know there's some really changing times when it deals with the mental-health community.

And what's important is, I want to make sure everybody's voice is heard. That we hear about the experiences that you're having, the situations that you're going through, so that we can work together to address them.

This past legislative session we had many successes.

We're still waiting for the Governor to sign some legislation.

And, we're hopeful that that will pass, and really continue the work that all of you have done, to make sure we provide the best level of support for people living with mental illness here in New York State.

So with that, we'll get right to the speakers.

Our first speaker is Glenn Liebman, who is the CEO of the Mental Health Association of New York State.

Glenn.

GLENN LIEBMAN: Good morning, Senator.

I want to thank you, first, for holding this hearing, and recognizing the needs of community mental health.

In your time as Chair, you've been a real champion for our community, and it's greatly appreciated.

My name is Glenn Liebman. I'm CEO of the Mental Health Association in New York State.

Our organization is comprised of 30 affiliates in 52 counties throughout the state.

Our members provide community-based

mental-health services, but we also are very involved with education and community advocacy.

Many of our members, including our affiliate right here in Rockland County, advocate passionately for community services, children's mental-health services...the whole gamut of services that you have strongly supported us on.

Today on the mental-health system, though, we sit on the precipice of change.

The system of care is undergoing changes that are unprecedented since the days of deinstitutionalization.

And, I think it's so important that we do not -- there were some positives that came out of deinstitutionalization, but there were a lot of failures. And a lot of the failures, frankly, were because the community service system was not well-funded. We were deinstitutionalizing thousands of people and not giving them appropriate community-support services.

And, we want to make sure that, in these changes, that there remain safeguards in place, and essential services as well.

So whether you're talking about health homes, Medicaid managed care, DSRIP, FIDA, HARPs, you name

the acronym, we've gone through about 20 acronyms in the last two years, all new ones, all bring with them significant challenges, but, also, we believe, significant opportunities.

Our members are very engaged with the changes in care. Many of the people we serve will be in the Health and Recovery Plan services (the HARPs). They will have enhanced 1959 waiver services.

What this means really, in layperson's term, and I know you know this, is that so much of the work that the MHAs have done for years in community engagement, peer services, family support, support education...the whole gamut...employment, prison/jail diversion, et cetera, will now become Medicaid-able, which will provide an enhanced funding source.

This creates great opportunity to expand the base of the services that we know help in recovery.

The combination of sound clinical care, with access to best practices, appropriate access to medication, and the myriad of recovery services, are integral to the continuum of care.

There are no cookie-cutter ways to recovery. Individuals need options.

The more active use of waiver services, the

great hope is that individual options will continue to expand.

It will, of course, means that health plans will also be active partners in Medicaid managed care, and we have to educate them about the services that we provide, while they will be educating us about their areas of expertise.

We also will have to be educated about Medicaid billing and other ancillary services.

We will be working with the State to help in the development of the training and funding for the billing of Medicaid.

This is like one of those issues that people aren't talking about as much, but it's really significant, because a lot of our MHAs are small operations.

Yes, we have a very large, effective MHA here in Rockland, but, a lot of our MHAs throughout New York State, we're talking about four- or five-people operations. And for them to start billing Medicaid? They don't know, it's like learning Latin. It's all something that's so new to them.

And we have to make sure to be vigilant with the State, to ensure there's preparedness money to

help with the -- you know, with Medicaid billing.

There are many things in the existing system that are, and always have been, recovery-oriented, and play a significant role in keeping people in the community and out of the hospital.

We want to make sure that these programs remain in place as a safety net for individuals with psychiatric disabilities.

Community systems have always been integral to recovery. A system of care must remain in place through local assistance funding.

And you've been a real champion on this.

The movement to Medicaid managed care should not be used as a rationale for cutting local assistance funding.

These waiver services for many community services could very well be a good thing that will significantly improve outcomes, but it will not happen overnight. We have to ensure that local assistance funding continues to exist in the future.

We also have to be concerned about those individuals who will drop out during these changes.

The sad reality is, that no matter how thoughtful the design and implementation, there will be people who will be confused by the changes and

will be lost to the public system of care.

We must find a way to help these individuals not fall through the cracks, and to help bridge their interactions between themselves and their new partners in the health plans.

This should include the creation of a hotline Ombuds-function program that will work with the health plans, the State, and the individuals to help amicably resolve outstanding issues.

Through our members across New York State, many of which run hot- and warm-lines, including the MHA of New York City, which runs the national suicide-prevention line, we would have capacity in New York State to run such a project.

The bottom line, though, is there is no system of care is better than the people who are running the programs.

We must have a fully engaged and financially supported workforce.

I want to really personally thank you, Senator. You fought as hard for the COLA as anyone ever has for the direct-care workforce.

We -- you know, having worked in Albany for many years, you hear a lot of stories.

And we heard how you went to the mat for us

in terms of COLAs for our direct-care staff.

So, we are so appreciative.

You are a real champion, and we cannot thank you enough for all you did in that regard.

We will have to continue that fight for better incentives for the workforce through additional financial incentives, enhancements for the mental-health workforce, tuition reimbursements, career ladders, and other programs.

When we talk about the program, we also recognize the importance of hospital and bed closures done in a thoughtful, planful manner.

MHANYS was on the frontline in support of both the Governor's Center of Excellence plan and the work of the Legislature.

We are pleased to see these pre-investment services are beginning to be funded around the state.

The Office of Mental Health should be commended for their work in getting the funding out to the community.

Programs, the community stakeholders have said our priority, like housing, mobile, and crisis -- other crisis services, peer support, ACT teams, et cetera, are being funded.

I know that in the lower Hudson River region, there was an announced distribution of $2.25 million for these services. Adding other ancillary services, it came to $3.2 million.

And we are appreciative of the Governor, and we are appreciative of you, Senator, and the other legislators, for this important pre-investment funding that will go a long way to helping provide essential services.

We hope to continue the State's commitment in the future, recognizing the over 40 million annualized, statewide, for these services, with a continued emphasis on those priority areas, especially around housing.

We know New York does more than any other state in community housing, but even more has to be done, because so much of the basis of recovery is housing safe and secure -- is housing and secure -- is safe and secure housing.

So, to encapsulate that point, a recommendation:

I just want to help to ensure and support the successful transition to Medicaid managed care;

Continue to ensure that funding is in place for our community-based services for local

assistance;

And, Medicaid managed care cannot be a vehicle for cutting this funding.

Thirdly, a strong role should be in place to ensure that those are individuals who have concerns about the changes to managed care have a responsive system in place through an Ombuds program.

And the final -- well, two more recommendations:

Continue to find funding opportunities and other incentives for the underpaid mental-health workforce;

And, ensure that new reinvestment funding is fully funded.

And I know that you will be vigilant in that end, and you have done a great job in that end, around community priority areas: around housing, and mobile crisis.

The second, just briefly, I just want to talk about the second area, which I've talked to you about before, and you have been a great supporter, and that's mental-health literacy. And we just don't talk enough about that.

There's a whole other chapter when it comes to addressing concerns about people with psychiatric

disabilities, and that includes ending the stigma of mental illness and educating the public about mental health.

Again, thank you for your support in embracing one of our key training programs: mental-health first-aid.

Through your leadership -- and I mean, your leadership; you were the one who was really responsible for this -- we were able to provide training to our members statewide on youth mental-health first-aid, including our members in Rockland County.

Thanks to your leadership, Rockland, and other corners of the state, have will trainers available through the local MHAs to educate teachers and other school personnel on how to respond to a student's behavioral-health crisis.

This training also serves as a great tool to help combat the stigma and discrimination of mental-health illness.

That's great, and you've been incredibly supportive.

Through your support and advocacy, and that of Assemblywoman Aileen Gunther, as well as our Education Chairs, Assemblywoman Nolan and

Senator Flanagan, we've made headway in the battle to bring mental-health education into the schools.

The mental-health education bill made it further this year than it ever has in the past. It passed the State Senate, and the movement -- and it moved to Ways and Means in the Assembly, which is the furthest it's ever gotten.

If we are ever going to end the stigma of mental illness, we have to start at a young age.

Educating our youth about suicide prevention, depression, anxiety, and other mental-health issues will not spread the illness.

This is not like when -- it's just like when we whispered about cancer in the '60s and '70s. Like, if we said it, loudly, somehow people would contract the illness.

We should be openly talking in schools about mental-health-related issues.

Education about mental health in health classes would play a significant role in decreasing bullying, and providing greater understanding and empathy for those 1-in-5 youth with a psychiatric disability.

We continue to urge your leadership in this important fight. And we know you will be there for

us as you always have.

We also urge your support in funding after-school services for those youth who have no place to go once school ends.

And, also, we have to ramp up the need for more clinicians in schools.

You know, unfortunately, the cuts to education in recent years have really negatively impacted these mental-health and counseling services.

So, we're advocating strongly for more social workers in schools.

And, we must continue to add our voice to those in college with mental-health issues.

And I know I've broached this subject with you before, and you've been very responsive.

I think what we should do, and this is just our perspective, is we should develop a survey to identify the services available across college campuses, including SUNY and CUNY schools and community colleges.

This survey should then be put into a report to be shared with college-aged youth and their families across New York State who would find the information most useful.

It would be a great document.

Can you imagine, you know, whether you're at Hofstra or SUNY Binghamton, or wherever you are, at Hudson Valley Community College, to have a guide for, if you have a child who has a psychiatric disability, who possibly might get one, you want to see what those services are in those schools.

And I think that could be a very effective tool; so that's something we are certainly advocating for.

And, finally, I'm asking our greatest champion in the cause in the Senate, to continue your fight for the mental-health tax check-off bill.

As we know, it's passed the Assembly several times, but been stalled in the Senate.

And no one has ever pushed harder than you have for that bill.

I know the Senate has, historically, been against additional tax check-offs, but when it comes to ending the stigma of mental illness, it's time for a change.

We urge your continued support and tireless efforts, as you've done on so many other agenda items, to fight to include, all we're looking for is a box, in the New York State income tax for

mental-health public awareness.

In the hundreds of thousands of pieces of legislation, there should certainly be additional room for a small check-off box.

So encapsulate -- just, briefly, to encapsulate the recommendations, there are four recommendations here:

Continued support from MHANYS and our affiliates in providing school and other stakeholders in youth and adult mental-health first-aid.

That's, clearly, the way that we are going to help stop the violence in school, help end the bullying, through youth mental-health first-aid.

And we're already seeing it.

And, in Rockland County already, they've done a lot of the training, to begin to raise training, so that's terrific.

Secondly, continued support and leadership in the mental-health education bill, and for additional community funding for after-school programs, and inclusion of social workers and other clinicians in schools.

Thirdly, developing a survey of mental-health services on existing college campuses, and create a

report to be shared with college-aged youth and their families.

And, finally, passage of a mental-health tax check-off bill, to end the stigma of mental health and the stigma of mental illness.

So, again, I can't thank you enough for all you've done.

And I also want to add, you know, Evan Sullivan has been terrific to work with. He's a great person, and very responsive as well.

So we're lucky.

You've been a great leader for us. And Evan has been a great person to work with.

So, if you have any questions?

SENATOR CARLUCCI: Well, no, Glenn. I really appreciate your leadership.

And, this is great.

Really what we need is a list of things to go through of what we need to address.

So, so many great ideas, and look forward to working with you on all those issues.

Thank you, Glenn.

GLENN LIEBMAN: Perfect.

Thank you, Senator.

SENATOR CARLUCCI: Next we'll hear from the executive director of Camp Venture, Dan Lukens. And joined with him is a man of many hats, our county legislator, John Murphy.

DAN LUKENS: My name is Dan Lukens. I'm the executive director of Camp Venture, a Rockland County-based agency serving people with developmental disabilities.

Thank you for the opportunity to speak today on Olmsted and mental-health services as they relate to supports for people with developmental disabilities.

Camp Venture is not a clinical-service provider, nor are we a mental-health provider, so our perspective is as a service consumer.

A dual diagnosis of a developmental disability and mental illness is fairly common, and many of the people served by Rockland County developmental-disability agencies also need mental-health services.

Providing these services to our population is, however, a very serious challenge for the mental-health system.

I credit the new Nyack Hospital program that has been accepting our people, but I think it has

been a struggle for us and for them.

People with developmental disabilities, especially our people who have very limited or no communication or self-care skills, are not typical for mental-health providers.

A crisis program serving people with developmental disabilities not only has to surmount these problems, but they also must manage and protect people who are particularly vulnerable.

The new environment that's being driven by Olmsted is built on two assumptions, I'd assert.

First, that we can support people in the community; not just some people, but everybody.

Second, it assumes that we can stabilize people in a short time, in a few days, and get them back to their lives.

My experience with people with developmental disabilities in crisis is that they very often challenge that second assumption. And if the person lives in a certified residence, they become a problem for that residence.

Keep in mind that, a certified provider, people are living in close quarters. It's a family-like environment, but they're unrelated individuals, and so a crisis becomes a crisis for

the entire residence.

In the case of the individual living with their family or in more independent living situations, which will increasingly be the case, that's a burden that may fall on the family or others.

In 2002, Camp Venture admitted a young woman. I'm going to call her "Mary." Obviously, that's not her name. Her primary diagnosis was autism. She had, virtually, no communication or self-care skills.

After she came to us, she experienced an acute psychiatric crisis that manifested severe self-injurious behavior.

These behaviors were such that she needed to wear arm restraints to limit the impact of the blows that she could deliver to her head.

She received community-based psychiatric care, but there was very little improvement.

Finally, due to the tenacity of her family, her service coordinator, and people in the community, she was admitted to the Kennedy Krieger Institute in Maryland there.

Mary was the focus of intensive analysis and treatment.

They got her off all her medications, and then they tried new ones under controlled conditions.

They worked with her on rudimentary communication and self-care skills, and they development a regime of therapies and an intensive response.

When she came back to us more than four months later, there was staff training for our people, so that she could retain the gains that she had accomplished over that time.

And that's not typical.

I'm sure -- other people, I'm sure, who are more familiar with the mental-health system, can tell you whether that's unusual or not.

Mary was not all better. She was certainly not cured.

She didn't go back to a job, or anything. She continued to be a very impaired young woman.

But in our -- the developmental-disability field, that's all we can hope for.

I can't describe what it's like to see someone in the kind of despair that this young woman was in, or to see someone, a young person, whose face is reduced to swollen bruises.

We don't need dark places to throw people like Mary away, but we do need a way to treat the most serious, persistent, and complex people with mental illness.

In this case, that care had to come from another state.

The value we assign to people is not a setting, a place, or a utilization formula. It's a commitment.

And so, as we move forward, I hope that's something we'll consider.

Thank you so much for your leadership, and for the opportunity to offer a few words today.

SENATOR CARLUCCI: Thanks, Dan.

Legislator Murphy.

JOHN MURPHY: Allow me to reintroduce myself so you can put my remarks in context.

I bring to this table 50 years of experience, not as a professional.

My career began in the '60s with the Orange Town Narcotics Guidance Council.

From there, I moved to Rockland Psychiatric Children's Center; and Rockland Psychiatric Center, where I still serve after 40 years.

I'm the president of Camp Venture.

I'm also the founder and president of Loeb House.

And I served for many years on the county Community Services Board, then-called the Board of Mental Health, Mental Retardation, Alcoholism Services.

I say that to you because I think I bring an institutional memory and a broad, broad view of our shared worlds, but I'm going to concentrate just on one topic, the only topic in which I have some degree of expertise; and that's residential services.

We must never forget that most of the people we all serve spend most of their life in a residence. Every night, every weekend, in a residence.

Compare those numbers to the hours they spend in a clinic, it's overwhelming.

The residential-service element is the strongest single component for maintaining mental health. And it's in crises, I tell you. "Crises."

And I'll tell you why.

There is a push, undeniable, to push people through the system.

They want to push them through Rockland

Psychiatric Center.

They want to push them through the psychiatric hospitals.

Where are they pushing them?

They're pushing them to an impoverished and under-resourced field.

We no longer, the State doesn't want to be in the real-estate business, and I appreciate that.

The State has reduced the number of steps in the ladder to the best possible place to live.

No more community residence. No more treatment residences.

They want to push them, primarily, to supervised apartments.

And I'm going to -- I talk street talk, not professional talk.

They're taking people who spent 20, 30 years in Rockland Psychiatric Hospital, and they're discharging them.

To where? To a supervised apartment?

It's patently absurd, and I don't here a hue and a cry about it.

If the State wants to move the people through the system to reduce costs, no longer-term care in Rockland Psychiatric Center, no long-term

hospitalization in the nursing homes, and such, I agree; but they have to enter a world where their adjustment to community life, where their adjustment to apartments, is staged.

You cannot give me, as a provider of services -- and I don't actually -- my executive director, Tom Zimmerman is here -- you cannot send a person who has spent 25 years in Rockland Psychiatric Center to Tom [unintelligible].

That's my point.

Now, I think I have an answer.

I support the Olmsted Act.

I believe our people should be fully integrated into the community.

They should not be stigmatized. They should not be isolated.

I believe they belong out there with us, but, but, in mixed-use non-certified residences.

But, you have to give these residences a whole lot more resource than they have now.

We're getting people with criminal records. We're getting people with sexual-offending records.

These are people we never got before, and we're not resourced enough to do the right thing by them.

Now, my solution is very simple.

New York State and the federal government have this huge amount of funding available for affordable housing.

Okay? It's for affordable housing.

I think it has to be slightly tweaked so that we have a category of capital dollars available to build non-certified mixed-use housing tailored to not only the people who need support in every case of the word, but to our staff.

We have the most underpaid -- our people make less money than the people in McDonald's.

It speaks to our values, our priorities.

It's absurd.

And in this county, you need a lot of money to live, and you need a lot of money to pay rent.

So what are we looking at?

We're looking at an unresourced staff of people who provide hands-on care to our loved ones;

We're looking at the Olmsted Act which insists that everybody be in mixed-use housing;

And we're looking at the fact that the State is eliminating all of the many manifestation of residential services.

That's what we're challenged with; and I say

there's an answer.

People like me would be more than happy to build affordable housing that's tailored to the people we serve and the people who we -- take care of, as well as other people in need of affordable housing.

My pitch to you, Senator, is one thing:

When you're looking at this incredible list of needs of our population, remember something:

Every single person on that list has to have a place to live.

Thank you.

SENATOR CARLUCCI: Thank you.

Thank you, gentlemen.

[Applause.]

SENATOR CARLUCCI: And we've been joined by Assemblywoman Ellen Jaffee, who is a member of the Mental Health Committee in the Assembly, and, we're in her district right now.

ASSEMBLYWOMAN JAFFEE: I apologize for being late. I had another appointment that I had to attend, with a group of young women from Suffern High School, and I didn't want to disappoint them. I had scheduled that meeting prior to knowing about this hearing.

But, thank you very much, Senator, and I look forward to hearing the response and information from the community that's so essential for us to be able to move forward and be responsive in the state.

SENATOR CARLUCCI: Thank you, Assemblywoman.

Our next panel is going to be on the topic of "Raise the Age."

We have Paige Pierce, Jeremy Kohomban, Gabrielle Horowitz-Prisco, and Avrill Lindsay.

PAIGE PIERCE: Good morning.

My name is Paige Pierce, and I'm the executive director for Families Together in New York State, a non-profit organization whose mission is to provide a unified voice for families of children and youth with social, emotional, and behavioral challenges.

I represent thousands of families from across the state, and as such, I've dedicated my career to advocating for children with mental-health and other cross-systems challenges.

As you can imagine, I've heard many heart-breaking stories over the years relating to children suffering needlessly. Often, those accounts have been from parents whose children are suffering from emotional disorders that -- and have

been thrust into the criminal justice system, with disastrous results.

Such accounts fuel our work every day at Families Together to provide better, and do better, by our children.

It is with this in mind that I sincerely thank you for initiating this dialogue regarding the intersection between mental health and juvenile justice.

As you're aware, New York State is one of only two states in the nation that automatically prosecutes 16- and 17-year-olds as adults in the criminal justice system, the consequences of which often bar opportunities to productive citizenship, propel youth toward a path of recidivism, and, all too often, leave permanent damage to their already-fragile brain development and mental health.

To date, this issue has primarily been regarded by the Legislature as a corrections issue; however, it's imperative that the mental-health components be examined and carefully planned for.

Accordingly, the National Center for Mental Health and Juvenile Justice -- according to the National Centers of Mental Health and Juvenile Justice, up to 70 percent of juveniles

cycling through the juvenile justice system suffer from mental-health disorders, with at least 20 percent experiencing disorders so severe that their ability to function is significantly impaired.

Their illnesses include major depression, bipolar disorder, conduct disorder, ADHD, anxiety disorder, and other potentially debilitating conditions.

Incarcerating a child suffering from one or more of these disorders in an adult facility, or even a juvenile facility, absent the appropriate supports and services, can, and often has, catastrophic results for their development and for public safety.

The Raise the Age New York campaign has been shining a spotlight on the realities of life for juveniles inside the walls of an adult facility. They're often sexually preyed upon by older inmates, physically assaulted, and placed in solitary confinement for up to 23 hours a day.

These deplorable conditions were elevated in a national level -- to a national level recently by a scathing report released in August by U.S. Attorney Preet Bharara regarding teens incarcerated at Rikers Island.

The details of this report provided for a shocking indictment of a system that is not only failing our children, but putting them at great risk of experiencing trauma, and even becoming adjusted to this culture of violence, contributing to increased recidivism when they are released.

The investigation and resulting report spanned a period of time between 2011 through the end of 2013, and exposes what is -- what it refers to as a culture of violence against teenage inmates, particularly those with mental illnesses.

51 percent of the teens incarcerated at Rikers Island have a mental-health diagnosis.

Chilling depictions of the experiences of these youth were detailed at length.

I have, in my written testimony, several of those citations.

The report goes on for a chilling 79 pages.

And while there have been -- there have been, and will continue to be, heated and outdated debates on "tough on crime versus smart on crime," I can't imagine anyone would sanction such treatment of juveniles affected by a mental-health challenge.

This is bigger than any one system.

All systems can play a role in ending the

school-to-prison pipeline.

Our current approach does not correct criminal behavior; it perpetuates it.

Our current approach does not treat mental-health disorders; it exacerbates them.

In current -- in direct conflict with all emerging evidence, we continue as a society to push youth into isolation at the very time when they need to be pulled back into their communities to understand and reconcile the consequences of their actions and learn to live with their challenges.

Every day we travel down this road is another lost opportunity to offer these youth a different course.

The time has come to offer more opportunities than we do barriers.

The time has come to reconstruct or adjust the system to one that is developmentally appropriate, driven by evidence, considers carefully the intersecting systems of care, such as mental health, substance abuse, education, and corrections, and examines the costs, both human and financial.

While the U.S. Attorney's report focuses only on Rikers Island, I'd like to tell you about a few

other families that we represent and put a face to such of -- to some of these families.

All the names in the stories have been changed for purposes of confidently.

I'd first introduced you to "Daniel."

In many respects, Daniel was similar to that of most teenage boys. He liked playing video games, socializing with friends, and playing basketball.

In some respects he's a bit different than most teenage boys, as he suffers from an untreated mental-health -- from untreated mental-health challenges.

In 2010, 1 out of 5 Americans experienced a mental-health challenge, and 70 percent of children and youth in need of mental-health services did not receive the treatment they need.

He could be my son, your son, a nephew, or a close family friend.

He could be any race or religion.

He could also be in a safe place today, but he's not.

His life trajectory was forever altered when Daniel was 16 years old. He was arrested for stealing Chinese food from a delivery car, a choice made under pressure of his peers, and one that would

find him in an unimaginable situation.

The official charge was robbery, a violent felony.

Because he was 16 years old, he was prosecuted as an adult; and, thereby sent to an adult facility, and the consequences of this incarceration have been devastating.

Tragically, the youthful-offender status he was awarded was not enough to protect him from what came next.

While in custody, he was raped by a fellow inmate.

Congressional findings reported in the 2003 Prison Rape Elimination Act that juveniles were five times as likely to be sexual assaulted in adult facilities rather than juvenile facilities, often within their first 48 hours.

Daniel, unfortunately, became such a statistic.

The impact of such trauma has had lasting effects.

Although he's since been released, he continues to suffer from severe and debilitating posttraumatic stress disorder.

Had Daniel committed his crime in a

neighboring state where children are not tried as adults, his life course could have been drastically different.

Perhaps he could be on a path to recovery, nearing the end of his college experience, looking forward to embarking on a career path that would lead to product citizenship.

I have a couple of other stories of young people with mental-health challenges who have been inappropriately placed into the criminal justice system, and I'll let you read those, in the interest of time.

I have to tell you about this one kid. He has Asperger Syndrome.

And I have a son who has Asperger Syndrome.

And, as you probably know, they often have, like, obsessions with certain things.

This kid was obsessed with women's shoes. And, he broke into a local gym and stole some women's shoes out of a locker, and he was arrested as an adult, because he is was 17.

You know, luckily, he ended up in county jail rather than state prison.

But, you know, clearly, he had -- it was a manifestation of his disability.

Given the Governor's prioritization of raising the age of criminal responsibility, and the anticipated recommendations of his commission on youth, public safety, and justice, we expect a package of reform bills early in 2015's legislative session.

We ask, that when the ensuing discussions take place in Albany, you recall what you have heard here today, and advocate:

That no youth are housed in adult jails and prisons;

Ensure that all youth are treated developmentally appropriately for their age regardless of the crime charged;

Ensure that a robust array of mental-health and substance-abuse services and supports are available;

Adjudicate all youth under the Family Court Act, where judges have a full array of -- or rehabilitative and restorative tools;

Reduce detention and placement in juvenile facilities;

And, increase the ability to divert cases from court and at arrest.

And thank you for your consideration.

SENATOR CARLUCCI: Great.

Thank you, Paige.

DR. JEREMY KOHOMBAN: Thank you.

Good morning, Senator.

Good morning, Assemblywoman.

Thank you for the opportunity.

I'm Dr. Jeremy Kohomban. I'm the president and CEO of the Children's Village and Harlem Dowling.

Together, we serve over 15,000 children, annually, in residential -- short and residential and community programs. Also, programs right here in Rockland County.

We also serve in the Netherlands, in Iraq, and in Australia.

Currently, in New York, we work with close to home, under the Governor's mandate, to return children to the closest location possible. And we work more with the children that are considered "specialized."

So these are the high-end, high-need children: the fire-setters, the young people who have problematic sexual behavior, substance abuse.

Our experience working with them has informed our thinking around this issue.

And as I heard Paige speak, I quickly made some notes here, because I want to try to go deeper into some of the statistics that Paige spoke about, and elaborate on some of the nuances that we see within that group.

So, let me start by saying, by repeating something that you already know, that the teens that we're talking about are predominantly poor, or they're Black or they're Brown.

That's it.

We're not talking about all kids in New York.

We're talking about select children coming from select neighborhoods, from certain families in our community.

And wherever we live, we know where these children are coming from, so this is not something that's -- we may not think about it, but it's not invisible to us.

They often come -- they, also, in many of our largest cities, they often come from segregated communities, and from -- and, most often, from highly-stressed family situations. For whatever reason, they come from highly-stressed family situations.

It is easy to believe with this group of

children that mental illness is a cause for their behavior and their lack of conformity. But in our experience, it's not true.

When it comes to these children, the term "mental illness" is often broadly applied, with little distinction between serious and persistent mental illness.

Think schizophrenia, that we often think about when we think about mental illness; or the symptoms of what we call "situational mental illness."

What is most damaging here is that, when we don't make the distinction between serious and persistent mental illness and situational mental illness, we kind of lump our children together with a broad-brush approach, and we expect treatment to be the final solution.

And it's easy to think about that, because when -- as you heard in Paige's testimony, the national statistics are pretty clear.

About 70 percent of our children have some type of emotional disorder that can be easily categorized as mental illness, but less than 20 percent of them have what we call "persistent and serious mental illness."

In fact, in our work, we find that number to be even somewhat lower.

But, if you -- if you followed some of the experts on this issue, and most recently, I think it was on Monday, NPR had a piece with Dr. Allen Francis, a noted psychiatrist, and the former head of the department of psychiatry at Duke, what he said -- and I want to quote him, he said, "No one is harder to diagnose than a child or a teenager. The tendency to over-diagnose is particularly problematic among teens."

So there's a lot of over-diagnosis that goes on, and a lot of assumptions that are made, that the kids who exhibit, maybe, some behaviors on the Asperger spectrum, or behaviors that are tied to emotional disorder, or family trauma, are somehow mentally ill.

Recognizing situational mental illness from chronic and persistent and serious mental illness is absolutely essential.

Situational mental illness is often caused by terrible pain.

The pain of family trauma.

The pain of loss.

The pain of long-term system enrollment.

You know, kids in foster care, when they have no one in their lives, can begin to exhibit situational mental illness.

Abject poverty. Living in some neighborhoods, living with the stress of race and racism, the lack of opportunity, and the feelings of abandonment, are often causes for situational mental illness.

In many cases, behavioral issues in community and school, and even gang involvement, and marijuana use, or low-level drug use, are coping mechanisms for kids that are dealing with situational mental illness.

Don't get me wrong; both kinds of mental illness can have long-term debilitating consequences, but the treatment approach for each has to be drastically different.

Treating situational mental illness begins with belonging, and I want to repeat that, it absolutely begins with belonging; meaning, that there needs to be at least one person who loves this child unconditionally.

A system or a government or a Children's Village, no matter how good we are, are not a substitute for that kind of belonging.

In the absence of belonging, it is incumbent that we find a way to create belonging.

That's our job.

It's just like with our own children. These children do better, and they often thrive, when they're loved and when they belong.

They deserve our optimism. They deserve our enthusiasm.

They need structure, they need guidance, they need support, and they need honesty.

They should not as be burdened with our well-intentioned but often misguided labels that encourage a culture of low expectation.

The reality is that, when you're labeled "mentally ill," you're often labeled as low -- with low issues of -- with -- it's often a prognosis of low performance, low expectations, and more often than not, in New York, you're part of a system.

And systems don't make you better; people and families do.

So I have two recommendations.

One is, let's raise the age.

We don't want to be behind North Carolina. Right?

We can't. We're better than that.

And, two -- actually it's three recommendations -- fund the services at two levels, because we can't just raise the age and not fund the services.

First, let's fund our communities where our kids come from.

You know, if we don't correct the root causes and address the issues at the community level, these communities will continue to send kids into the system.

And we don't want kids growing up in the system. We don't want kids growing up at Children's Village.

We don't want that.

Kids need families, kids need communities.

And, then, 30 percent of our funding should to go individual wraparound that support parents, and loves parents that care and love, and foster-parents our children, to be able to take care of them.

And the third recommendation is, we need a transparent tracking system.

And I bet you Gabrielle is going to say this.

We need to know what works, and what doesn't.

We don't want to just put money, year after

year, and assume that it's working. We have too much of that going on.

Let's track this carefully.

It's a small group. We can do this by child. We should track them well into their 20s.

What's working?

And if it's working, fund it.

If it's not, let's stop.

Thank you.

[Applause.]

SENATOR CARLUCCI: Thank you.

AVRILL LINDSAY DENNIS: Good morning.

Thank you for having us, and thank you both for your leadership.

I'm Avrill Lindsay Dennis. I'm a licensed clinical social worker, 20-year NASW member, and social-work advocate, mental-health clinician, and administrator.

Founded in 1955, the National Association of Social Workers (NASW) is the largest membership organization for professional social workers in the world, with 132,000 members in the United States and overseas. In New York alone, there are more than 16,000 NASW members.

The New York State chapter, which encompasses

all of New York, except for the 5 boroughs of New York City, has over 8500, while the New York City chapter has the remainder.

Both nationally and statewide, the organization works to enhance the professional growth and development of its members, to create and maintain professional standards, and to advance [unintelligible] and social-work policies.

As a representation -- as a representative of NASW in New York State, I stand before you today on behalf of more than eight and a half thousand social workers in strong support of raising the age of criminal responsibility.

Science and research have shown, time and time again, that the adult correction system does not work for adolescents.

20 years of experience in New York State has shown us the same.

We need to change this. We have yet to change this.

Based on my experience with these youth, I could quote numbers to you, or tell you life stories.

The youth we work with, the children, were missed for services at some point in their lives;

did not receive accurate or effective diagnosis, treatment, or supports; and, largely, as a result of untreated mental-health issues, have behaviors that, in turn, lead them to be criminalized.

I choose to share with you life stories, and as you have heard, and will hear, from my colleagues in regards to the scientific evidence of youth resiliency, brain function, cost analysis, and family involvement, we know that adolescents and children are resilient and can learn, and they're still growing into the persons in which they will be.

Experience has shown me that our society's focus should to be treat and rehabilitate these young people, to give them a chance at a future instead of criminalizing them and traumatizing them further.

Outcomes for society are much greater and safer when we choose this route.

It is an investment in the individual and in our communities.

Despite the fact that, in New York, a 16-year-old youth is not considered old enough to vote, nor can get an ID without parental consent, drive without parental consent, get medical or

psychiatric care without a guardian, they are automatically treated as an adult once they commit a crime.

Why do we still think they have adult responsibility for some really bad decisions, when we show that we know they're not able to make most adult decisions alone.

There's a public misconception that these youth come from broken homes, non-existent homes, or families who don't care about them.

A fair percentage of these kids do, in fact, come from homes with caring and supportive adults.

Those adults may face challenges in understanding the mental-health needs of their youth, because they're unfamiliar with diagnosis trajectory, or believe that the moods and behaviors associated with the underlying issues are within the youth's control.

Other adults have spent years pleading us for help with their kids, fully understanding the risks.

A small percentage do, in fact, have limited stable adult connections, sometimes due to family issues themselves, but, more often, due to having had such difficulties for so long without those supports that the adults, too, are tired.

Families need support in understanding the benefits of treatment, but, more so, in how to access treatment options.

This last group of youth is at greatest risk, with the correlation between the history of being abused and neglected and criminal behavior.

These crossover youth we touch in our systems; those same systems that we need to increase the assessment process, to work towards treatment for early trauma of youth, gearing towards prevention of later, more complex mental-health issues.

Youth in our systems -- this has been spoken of already -- are disproportionately Black, Brown, and impoverished.

Close-To-Home legislation was a huge step in the right direction. It affords us the ability to treat youth in the community, to link them to services and education, community programs, and to be close to their families, receiving passes and therapy with the family as a whole.

We're moving towards a treatment focus that replaces the punitive-detention model, one we know does not work for adolescents.

Current administrators are demonstrating

interagency collaboration from New York City and New York State agencies to the not-for-profits, all working for the same common goal: to reach youth, rehabilitate and treat youth, strengthen families, and, in turn, our communities and everyone's future.

New York State needs to increase and strengthen mental-health services available.

Budgetary concerns over the last 10 years have had a significant impact on the number of in-patient hospital beds available, mandates governing clinic hours, and the availability of effective crisis response that does not involve a police-department response.

Lack of access to services, combined by ongoing stigmatization of mental-health issues, are impediments to treatment availability.

It's vitally important to these -- to supporting these young people is adequate, affordable, accessible, and comprehensive mental-health assessment and treatment.

Some successes:

A 15-year-old young lady with some depression and impulsivity, both linked to untreated PTSD which led her to make some really bad choices.

Within her first month in placement she was

hospitalized for bizarre, aggressive, dangerous, and regressed-looking behaviors.

Following six months in treatment, duly placed in both juvenile justice and foster care, she returned to mom's home, with the goal of attending nursing school, after receiving the foster-care award for the year, a very different young lady than the one who we first met. Realizing her potential and accepting those in her life who could help her, she moved in the right direction.

A 17-year-old that had all but given up, also duly placed. No stable adult relationships to mention.

The first sign of progress we saw was being released from criminal court one night at about 11 p.m., to herself.

Instead of hitting the streets, we got a call asking for a ride back to placement.

We saw that as a huge strength and huge progress.

It was a long road from there, but with treatment, and a relationship with her father began, later she returned to his home, and enrolled in a GED program.

She learned to express herself through

poetry. And for the first time in a long time learned to develop trusting relationships.

Another youth we work with speaks of his time in Rikers by saying that the corrections' "violence being condoned" attitude really leads to helplessness.

All these youth have really done is missed opportunities for treatment in other venues.

Some families have tried diligently, as I mentioned, to reach services, only to be turned away, or to have their case closed when an adolescent doesn't make an appointment.

Adolescents soak up the environment around them. They can learn and grow and will take in what they experience.

What experiences are we going to provide to them?

Moving youth into an adult system that has a known culture of violence only leads to traumatizing youth.

The trauma often presents itself in behaviors, leading to youth -- leading youth into similar situations where they would be traumatized again.

Ongoing trauma we know is a trigger

underlying mental illness, or takes some of those simpler mental illnesses, as Jeremy spoke about, and make it much more complex. The cycle then continues.

There are a multitude of issues in the adult correctional system that need to be addressed, and this is a separate issue.

Adolescents should not be part of this process.

To quote one young lady from early in my juvenile justice experience, on the phone with her mother, begging her mom to sign Consent For Medication so that she, and I quote, "didn't have to go through this over and over again in her life, remaining locked up. To give her a chance at treatment and in life."

The headlines grab the outliers in our youthful-offender system. They sensationalize a handful of heinous violent acts that are committed by a handful of youth.

This paints a very skewed picture for society about who these youth are we're talking about today.

We're talking about the majority that get caught in our criminal justice system here and now; those who we can truly change the trajectory of

their future.

Critics argue that victims of youthful offenders have to live with the trauma of being a victim, so why should the offender get off easy?

Not treating a child as an adult does not correlate with letting an offender off easy.

The road to treatment and rehabilitation is not an easy one.

The reality is, that treating all youthful offenders as youth actually decreases recidivism; increases the likelihood of those individual successes.

The victim is still, unfortunately, a victim.

But with treatment, assessment, and care, the offender has a greater chance of not offending again.

Adolescents are impulsive here and now. It can take many, many months to have a case heard in a criminal court, meaning that no matter what the punishment, the youth is frequently unable to connect to those too.

We ask New York State to change its position and become a leader in the evidence-based policies, uhm -- policies and practice, ongoing research and evaluation, with input from families and

stakeholders, to be used by service providers in the juvenile justice system, as NASW tasks social workers to do.

We should be encouraging the child-welfare system and the juvenile justice systems to develop strategies and policies that will provide for greater levels of collaboration, screening, data sharing, assessment, case management, supervision, and interagency collaboration.

Kids need care, individualized assessments, family work. Some need very specialized treatment, and some need to catch up on school, rebuild or build important adult connections.

With the variety of needs, all youth coming into the system should be treated as youth and individually assessed for what they and their family truly need.

Programs should have the capacity to do individualized treatment plans for youth and families, to address short-term and significant mental-health issues, to make referrals post release for continued treatment and continuity of care.

There should be no one-size-fits-all answer.

One size never fits all.

SENATOR CARLUCCI: Thank you.

GABRIELLE HOROWITZ-PRISCO: Good morning.

My name is Gabrielle Horowitz-Prisco. I'm the director of the Juvenile Justice Project at the Correctional Association of New York.

We're an independent non-profit founded in 1844, tasked by the New York State Legislature with monitoring conditions inside the adult prisons.

We also do policy work and work with young people in the system.

Thank you both.

As you've heard already, trauma and abuse and mental illness are actually the consequences of our current criminal justice system, so they both drive children to enter the system, but the system also causes exactly that which, ostensibly, it is designed to alleviate.

I talk sometimes about how I came to this work as an attorney for children in family court in child abuse and neglect cases, and I sometimes talk about the dinner-party conversation.

And I'd be at a dinner party, and it would go like this:

"What do you do?"

"I'm an attorney."

"What kind of attorney?"

"I represent children in child abuse and neglect cases."

And people would act like I was Mother Teresa.

You know, "How do you that? That's so hard. I could never do that. Wow, I really admire you."

And I would say, like, Yes, you could it. It is hard. But, you know...

And, then, I also represented kids in the juvenile justice system in juvenile-delinquency cases.

So, same dinner party, different day, it's not that I went to so many of them:

"What do you do?"

"I'm an attorney."

"For who?"

"For kids."

"Kids, what?

"Kids accused of crimes."

"Oh. How do you do that? What if they're rapists? How do you represent those? What if they've done a murder? Really? How do you -- you feel okay about that?"

And I always thought, it's the same kids, I had the same job. And how society viewed even me

as a helper.

In one hand, I was elevated, practically beatified. And in the other hand, there was sort of a disbelief, and a distancing, "How can you represent those kids?"

So I'm here to talk about how -- two things:

One is adolescent brain development;

And the second is the incarceration of children, and the impact on their wellbeing, particularly young people with mental illness.

But I'm also here to just kind of bear witness to the fact that they're all our kids.

That as you've heard from my colleagues, they're kids who need our help and our love and our connectedness, and need, if anything, treatment and services; but absolutely do not need to be locked in cages, locked in solitary confinement, and abused at the cost of taxpayer dollars, which is what is currently happening.

A little bit on adolescent brain development.

As you heard from Avrill, the New York State law is currently riddled with hypocrisy.

We don't allow children at 16 to get a fake tan.

We don't allow them to get a tattoo, or to

get an AT&T cell phone contract, or to purchase cigarettes.

However, they can be interrogated by the police without a parent present.

If a child is 16 or 17, their parent doesn't even have to be notified.

Your child could be taken and kept overnight by the police, and there's no legal requirement that a parent even be notified, because that parent -- that child is considered an adult under this one provision of New York State law which contradicts all the rest of the law.

Not only does this not make sense, it's not consistent with an extensive body of scientific literature that talks about why kids are different.

The prefrontal cortex of the brain is the part of the brain that weighs risk versus reward, future planning, impulse control, rational decision-making.

It's also one of the last parts of the brain to develop, and it's not fully mature even in late adolescence.

The literature actually talks about 24, 25, being the age at which the brain completes this stage of development.

I don't need to go through an extensive list of adolescent, you know, brain-development research, but I'll say, we know this.

If you've been a teenager, if you've raised a teenager, if you love a teenager, you know that teenagers make very stupid decisions.

I sometimes talk about, when I was 17 years old, growing up in Staten Island, New York, I shoplifted in Macy's because the line was too long, and my boyfriend was waiting in a car in the parking lot. And I actually believed that it was unfair of Macy's to have such a long line when I needed to go.

I mean, I really remember thinking, like, It's their fault the line is so long, and I have to go, and he's waiting, and this is very important.

It was related to my prom, I think. It was, like, something I needed for prom, so, I'm going to take it.

And, you know, I wasn't caught.

And, in retrospect, had I been caught, I would have been shielded by my race, by my privilege as a middle-class, you know, young girl growing up on Staten Island, by having educated.

The system I would have entered, if I even

entered a system, would have been a very different one.

I probably would have been released to my parents. Maybe done some community services.

Whereas, I represented children who went to prison for similar things.

But when I tell that story, it's like a human way of putting a face on what the evidence tells us; which is, teenagers make terrible decisions, and they outgrow that, because the reason they make terrible decisions, particularly when in groups, is because their brains have not finished developing.

However, there are ways that we can support children, including during adolescence.

And the very same scientific body of research tells us we can design interventions that have adolescent brain development in mind.

So some of the options you heard about from Jeremy and from Avrill are the smart, forward-thinking, twenty-first-century solutions that New York State has a chance to design.

You as policymakers have the ability to become a national leader to help New York go from being last into the country to the forefront of harnessing the power of evidence and research, to

say, What works? How do we fund what works?

And I want to talk a little bit about kids in adult jails and prisons, but I want to say one thing before I do that, which is, as you've heard from my colleagues, prosecuting children as adults is the opposite of tough on crime. It creates crime.

So if your colleagues say to you, "Well, what about victims?" I think a very smart answer is, "We're creating more victims in the current system. If you're so concerned about crime, then help kids get help, so they don't get released from jail and prison to go on and create more future victims."

This is demonstrated.

The non-federal Task Force on Community Preventive Services, which is a long way of saying an independent task force, did a systematic review of published scientific evidence, looking at kids who are in the adult system versus the youth system.

This is a meta-study, so they looked a seven studies out there, and they found a 34 percent relative increase in subsequent violent or general crime for kids who are in the adult system versus the youth system.

A 34 percent increase.

Other studies have shown that violent crime,

in particular, increases when kids are prosecuted as adults.

So I want to conclude by just talking about some of the risks for kids in adult jails and prisons.

You've heard a little bit about kids in adult jails and prisons are at grave risk.

Kids in adult jails are 36 times more likely to commit suicide than those in youth facilities.

They're more likely to face an armed attack, by 50 percent, as compared to young people in youth facilities.

And they're nearly 100 percent as likely to be beaten by staff when compared to young people in youth facilities.

They also can be placed in solitary confinement, as Paige spoke about, for up to 23 hours a day.

Although New York City has recently said they're going to stop this practice for Rikers, there are no plans to stop the practice in the county jails.

And even the Department of Corrections and Community Supervision that runs the state prison system is currently in settlement for a lawsuit,

where they may reduce some of the hours of solitary confinement, but there's still, essentially, solitary confinement of young people.

And I want to say this, going back to my days in family court:

When I represented kids in child abuse and neglect hearings, if we got a case in which a parent locked their child in their bathroom for 23 hours a day, and cut a hole in the bathroom door and shoved some school papers through the door, but didn't let the child out; and, when they did let them out, it was for an hour a day to stand on a balcony and walk in a circle or do a pull up on a door; and, they gave them only limited food shoved through that same slot in the door; and, they denied them all human contact, child-welfare services would emergency-remove that child.

There would be no hearing first.

The child would be emergency-removed from the home. All other children from the home would probably be removed.

The parent would absolutely be charged with child abuse, and, potentially, criminally charged in criminal court as well.

Right now, as we sit here, despite the

Department of Justice investigation that Paige spoke about, where the U.S. Attorney found that children on Rikers Island are being brutally abused. They're being abused physically by corrections officers, and they're also in solitary confinement, they remain in those conditions.

Those children need to be emergency-removed from adult jails and prisons, including Rikers Island.

Not develop --

[Applause.]

GABRIELLE HOROWITZ-PRISCO: Thank you.

Not develop a plan and wait three months. Not figure out where they're going to go.

We would not allow a parent to do to a child what New York State is funding, paying for, government employees to do to children.

It is child abuse, and it must end.

It must end right now.

The answer is getting children out of adult jails and prisons and into the youth system.

Ideally, keeping kids in their communities with the kinds of intensive services that you heard about from Avrill and Jeremy.

But if kids are going to be confined, they

should never be in an adult jail and prison.

The last thing -- I'm a little worked up so it's hard to pause.

The last thing that I want to say, is that you and your colleagues in the Legislature have done a great job of supporting and developing the youth justice system in New York State.

So it is even more reprehensible that 16- and 17-year-olds are denied the access of the youth justice system.

For example, under the past couple of budgets you created and passed, the Supervision and Treatment Services for Juveniles Program, which is the "STSJP" funding, it's a permanent funding stream to support community-based services for youth, with the goal of keeping kids out of detention and residential care. Specifically, it provides support for young people with mental illness.

You as legislators have done a great job creating fiscal infrastructures in the youth justice system; yet, 16- and 17-year-olds don't have access to those advantages.

So in conclusion, there are five recommendations that I urge you to consider:

The first is, obviously, that New York State

has to raise the age of criminal responsibility.

Like Paige indicated, the Governor has shown this to be a priority. He has created the commission on youth justice and public safety, which our executive director, Sophia Elijah (ph.), is one of co-chairs of.

We look forward to the commission's recommendations, and to seeing the specific suggestions for how this could be done.

The second, is to remove children from adult jails and prisons immediately.

Again, we would not allow a child to remain in these conditions in their parents' home. We certainly shouldn't allow them to remain in government custody in these conditions.

The third, is to end the practice of solitary confinement for all children, period, regardless of where they are. And also pointing out that the solitary confinement of children is considered torture.

And the U.N. and other bodies -- and international bodies have spoken about it as a violation of, really, basic human rights, and as torture.

Finally, as Jeremy spoke about, funding needs

to go, not just into rejiggering the system so kids are now locked up in youth facilities, but into the kind of community-based programs, prevention, wraparound services, and treatment that works.

And, also, investing in communities so kids don't need to be in any system.

I regularly speak to kids and parents who are in the system, and I hear things, like:

In my neighborhood there is no after-school center. There are no programs. You walk out of my house and there's a deli, and there's a fast-food restaurant, and there's a Chinese food restaurant, but there's no YMCA or no JCC or no park, no green space, no after-school program. The school shut down and there's no place for the kids to go, so they go to the corner.

Kids need spaces to play, to dream, to be with other kids.

They need options other than a system.

And, finally, for those kids that are in the system, the fifth recommendation is, as Jeremy said, we need transparency and we also need oversight.

It is appalling that it took the federal government to come in and document the conditions on Rikers.

Why was that not done at the state level?

Why did we need the U.S. Attorney to tell us what was happening in our own state?

We need oversight;

We need transparency;

We need to know what is happening;

We need to be able to get kids out of abusive situations;

And we need to create and fund something that works, so that New York moves from being last in the country to being the leader.

We deserve to be; but most importantly, that our children need us to be.

They need us.

They count on your leadership, and we thank you.

[Applause.]

ASSEMBLYWOMAN JAFFEE: I would just say, having taught in a junior high school for seven, eight, and nine, for over twenty years, and I've watched the brain development and the changes, and that's a very real issue that I think needs to be acknowledged and discussed on a regular basis; because they do change, and they do behave sometimes in outrageous ways, given the instability of their

situations as well.

So, thank you for your testimony.

SENATOR CARLUCCI: Just a couple of questions.

Now, is there a legislation that you support that's currently out there right now, or does this need to be created?

PAIGE PIERCE: The commission that Gabrielle and I both talked about is -- the recommendations are due at the end of this year, at the end of December.

And the expectation is that there will be a package of bills that will address those specific recommendations.

SENATOR CARLUCCI: All right, great.

And then the other question, about, when we talk about tracking and the transparency, and not to get into the, you know, micro details, but what do you envision? What type of tracking system?

DR. JEREMY KOHOMBAN: Senator, I think because this is both controversial and requires us recreating the wheel here, right, I mean, we haven't done this well, I think we need person-centered tracking.

We have a group that we'll begin with.

You know, ideally, legislation will pass.

We'll have an identified group of young people that we start working with across New York State.

It's not a large group, so we can begin to track these children to say, you know: What did we do? Did it work; did it not? What were the recidivism rates?

The current system doesn't have person-centered tracking, so children could move from one system to the next and completely disappear, and we never know whether we are spending money wisely.

So we need person-centered tracking, at least for the first [unintelligible] and the second [unintelligible].

SENATOR CARLUCCI: Okay, so no matter what agency they're in, we can follow them from agency to agency?

DR. JEREMY KOHOMBAN: I think it's a group that's small enough that we can do this.

GABRIELLE HOROWITZ-PRISCO: And I would just add to that, that tracking is certainly an incredibly important component. And I think person-centered tracking is a great solution.

Also, talking about oversight, that there needs to be a single agency.

There are currently 11-plus agencies, I believe, in New York State that have various pieces of oversight over the prison system, over young people in the system.

There is the justice center, which I sit on the advisory council for, and is a tremendous step forward.

However, the justice center does not cover 16- and 17-year-olds in the adult system, except for in certain situations when they fall under the protection of other agencies.

In addition, you know, there needs to be an agency that has subpoena power; the ability to make unannounced visits and inspections in prisons.

There are, and I'd be happy to share with you, recommendations that the American Bar Association has put out, as well as national prison-monitoring experts, like Michele Deitch, have put out, about what oversight should look like.

And I'd be more than happy to share those.

And there are very specific, concrete recommendations that the ABA and other experts have said, such as, an agency must have confidential

interviews with children, with families, and with incarcerated people, about conditions.

They must have subpoena power.

They must have the ability to shut an agency down.

If you have an oversight agency that can't actually put the incarcerating body -- you know, have any enforcement, or can't shut them down, there often isn't any teeth to oversight.

So there needs to be an ability, when children -- when the U.S. Attorney, again, documents what we found on Rikers Island, what happens with that? What is the response?

And who then has control over making sure that those kind of problems don't occur?

And those problems are systemic. They're not isolated to Rikers Island, although the U.S. Attorney looked only there.

So we'd really consider -- urge you to look at oversight mechanisms.

SENATOR CARLUCCI: And that leads me to my next question:

Do you have a number of the amount of 16- and 17-year-olds that are currently in county jails or state prisons, or that, you know, in a given time

are there?

GABRIELLE HOROWITZ-PRISCO: I will say the numbers --

SENATOR CARLUCCI: And is it more a county-jail issue? state prison?

GABRIELLE HOROWITZ-PRISCO: Yeah, so the numbers vary, depending on how you count.

What was put forth by the governor's Children's Cabinet about several administrations ago, when this issue first began being investigated at the state level, was close to 11,000 kids in county jails, Rikers, or state prisons.

However, my understanding is, those numbers looked at kids who spent, including, like small periods of time. Like, if they were detained for a couple of days, which can still be devastating.

And as Paige said, kids are often raped in their first 48 hours in a facility.

But just to say that number is high, when you look at kids who are in jails and prisons for a short period of time, or, who, in their sentence, are sentenced to time served, which means they're sentenced to time they've already spent while awaiting trial, if you look at the number of kids who are sentenced to jail and prison, then the

number drops significantly.

So sort of where the number is, and where you can get a snapshot, depends on how you measure, and whether you're looking at, you know, Rikers, DOCS, or the county jails.

But we can correspond offline and I can get you some of the different breakdowns, because they do change depending on what you're trying to measure.

SENATOR CARLUCCI: Right, okay.

And when you talk about solitary confinement, is it the case -- I know, you know, the correctional officers are working with the guidelines that they're given.

And is it a matter of segregation? Or are we talking about just absolute solitary confinement?

Is there a difference, or -- to segregate the 16-year-olds from the adult population in these prisons or jails?

GABRIELLE HOROWITZ-PRISCO: It's a great question.

So, the Prison Rape Elimination Act (PREA) says that localities must make all efforts not to use solitary confinement as a means of separating 16- and 17-year-olds.

So New York State, which has indicated it will become PREA-compliant, is, under PREA, not supposed to be using solitary confinement as a way to keep 16- and 17-year-olds segregated or safe.

My understanding is that, at least when I'm talking about solitary confinement, and, like, some of the statistics that we have about the number of kids who are in solitary in DOCS, the state system, or in Riker's, or in county jail, those are kids who are generally there for disciplinary confinement, what's called "punitive segregation," or "disciplinary confinement," which is they're there for some kind of alleged infraction.

It is important to know, however, that those infractions in the culture of a jail or prison can be incredibly minor.

We have many documented cases, and there have been reports done by the American Civil Liberties Union and Human Rights Watch and other organizations, documenting that kids who go to solitary confinement, and adults, it can be for very minor things, such as, you know, maybe speaking back to a corrections officer. Again, which can be part of the adolescent brain.

I've heard firsthand testimony from people

who went to solitary, adults, for things like having vitamins, which aren't allowed in the system. For having too many legal materials.

I've heard a man testify personally, who was put in solitary because he had too many legal materials in his cell beyond what was allowed.

So just to say, even when you hear "disciplinary confinement," it doesn't mean -- and we would say, no matter what a person has done, they should never be in that position, in solitary. But it's important to drill down and say "disciplinary" means something very different in the context of a jail or prison.

PAIGE PIERCE: Well, and, also, under PREA, the -- you know, in order to be PREA-compliant, jails and prisons are not supposed to have young people, minors, with adults.

The only way to do that is solitary confinement. Otherwise -- you know, you've got to lock up somebody. You've got to, like, separate them somehow.

And most of our jails and prisons in the state are not PREA-compliant, just by the physical structure, and the fact that we have 16- and 17-year-old physically there.

And one way to get PREA-compliant on that part of PREA is to segregate them in solitary confinement. But then you're violating other parts of PREA.

AVRILL LINDSAY DENNIS: The other piece, just to add to that, is if you take into consideration the adolescents who truly have the mental-health issues, and the behaviors that are driven out of the untreated mental-health issues, leading to some of the examples of behaviors, and the minor infractions that would lead them to solitary confinement.

So instead of accessing treatment, or accessing either known or unknown assessments in treatment for the youth, they're then placed in solitary versus treatment or assessment.

SENATOR CARLUCCI: Great.

Well, thank you so much.

PAIGE PIERCE: Senator, can I just add one more thing, about, when you talk about oversight and tracking, one of the things that we know about young people who are in prison now, at the age of 16 or 17, is that they didn't -- that wasn't their -- the first time that anybody ever heard of this kid.

You know, they were, you know, suspended from

kindergarten; and, preschool, kicked out of preschools.

You know?

So we're talking about kids who -- if -- but that was a different system.

So, tracking that kid into a different system is often not -- doesn't happen, and so they just go from system to system.

I've had family members tell me: We have four different case managers that come to our house, from different systems. None of them even know the other exists.

You know?

Families are the case managers for the case managers.

And, our system needs to have a better sense of where -- you know, who are these kids?

There's the ACES study (the Adverse Childhood Experiences Study) that shows, you know, the trajectory of kids who have had high scores on the ACES. And they -- we can -- we know these kids, and if we track them and help them, and provide the kinds of supports to their family and to the community on the front end, we wouldn't even have to talk about how many 16- and 17-year-olds are in

adult prison.

SENATOR CARLUCCI: Great.

Well, thank you so much. Appreciate it.

Thank you.

[Applause.]

SENATOR CARLUCCI: Next we'll hear from Toni Lasicki, who is the executive director at The Association for Community Living.

TONI LASICKI: Good afternoon, Senator.

Well, that's a very tough act to follow, I think.

As you know, ACL represents 120 nonprofit community-based mental-health agencies across the state that provide an array of mental-health services, including over 20,000 housing units with a rehabilitation focus.

Our members serve primarily consumers who are affected by severe and persistent psychiatric disabilities, many of whom have co-occurring serious -- medical conditions, substance addictions, and developmental disabilities.

Virtually all of their clients are eligible for Medicaid.

Our members' agencies are primarily funded and regulated by the Office of Mental Health, and a

substantial portion of their revenue is from the Medicaid program.

Thank you for accepting my testimony.

I just want to -- just to put a context, I am going to focus just on the RCE plans and Olmsted, as was in the title of the request.

So, as you know, there are many other issues that we can talk about, and I'm sure we'll have an opportunity to do that in the coming months, but I am going to focus on those two areas.

Although it's my understanding that the regional centers of excellence plans, as originally considered, are no longer being considered by the State.

The State's field offices, along with communities around the state psychiatric centers, are planning for the use of funds, save from bed closures, reinvesting those funds into the local -- into communities.

We have heard from providers around the state that the services that are being funded in each community do closely follow the recommendations of the original RCE committees in each region, with additional input from providers, county directors, families, and consumers.

That said, providers report that there are varying levels of participation from community members and providers in the different counties, resulting in a few that are unhappy with the process.

Concerns were raised mostly in areas where services and/or housing slots were awarded without an RFP process.

However, most are satisfied with the process and the services that will be funded.

The services are too varied to list here, but an example -- but examples include: supported-housing slots; enriched services for people in housing; mobile crisis; warm-lines; hotlines; self-help; outreach; crisis-intervention programs to provide peer engagement and wraparound services; children's crisis intervention and mobile integration teams; ACT teams; child and family intensive case-management slots -- just to add to Paige's *, all those case managers that are running around -- mobile residential support teams; hospital return and respite centers; and recovery centers; and more.

So we realize that the plans to downsize the hospitals will include ways to preserve state jobs,

although we're not quite sure what that will look like.

We believe that this is a reasonable goal and planners should strive to reach it.

However, it's a well-documented fact that the same service provided by the State is both much more expensive and less flexible than when provided by non-profits with no loss of quality.

We're also concerned that the State will expect non-profits to allow State workers to work in non-profit settings, side by side, in the same jobs with non-profit staff who make one-half-or-so less than the State staff.

That would create an inordinate amount of discontent among our workforce, and is really not recommended.

However, we do have a need for specific services that State staff might be able to provide where there are few or no equivalents. Those include mobile-nurse services, building maintenance, security, grounds maintenance, mobile psychiatric staff, and I'm sure there are others.

In addition, we have concerns about the sustainability of new services.

The current community-based system has been

starved of funding increases so much so that programs have experienced up to 43 percent in cuts due to inflation.

Creating new services that will also be similarly starved is not a recipe for a robust system of care that can take the place of inpatient settings.

No matter what happens with reinvestment in communities, the existing system of care and the new must be sustained by providing regular, consistent cost-of-living increases to the entire budgets of these programs.

ACL is strongly opposed to targeted increases that go only to certain workers or to portions of providers' budgets.

Providers must able to manage their finances in as flexible a manner as possible.

In addition, as we move to managed care, we need a much more robust administration.

Ours have been weakened and reduced, as providers have moved money to direct care and to programs to keep them afloat.

We now need to replenish those areas that have been neglected.

Many of my members report that their

administration -- the administrative share of their budgets is now down to 10 percent.

10 percent is extremely low to manage 24/7 highly regulated programs, to move into managed care, and to continue to keep up with all of the burdens that the State puts on them.

So just on Olmsted, we will be releasing a white paper in the next few days on Olmsted and OMH housing.

I'll excerpt it here, but please allow me to send that along as soon as it's done, probably by Friday.

New York State's Office of Mental Health has successfully integrated tens of thousands of persons with serious and persistent psychiatric illnesses into the community over the last 35 years, but this next statistic is telling:

New York once had 24 adult state institutions that served 93,000 people.

It now has 17 adult state institutions that serve 2800 people.

So we went from 93,000 in 24 facilities, to 2800 in 17 facilities, using approximately $2 billion of the state's mental-health budget. All hospitalizations account for $3.3 billion.

As the hospital population decreases, without a proportional decrease in the number of institutions, the cost per person goes up.

It is now at an all-time high.

By my calculations, it's approaching $700,000 per year per person in a state facility.

In contrast, the entire local system, all programs, not just housing, is funded at only $1.3 billion for 600,000 people; or approximately $2100 per person per year.

Although housing has been proven to keep people out of hospitals and institutions, resources have been diminishing in community settings for years.

For example, housing programs have lost 20 to 40 percent in funding to inflation over the past 20 years at the same time that the clients' needs become much more challenging.

That said, the Supreme Court did observe that the ADA does not compel states to phase out institutions. That it does not mean to drive patients into community settings that are inappropriate. That some patients may need to revisit an institution from time to time, and that some patients may never be able to actually leave an

institution.

It also opined that the State did not have to fundamentally alter their programs or services to operationalize the integration mandate of the ADA.

However, I believe that if the Supreme Court were to revisit Olmsted today, it would be shocked that so much of a state's resources go to so few people at the expense of the majority, when there is a way to change that; that is, to consolidate hospitals and move that money to where the clients are in the community.

One can only wonder what the Supreme Court would think of New York today; in particular, what Justice Kennedy would think.

Justice Kennedy, in his concurring opinion, cautioned, that if the principle of liability announced by the Court today is not applied with caution and circumspection, states may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition.

I believe that this is happening today because of the misguided attempts to save every state hospital from extinction, requiring massive

amounts of money to maintain a handful of people.

As evidenced, look at what the State is willing to pay for a housing slot for a person coming straight out of a state facility.

In the central region, that's $7600 per year.

So somebody comes from a $700,000 bed in a state psychiatric facility, and is expected to be served by a provider in the community for $7600 a year, and that includes rent.

New York has the highest cost of living in country, so that the OMH publicly-funded housing continuum for people with serious mental illnesses in New York is critical and necessary, and, it needs to expand.

Few have enough income to be housing-independent.

A modest apartment in New York costs, on average, 133 percent of the SSI rate that clients receive.

Employment may often be a goal for the vast majority in the system; however, 85 percent of persons with mental-health diagnoses are unemployed.

The subset that needs supportive housing are the least likely of those 85 percent to obtain employment that will pay them in the amounts needed

to be housing-independent in New York State.

We simply cannot continue to spend $2 billion on 2800 people if we are going to be responsible stewards of state resources and meet our obligations to the most ill among us.

The State Office of Mental Health has funded a variety of program and housing types in the community over the years.

However, we are hearing that some types of facilities may be in jeopardy due to the way in which the Department of Justice interprets Olmsted.

We believe that the New York State Office of Mental Health's effort, however, to deinstitutionalize patients from the state hospitals and other settings have largely been within the parameters of the ADA, as interpreted by the Supreme Court's decision in Olmsted.

That well-known decision sought to place two women with co-occurring developmental disabilities and psychiatric illnesses from state institutions into small group homes in the community.

In interpreting the Americans with Disabilities Act integration mandate, and in answering the central question posed in the lawsuit,

whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than institutions, the Olmsted Court held that it did in the following circumstances:

When the state's treatment professionals have determined that community placement is appropriate;

When a transfer from institutional care to a less-restrictive setting is not opposed by the individual;

When the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities.

All of that leads one to believe that a continuum of services for people with varying needs is appropriate.

After all, if the Court recognizes the need for institutions, it is reasonable to think that the Court would approve a step-down setting from institutions, including highly-structured community settings that are close to or integrated into neighborhoods.

It would also be surprising for the Court to object to even a lifetime community placement in a

highly-structured community residence integrated into a neighborhood as an alternative for those that would otherwise need to spend their entire lives in a segregated institution.

For some, these are the only choices; or, the choices that many would make even if the state had unlimited resources.

So ACL encourages New York to continue to expand its housing system and to sustain each model in the continuum.

We also strongly urge New York State to continue to make available capital dollars directly to the State Office of Mental Health so that it can continue to make available a large number of housing units to people with serious and persistent psychiatric illnesses.

If all capital dollars were to go through one central housing office, which seems to be a possibility under the Governor, developers might be tempted to reject people with serious psychiatric disabilities who are often the most difficult to serve. However, these are the people who are some of the highest users of Medicaid, and housing has been proven to reduce those costs.

We can provide any additional information

that you might need, and thank you for the opportunity.

SENATOR CARLUCCI: Great.

Thank you, Toni.

Appreciate it.

TONI LASICKI: Thank you.

[Applause.]

SENATOR CARLUCCI: Our next speaker is Mary Grace Ferone. She's the program manager at the Legal Services of the Hudson Valley.

MARY GRACE FERONE: My name is Mary Grace Ferone. I'm the program manager for disability and public benefits at Legal Services of the Hudson Valley.

Thank you for giving me the opportunity to speak with you today.

I come here today wearing three very different hats.

The first is as an attorney who, for over 15 years at Legal Services of the Hudson Valley, has represented individuals with serious and persistent mental illness in matters that help them maintain and secure the basic necessities of life.

My second hat is as the board chair of CHOICE, a mental-health peer-advocacy and

case-management organization that works daily to assist persons with mental illness, and navigate bureaucracies, fight against the stigma of mental illness, and to live life to the fullest.

Lastly, I come as a sister who, 32 years ago, lost her 20-year-old brother to suicide.

Knowing what I know about services to persons with mental illness; particularly, what the services were back in the '80s, there weren't many. Hospitalizations and day programs seemed to be the only answer for my brother.

While I acknowledge that New York State, in particular, has come a long way in providing services to individuals with mental illness, much still needs to be done to help people live healthy, alive, and living in the community.

I'd like to speak with you about a service I know makes a difference in the lives of persons with mental illness; and that is civil legal services.

Legal Services of the Hudson Valley is the premier provider of comprehensive legal services to low-income individuals in the Hudson Valley.

We have eight offices, including Spring Valley, White Plains, Yonkers, Mount Vernon,

Peekskill, Poughkeepsie, Newburgh, and Kingston.

We strive to serve as many eligible individuals and service as many persons with various disabilities, but the need outweighs our capabilities.

Individuals who suffer from mental illness, like most other populations who are marginalized by society, regularly face legal battles to maintain the basic necessities of life.

Often, these individuals struggle to maintain their housing, secure benefits to which they are entitled, struggle to keep their families together, and struggle to live with dignity and the civil rights to which they are entitled.

The struggle to maintain the basic necessities of life can be overwhelming to a person struggling with mental illness.

Legal problems cause increased stressors that have harsh effects.

Mental health can deteriorate, cause hospitalizations.

One can become homeless.

One could lose their income and live without a support network.

Since the early 1990s, Legal Services of the

Hudson Valley has been providing free legal services to Westchester residents, only, who suffer from severe and persistent mental illness, as a result of a grant from the New York State Department of Mental Health.

This grant, known as "Community Support Services," should be a model replicated across the Hudson Valley and New York State.

The funding provides for two full-time attorneys to provide civil legal services to the SPMI community.

Of over the 350 cases handled by the project last year, the vast majority involved providing for or maintaining the necessities of life.

Evictions were prevented.

Benefits were obtained.

Parents were reunited with their children.

The experienced attorneys who work on this grant, and in conjunction with medical case managers and care coordinators, to ensure client services and avoid crises.

Our attorneys also provide training on substantive legal issues relevant to the mental-health consumer community and to social-service workers.

I have worked in civil legal services for over 20 years, and have provided services to this community for the majority of that time.

It has been my experience that services are the key to keeping people healthy and free from hospitalizations.

More services are needed to create networks and referral systems so that consumers get to professionals before a crisis becomes a problem -- a problem becomes a crisis.

I'm sorry.

Prior to the introduction of services, homelessness, loss of income or benefits, unstable family relationships, would be the norm.

Increased legal services, combined with increased availability of case management, is a key component for the success in recovery of persons with mental illness.

Without the basic necessities of life being taken care of, the person can focus on being well.

Thank you for your time.

SENATOR CARLUCCI: Thank you, Mary Grace.

Our next panel is regarding eating disorders; and we have Neil Weiss, who's a parent-advocate, and we have Doug Bunnell, who is the national clinical

development officer and clinical director at Monte Nido.

NEILL WEISS: Thank you, Senator.

Nice to see you, Assemblywoman Jaffee.

My perspective on this is as a parent.

You obviously see that I don't have any notes, so I'm going to be speaking from the heart.

A lot of the issues that I've heard today are similar, and yet different, for someone who has an eating disorder.

My daughter was diagnosed, quite by chance, because one of her friends at school, when she was at South High School, went to a person that was a counselor, and actually went to our daughter and said: I think that you have an eating disorder. You actually have 24 hours to speak with your parents because, within those 24 hours, I'm then going to be calling your parents."

It was very lucky that we happened to have known personally this counselor at the school.

What we didn't know at that time, we didn't know the hell, and all the issues, that were going to be coming along with it.

One of the things that we discovered was that, in the New York tri-state area, there are very

few eating-disorder specialist units, not only on a private insurance, but also through Medicaid.

Medicaid has units that do look at eating disorders, but they do specialize in others areas -- alcoholism; drug use; violence, whether it's domestic violence or whether it's sexual violence -- and they always tag on the eating disorder with that.

One thing that I've learned, you cannot place a student, a young lady or a young man, in a unit that has other people affected by other illnesses, because, as I call them, "'Ed,' the monster," will rear its ugly head and will soak up some of the other issues because it just loves and it thrives on making an illness worse, stronger.

Now, one of the things that happened to me is, I had to actually leave my job, because my daughter got so ill that my wife, actually, previously, when she was younger, she had an eating disorder.

Her eating disorder came out with a vicious cycle, that one was feeding off of the other.

When I lost my position, I lost the insurance. I had to go onto Medicaid.

And, again, this is where the system reared

its head in my face, that I actually went to anybody that would listen. That nobody has able to direct me to any different institution or facility that actually looked after eating disorders.

Luckily, the Jewish Family Services had one person that joined their staff that was willing to look after our daughter on one hour per week.

Now, the symptoms can actually come out earlier in life.

When my daughter was placed into one of the facilities, when we did have insurance, the only two facilities that would take her, that were local, one was in Philadelphia, one was in Boston.

That was the closest that we could have gone.

Insurance doesn't pay for the excess gas, for tolls...for everything else that goes along accordingly with looking after someone that has an eating disorder.

But the symptoms, and all the classic signs of someone with an eating disorder, these are young men and women that are highly intelligent. They have a level of OCD with it. They will actually hide the illness from those that are closest to them.

One of the things that I would like to put

forward is, there is a program that I --

And, Senator, you know that I lived over in Europe for over 25 years.

-- they actually, and what I'm hearing from many different people here today, is early detection, early prevention, and early intervention actually works very well, over in England particularly.

The money that is invested early on keeps the cost at a longer figure, going down the road, from escalating and getting higher. And the earlier that you can actually attain and get a hold of the illness is something that is so important.

At one of the facilities that I knew --

Bless you.

-- one of the facilities my daughter was at, they had young ladies there as young as 10, 11, and 12. And they also had women there that didn't get diagnosed early, but were in their 40s, 50s, and 60s.

There was one woman that my daughter got very friendly with, that we are still friendly with as a family. She is a consultant gynecologist from a woman's hospital in Boston.

She has an eating disorder that keeps on

coming back, and she is the first one to admit, it wasn't diagnosed and worked on earlier.

Not only is she a gynecologist, but she's also pregnant, with an eating disorder.

And this is a system, whereby, if not caught early enough in the school; we got a lot of information regarding drug abuse, regarding alcoholism, but not one piece of information came from the school about eating disorders.

And I can tell you now, when I found out early on about eating disorders, my whole concept of what it was, was nothing like it actually really is.

You do not always have young ladies, young men, looking like they're famished or that they're starving.

They eat when they need to before they start collapsing.

And one of the things that an eating disorder will do, it will actually affect many organs, physically, in the body a lot faster than a lot of other illnesses.

They always have heart checks.

Potassium levels are lower.

You will find that many of these young children and young adults and young people are dying

from heart conditions, a heart attack.

Now, one of things that I know personally is that this is in the shadows, but it really isn't.

I could take you to the lobby of Spring Valley High School, of South High School, of North High School, and I could stand on one step, and I could almost point out some of the people that do have eating disorders that are not being caught by the staff.

And a little training by the staff will go a long way. That's money that could be well spent to prevent longer-term issues.

And these, again, are highly intelligent people that will actually have a very big effect on society.

So, really, in conclusion, I don't really have a lot to say; just that, my family is, literally, tearing apart because of this.

My wife and I are at odd's ends.

My daughter and I are constantly fighting, so much so, there was one time that we had to call the police, because my daughter threatened to harm herself, and she was placed in an isolation unit at Nyack Hospital.

She was there for 72 hours, because we didn't

have private insurance at that time. Medicaid was not able to send any psychiatrist to speak to my daughter until three days later.

Now, frankly, I know that my daughter wouldn't have harmed herself dramatically; but, again, I don't know that, because I don't know what's going on in her mind.

It's only lately that she's really starting to come out of her shell.

And I will tell you this:

The gentleman sitting next to me is from an organization called Monte Nido.

They, literally, saved my daughter's life when she was in the facility up in Boston.

And, again, we had to travel almost every week, and at some point, every other week, to go up and visit her, because this is a family issue that needs family involvement, very much like almost all these other illnesses that I'm hearing today.

And there's no support from anyone else, other than the family.

And more importantly, there is nothing in this immediate area that we can actually turn to, other than day treatment or outpatient treatment.

So, that's what I have to say.

And I really would like to turn it over to Dr. Bunnell.

DR. DOUG BUNNELL: Thank you.

Thank you, Neil.

And thank you both for providing leadership on this issue and bringing some light to eating disorders; and mental-health issues, in general.

Mr. Weiss's story is one I've heard over and over again in my 30 years in this field, both as a clinician, and as a -- I was actually past board chair of the National Eating Disorder Association, really targeting these sorts of issues.

So the good news in New York State is that New York State's actually been at the leadership of trying to craft legislation and systems to address some of these issues.

The bad news is, that they remain largely underfunded, and we need to find ways to actually bring life to these organizations.

So, I want to sort of start with the good news, and sort of close with the needs.

Let me just give you a little context; again, the personal face of the story.

This is a story that many families go through. Like, they don't know about eating

disorders until they have to know about eating disorders, and then they are trying to navigate their way through a system that is complicated through an illness that is multi-dimensional, often requires multiple care providers, often has a prolonged and protracted course.

Most people do get better, but it often takes a long time, and it can wreak havoc, not just on the individual, but on families as well.

In the United States, approximately 30 million people suffer from eating disorders.

Those are from diagnoseable disorders, such as anorexia nervosa, bulimia nervosa, and, now, binge-eating disorder.

If you sort of extend the labels a little bit, or the criteria a little bit, we're looking at a sizable proportion of people; upwards of 30 percent of high school girls, and 16 percent of high school boys, who endorse symptoms of disordered eating that may not reach the threshold of formal diagnosis, but, are troublesome.

So, we're talking about laxative use, self-induced vomiting, dietary restriction, overexercise.

With boys, we're looking at issues like

growth-hormone abuse, steroid abuse, things like that, to build their bodies, because of their anxiety about bodies.

So independent of whether they have an actual formal diagnosis, there's a tremendous amount of pain, distress, dysfunction, and impairment associated with disordered eating that we need to be mindful of, as well.

Eating disorders have the highest mortality rate of any psychiatric illness. It's a little known fact outside of the eating-disorders world. Most people still perceive eating disorders as relatively benign diagnoses.

These are serious mental illnesses that really do great damage to the psyche, the body, as Neil mentioned.

Among the 15-to-24-year-old age range, you know, people in that range with an eating disorder have a 12 times higher risk of premature death than their non-eating-disorder counterparts.

So these are serious illnesses.

Actually there's some evidence -- I can get you the citations -- that the greatest amount of health-care dollars spent on behavioral issues in adolescents is around eating disorders.

If you talk to the insurance companies -- and I'll come back to that in a moment -- the insurance companies, their greatest distress is around the amount of money they have to pay to provide care for this population. It's actually the number-one behavioral-health cost for the insurance companies.

So we need to do a better job of, as you said, intervening early, preventing some of the downstream more -- complications, that include things like bone loss and brain shrinkage and infertility and depression and anxiety.

There really is tremendous amount of damage that cascades out of an eating disorder if it's left undiagnosed, untreated.

It is actually anorexia nervosa, which is actually the least-common eating disorder. It's sort of the face of eating disorders, so the face is usually a young woman who is starving herself.

That woman is -- and the misconception is usually Caucasian and upper-middle class.

Those are misnomers, misperceptions.

These are illnesses that affect all ethnic groups, all religious groups.

You know, as I mentioned earlier, they affect both genders, with some differences, but we know

boys are under-diagnosed, under-attended to, in terms of these disorders.

And just to shift to the current snapshot of what's going on in New York:

Until -- well, up until tomorrow, OMH willing, we will open up a residential treatment program in New York, in Irvington.

It will be the -- only the second residential treatment program in New York State history for people with eating disorders.

The other one was in the Elmira region, and closed down several years ago.

So we are -- we sort of worked through the process of getting that program open. It's been complicated and challenging, but, I think we've heard from -- over and over again, from families and providers in the area, there's is a great need here.

The story that Neil describes of families needing to go out of state for treatment is gut-wrenching.

Can you imagine having -- you know, being newly diagnosed, and having to say to a 15-, 16-year-old, let's say, daughter, you're now told that, for her to get comprehensive care, she's going to need to go to Philadelphia. Often even go to the

west coast. There are programs in Utah, of all places, that do this.

But imagine the distress that causes the family.

Beyond that, we know, too, that the most effective treatments for people with eating disorders involve family. And we have to find ways to facilitate that.

So to be able to provide treatment in New York State for New York State residents is absolutely critical. It improves treatment outcomes, and will help to deter some of those downstream costs.

If we're going to do that, it's critical that we build a network of treatment providers and treatment resources across the state.

The Comprehensive Care Centers for Eating Disorder -- the CCCED, which is the last time I'll say that, because I can never say it without stumbling -- but, the Comprehensive Care Centers have centers in the Rochester area, the Albany area, and downstate.

It's essential that we continue to try to link those centers together, and link treatment providers in between those regions with those

providers. That takes resources.

This CCCED mandate, as I mentioned, they do exist, and they are, really, sort of models for what other states should be doing, but they remain underfunded.

Most eating-disorder patients in New York struggle to find a single point of access for care, so that the normative experience for people or families with an eating disorder is, they go, Oh, my God, where do I go?

No sort of sense that it's, you know, a very complicated system.

There are organizations, like National Eating Disorders Association, that can get people pointed in the right direction. But, we need to do a better job in New York State of directing people to care.

The bill also established support in coaching and case-management resources, which are just essential.

Again, if we can help people find their way to treatment, provide community supports, we can actually avoid or deter inpatient admissions, which are costly and problematic, obviously, for families.

So I think that one of the developments in the field over the past several years has been

extending this continuum of care, to look at providing outpatient treatments, supports, that help patients and families stay in their homes, stay in their communities.

Residential care is one piece of that continuum, but, the critical part of the treatment actually takes part in recovery. It takes part after people step out of 24/7 care and need to reenter the community.

And the dropoff from a 24/7 environment to once-a-week outpatient therapy is precipitous, and many patients struggle in that shift.

So we're looking to be creative at trying to provide resources and support in that, that link, if you will.

Again, I really want to stress, trying to build and facilitate residential care here in New York will allow families to stay here in New York, and really benefit, you know, patients and their families.

I also want to just briefly highlight a success.

Assemblywoman Gunther and Senator Hannon were part of a bill that mandates now public awareness and education for eating disorders, that's so

essential.

The issue of stigma in all mental illness, but certainly with eating disorders, is just profound.

There's such shame, and sort of misconception associated with these disorders, that whatever we can do to educate is going to be helpful.

So, I just conclude by saying:

We know that providing a full continuum of care with easy access, and referral across that continuum, will help patients and families.

We can save lives, we can save resources, and at the same time, facilitating that sort of fully functional comprehensive-care model, we really have sort of the skeleton in place to do that, but, can we bring resources to really bring that to life?

Thank you.

NEILL WEISS: I would like to add one thing on this.

One of the -- as Doug mentioned, one of the areas that New York really does have that's well, is we have the National Eating Disorder Association located in New York, in Manhattan.

They're a phenomenal resource, but that's all they are, they are a resource.

What I'm advocating is, an education early on, that, we're educating the educators so that they then can go out into their field. And we're speaking -- I'm speaking of the teachers, of principals, because they are the ones that see the students early on, and they are the ones that see the changes more than the family does.

And you have an option, and you have an opportunity here, to actually make use of the facilities in the New York area, and it all doesn't have to come from public money.

There are numerous amount of companies that I have actually approached, with regards to eating disorders, that are more than willing to actually get on board, and help lose and help get away from the stigma that's in this, and raise the awareness.

So this could actually be a very good opportunity for yourselves to actually point the way to actually use not only public and private funds, but to really use this knowledge that we have in this area, and get it out there to the right people.

Thank you.

Do you have any questions?

SENATOR CARLUCCI: Just one question about the Monte Nido, and, you said you're opening

tomorrow?

DR. DOUG BUNNELL: We are awaiting formal approval from the Office of Mental Health on that; but, yes, some time in the near future we will open.

SENATOR CARLUCCI: And how many people will you be able to --

DR. DOUG BUNNELL: 14 beds for, at this point, women, 18 years of age and above.

We hope to actually be sort of spinning off a male program within the next year.

SENATOR CARLUCCI: And those 14 people that will be taking advantage of those services, where will the funding come from?

DR. DOUG BUNNELL: Mostly through their private health insurance.

We will have a percent of, sort of, non-revenue care that we provide as part of our --

SENATOR CARLUCCI: Do you anticipate an issue with Medicaid?

DR. DOUG BUNNELL: We have been working with that issue, and how we're going to sort of manage the Medicaid relationship.

It's complicated.

SENATOR CARLUCCI: Okay.

NEILL WEISS: Well, I just want to add one

thing.

My daughter, being that she is actually in the New York unit, Monte Nido does have scholarships, and they have given my daughter a scholarship.

Again, I say that they saved her life, but most importantly, this is a facility, these are people, and it's not just Monte Nido, they do care.

And there are scholarships.

And Medicaid is -- as I know personally, it is absolutely diabolical when you're trying to get a hold of people. And, I hate to say it, sometimes to them, it's a 9-to-5 job. But, more importantly, they are constrained to what they are able to do.

SENATOR CARLUCCI: And just another question for Dr. Bunnell.

The -- has your experience been that private insurance is good in covering people with eating disorders?

Because that's what it sounded like so far.

DR. DOUG BUNNELL: Uhm, it's important to provide access to care based on people's insurance, so I think it does pay for a level of care that helps many people.

There are many people who struggle to

actually get comprehensive and fully effective care based on their health-care insurance, and, ongoing tensions. So many people, one of the issues we see, is that people will be sort of pulled out of treatment prematurely, based on sort of, you know, pulling back with funding, and so forth.

You then sort of relapse, and, you know, they're partially recovered, and then, sort of relapse, and then actually need to spend more money to go through another cycle of treatment.

SENATOR CARLUCCI: Because one of problems we've seen on the work we've done with people with addiction, particularly the rise in heroin addiction that we see, is that we've had a real problem with private insurance.

And it's been around, What is the definition of "addiction"? And when do we meet that threshold to have inpatient services?

So that's why I was wondering if you've come across --

DR. DOUG BUNNELL: No, I mean, it's a very complicated issue, and I would be happy to talk offline further about it.

But, one of the issues that comes up is the point at which you -- or, how you define "recovery."

And one of the issues we run into, both in the addictions world and, certainly, with eating disorders, is that full symptom remission; meaning, cessation of symptoms, like binge eating or purging or starvation, would be one marker of recovery.

What we understand, for most people, is that there's work that needs to go on beyond that. And, often, that can be longer term sort of work. And, insurers are reluctant.

I mean, if I'm in their shoes, I understand their reluctance, but, they're reluctant to pay beyond a certain threshold.

So we often have people sort of getting just to that point, and then needing to be, you know, drastically reduced in the level of intensity. And that, actually, is where the relapses tend to occur.

NEILL WEISS: When my daughter was in both of the different facilities, there were times that she would -- we would be speaking on a regular basis if we weren't visiting her, and she would actually come and say to us:

"I've been given three more days from the insurance company, and then they have to reevaluate";

"I've been given another two more days";

Or "I've been given another week."

She would have her bags packed, until the actual phone call with the eating-disorder facility and with the insurance company. And she would not know, even that day, if that was going to be her last day at the facility.

So, when you speak of the addictions with heroin, it's very similar.

They have a different definition than what's out there, than what is actually from life experience.

So, if you -- when you say, Have we had a good experience with the insurance companies?

No; because, literally, at a moment's notice, our daughter would have called us up and said, This is my last day, you have to come and get me.

And that's gut-wrenching, because we know that she's not cured.

And we know that from other people as well.

The eating disorder will pick up and it will thrive on that, because it will say, Oh, I'm cured, but, I want to do more. I want to just -- I really want to take over.

DR. DOUG BUNNELL: So certainly one other frontier for work, if you need more work, would be

to look at, sort of, the insurance, sort of, standards.

I mean, they vary tremendously across policies, across states.

Definitions; insurance companies have different level-of-care criteria that are increasingly transparent, but not always easily transparent, so it's hard to know how they're actually making decisions or authorizations about level of care.

And, so, there are other states that have done some work in this area too.

SENATOR CARLUCCI: Great.

Well, thank you so much.

DR. DOUG BUNNELL: Thank you both so much.

NEILL WEISS: Thank you.

SENATOR CARLUCCI: Our next panel is on mental-health supports and services.

We have Edgardo Sanchez, and Ilana Slaff-Galatan.

EDGARDO SANCHEZ: Good afternoon.

SENATOR CARLUCCI: Good afternoon.

EDGARDO SANCHEZ: Senator, it's nice to see you again.

SENATOR CARLUCCI: Yes.

EDGARDO SANCHEZ: I'm going to say, thank you for holding today's public hearing, and for giving us the opportunity to testify.

We appear before you today, not as mental-health professionals or governmental experts; but, rather, as a family with nearly 38 years of experience with the New York State provides -- excuse me, which the way New York State provides, or, in many cases, is unable to provide, desperately-needed services for those with mental illnesses in developmental disabilities.

Let us tell you about our experiences.

First I want to say, my wife -- I get very emotional -- my wife can't, or won't, make these meeting because she feels very guilty about our son.

Okay.

Our son Brandon (ph.) Sanchez began to exhibit alarming behavior very early in his life.

He suffered with generalized grand mal seizures from the time that he was six months old, and was diagnosed with a medical condition known as "tubular sclerosis."

Tubular sclerosis is a rare multi-system genetic disease that causes tumors to grow on the brain and other vital organs.

A combination of symptoms, including seizures, intellectual disability, developmental disability, behavior, problems in skin, and other abnormalities; all of which my son suffers from.

At the age of 2, he was enrolled in a day program close to our home.

Staff in the facility were trained well enough to work with children with Brandon's condition; those that mentally challenged and suffer from autism.

So my son has the double-whammy.

From the age of 6, Brandon began to exhibit violent self-injury behaviors, such as slapping, pinching, biting, himself, and sometimes others.

At that age, also, he was breaking all the windows in the house with his head.

Never got cut.

I got cut.

He displayed this behavior so frequently that, physically, he appeared to be an abused and battered child, which have been called many times, cops used to come to my house.

He also exhibited rumination and projectile vomiting, which has caused some ulcers and scarring of his trachea and stomach.

Due to the force which he slapped his face, Brandon suffered detached retina, which had to be surgically reattached.

Because of all the dangerous and maladjusted behaviors that my son was displaying, the day program was no longer acclimated to or functional. The staff could no longer meet his needs. His behaviors had become extremely self-injurious and life-threatening.

We did much research, and visited numerous facilities recommended by the mental-health officials in New York.

Okay, one of them was Creedmoor.

If anybody knows about Creedmoor, that's more like a freaking prison than a mental institution. Okay? High fences, barbed wires, I ruled that out.

When Brandon was 12, we chose the Judge Rotenberg Center in Canton, Massachusetts.

Brandon has been at the center for 25 years.

He is now almost 38 years old.

Honestly speaking, it was a heart-wrenching decision to place him outside of our home, but our first visit to the Judge Rotenberg Center, we sensed that this might be the right place for Brandon.

Upon presentation of the center's strong

behavior approach, the extensive monitoring of staff, and rigorous quality-control measures, and consistent approach to treatment, we became convinced that this program was capable of effectively treating our son's dangerous behaviors and could afford him the quality of life that he is entitled to.

Our initial apprehension, when Brandon first came to JRC, which was formerly called "Behavioral Research Institute," which I'll explain how they got "JRC" later, has given way to acceptance, and then gratitude. This program has proven to be a lifesaver for our son.

After admission to the Judge Rotenberg Center, Brandon's life-threatening behaviors plummeted, and he started to smile again. He spends most of his days happy and relaxed.

His skin was healed, but no longer looks bruised and battered.

We thought this was where Brandon would find a safe haven, and time has proven us right.

We have learned through the years how capable and compassionate and well-trained their staff are, which makes us extremely comfortable in knowing that his every need is being met in a professional manner

and safe environment.

When he comes home, and he's home for the weekend, we almost thought he would have a problem to go back.

Come Sunday, he's ready to go back, on his own. And this is from a young man that really doesn't have the capacity, you know, to fully understand.

We couldn't be happier in his progress and his current quality of life.

Brandon is content at JRC, and that puts our minds at ease.

Were it not for this program, we would fully believe that our son would not be alive today.

And I'm going to give you an instance.

Some years ago, my son's program was taken away from him, because of the contribution -- controversial procedures that they use at the school.

Finally, Judge Rotenberg had the insight, and the compassion, to restore his program.

My son dropped down to 35 pounds.

Talking about disorders, eating disorders, that's a biggie.

And, that's why they changed the name from

BRI (Behavioral Research) to Judge Rotenberg Center.

He was our crusader for the school and the rights of the children.

We are not lawyers, and we cannot speak to you about Olmsted decision, and how New York goes about the task in implementing it, but we urge you to remember, that bringing Brandon closer to home or putting him in a less-restrictive environment is not doing Brandon any favors.

Huh, just the contrary.

Unless and until New York State has developed programs that have the experience and resources to treat our son effectively, and to continue to keep him safe and healthy, bringing Brandon back to New York will only harm him.

I sincerely feel that from my heart.

My son comes back to New York, without the proper program, just put him up against the wall and shoot him, because he's not going to last long.

We have been told by many professionals that if our son is forced to return to New York and he fails one of the [unintelligible] community programs, he would not likely -- I mean, he would most likely end up in a development center or other type of psychiatric facility.

My son deserves a continue -- to continue to remain in a highly-structural program that has served him well over the past 25 years.

Forcing him to return to a system of care that failed him so badly would definitely prove to be cataphobic (ph.).

We don't want to see Brandon placed in a life-threatening situation, robbed of the opportunity that we all entitled to as human beings, which is life itself.

Sometimes I feel an inmate gets better treatment in prison and has more rights than my son does.

I mean, to feel like that, I tell you (makes a sound).

New York maintains a philosophy of person-centered planning for individuals with developmental disabilities.

Because our son does not have the capability of making decisions for himself, he does not speak.

His IQ, people don't have to worry about "mental retardation."

I use it. I'm not afraid of it. It's in the dictionary.

People get offended sometimes.

I do not get offended by that word.

And to me, my son is brilliant.

In his own way, he is brilliant.

However, we are sure that if our son could express his choice, he would choose to live in the home that he has resided for the last 25 years with the people that know him best and are most capable of caring for them. And they do.

I see it every time I go.

I go there unannounced. I have leeway; I decide.

My brother, he's a big crusader.

He's a state rep, Jeffrey Sanchez, from Boston. He's been fighting for the school for years now.

Olmsted implementation must be done in a manner that reflects compassion, common sense, and sound judgment.

Tearing Brandon away from the home where he has found respite for the past 25 years, to try and improve a potentially dangerous place, is cruel, dangerous, and counterproductive.

We urge you, as the Chair of the Mental Health Committee, to show that people like our son are not put at risk in had name of

implementing the Olmstead decision.

That Olmstead decision is -- if there was a program in New York, man, bring him back.

I would love to have my son back.

But, that's the reason that we were sent to Massachusetts, because there wasn't.

There wasn't a program 25 years ago, and there isn't one now.

So, I don't know, how -- how -- what the result of this is going to be, because, I don't know if the Governor is going to have enough compassion to pass that bill.

I don't know.

I don't know.

ASSEMBLYWOMAN JAFFEE: That's my legislation.

And I wrote that legislation in response to situations that I heard about, families that I have discussed this with.

And, truthfully, I think it's unacceptable to arbitrarily demand that they return, especially over 21.

So, the legislation would provide the opportunity for the parents to seek -- to be able to contest that in court.

At least have an opportunity to suggest that

the placements that are suggested are not acceptable, based on the circumstances.

So, we are waiting to pass both the Assembly and the Senate, and we are awaiting the Governor to sign it --

EDGARDO SANCHEZ: We were informed, and we were told, that if our children are placed in a state institution, right, we might have no rights.

If it doesn't work, we may not have no rights.

ASSEMBLYWOMAN JAFFEE: That's right.

EDGARDO SANCHEZ: They might take our rights away from us.

I'll be damned if they do that.

ASSEMBLYWOMAN JAFFEE: It's unacceptable, you're right, and that's why I sponsored the legislation.

And I hope that the Governor will hear your message.

EDGARDO SANCHEZ: Well, I hope he does.

I sent him enough e-mails.

ASSEMBLYWOMAN JAFFEE: Thank you for your courage.

EDGARDO SANCHEZ: Thank you.

SENATOR CARLUCCI: Ilana.

ILANA SLAFF-GALATAN: Hi. Thank you, Senator Carlucci, for holding this public hearing and giving us the opportunity to have our voices heard.

And thank you, Assemblywoman Jaffee, too, for listening us to.

I have identical twin brothers, and I have a daughter, with autism.

I'm also a practicing psychiatrist. I completed many fellowship at the Mount Sinai Seaver Center, in autism.

And, I am concerned about the supports and services for individuals, and families, dealing with developmental disabilities in New York State, particularly regarding my brother.

My brother Matthew has been living at an out-of-state residential adult facility in Massachusetts, the Judge Rotenberg Center, for over 25 years, after he was placed at the Judge Rotenberg Center, at age 17.

He's on seven positive-behavioral contracts at once, and, he earns preferred items all day long, for being safe.

He also receives functional-communication tokens to help him to request breaks rather than

having a dangerous behavior.

When living at home, my brother banged his head into sharp corner. He also developed neuroleptic malignant syndrome. That is a deadly side effect you can get from anti-psychotic medication.

He developed it from Haldol.

And, he also required surgery to his head for self-injury.

He was in the hospital for 5 1/2 months, and despite having a staff member present with him around the clock, he continued to need repeated suturing for repeated headbanging.

And this all occurred despite polypharmacy, with five medications, which gave him obesity, tardive dyskinesia, loss of ability to verbally communicate, drooling, and daytime -- excessive daytime sedation.

He was sleeping about 16 hours a day.

The Board of Education told my mother that there's no educational facility that will accept him, and, she was requested to waive his right to an education.

In other words, they felt he was untrainable.

She refused.

Furthermore, the medical insurance was running out, and my parents were told that they could be held responsible for the hospitalization costs.

And I remember my father wondering, Could the hospital possibly take our house from us?

However, through my mother's, physician, she was informed about the Judge Rotenberg Center.

He's been doing quite well there for over 25 years. No more headbanging, and no medication.

He was on an aversive device, a 2-second skin shock. He hasn't needed it now for over two years.

And, we've taken him on trips to other states.

My other brother who is not at JRC, he was functioning quite well in the past. And as an adult, had a full-time job for about three years, without any medication, and he was travel-trained.

He moved into a New York State Office of People with Developmental Disabilities (OPWDD) -funded agency residence while holding this job.

He lost his job after a fellow co-worker teased him.

My brother, because of his autism, he knew he worked nine to four. And this co-worker kept

repeating to him, you have to work until five today.

My brother got more and more agitated, grabbed this butcher knife, and lost his job.

And then, after he lost his job, he totally deteriorated in his functioning. He became obsessed with setting fires. He tried to set a pier and himself on fire. He's had numerous hospitalizations.

Although the staff at the residence where he lives, they're kind and concerned, he has failed the positive-behavior supports with the functional-behavior assessment, determining the functions of the behaviors. And, he has had the positive therapies, but they have never been nearly as intensive as what JRC has been able to provide to his twin.

He's been on at least 15 medication trials which has caused obesity, tardive dyskinesia -- those are permanent, abnormal, involuntary movements that he has -- sedation, and seizures.

At a family gathering, he became agitated, obsessed with material, and he hit my grandmother, who was then 99 years old, in the face.

He was too agitated to attend her 100th birthday party, even though he lived in the

neighborhood.

And his twin came in from JRC.

So, the Olmstead decision is not applicable if someone has dangerous behavior.

You can't -- dangerous behavior precludes community integration.

In the past, at least in New York, people are discharged and suspended from their day programs due to behaviors.

This happened to a number of my patients.

They're left alone at home with an elderly parent in a potentially dangerous situation.

So, in other words, if the day program, with all their professionals, can't handle the behavior, they dump the problem onto the elderly parent.

Two prior students from JRC (Judge Rotenberg Center), who returned to New York, they died from their behaviors in their 20s.

I do not want my brother to die too.

There are many problems with medication management for self-injury. And this, unfortunately, is being used pervasively in New York in replacement for applied-behavior analysis.

Yes, there are some people who need medications, but we should not be replacing ABA with

medications. It's completely unethical; it's wrong.

Risperdal received FDA approval for autism. However, in the -- those clinical trials, that were placebo-controlled, they did not differentiate between mild and severe behavior in their outcome measures. And, they used an outcome measure known as the "Aberrant Behavior Checklist."

Only 3 of the 15 components on that list relate to self-injury. They never published the breakdown of those components.

And, also, the sedation rate for those individuals with autism in the Risperdal trials was 49 percent.

That's opposed to the single digits for schizophrenia and bipolar disorder.

Okay? All right?

So we're using a lot of chemical sedation.

And we don't know if those -- because of the high sedation rate, we do not know if that reported improvement in the total behavior and that -- in that outcome-measure score was due to -- had the sedation had an influence on that.

In addition, when we looked at ABILIFY (aripiprazole), which also received an FDA approval, they did publish that breakdown on that

Aberrant Behavior Checklist outcome measure -- irritability subscale outcome measure.

And when they looked at self-injury, those three components, they did not do better than placebo -- they did not do significantly better than placebo, even though the total score showed an improvement.

So, that's really important to note when we're using these medications for self-injury.

Furthermore, up to 60 percent of individuals with autism, without clinical seizures, if you do EEGs (electroencephalograms) on their brain, you will notice that they have subclinical seizures. They have seizure activity that you don't see clinically.

Now, you put them on these anti-psychotics, you can bring out the seizures.

And that happened to my brother.

It also can be particularly dangerous to use medication in individuals who can't communicate their side effects, and, you can't get them to comply with the prescribing guidelines, such as blood pressures and blood tests.

I do not want my brother at JRC to be placed on medications again, when intensive-behavior

management has shown them both to be unnecessary and previously ineffective for him.

I have been working with the developmentally-disabled population, exclusively, for eight years in New York.

And like my brother who also lives in New York, there is no choice but to administer polypharmacy that makes these individuals sleep much of the day to control their behavior.

They have diabetes, heart disease, liver toxicity, among other adverse effects.

Sometimes they die very young from these adverse effects, in early adulthood, because they have all of these adverse effects for years.

When I see them, I think of my brother at JRC, and how, by returning him to an inappropriate placement in New York, he will be like them, either sick or dead.

And that precludes the Olmstead Act, because that's not community integration.

Recently, an OPWDD-funded agency where my cousin resides attempted to remove his parents' legal guardianship, because his parents refused to consent to more toxic medication.

They took my cousin to court.

In the past, OPWDD has sent my parents a letter, asking for our agency preferences.

I left messages, return messages, on the phone number provided in that letter.

No response.

I sent a certified letter to OPWDD.

No response.

My school district has never been unresponsive to this degree with my daughter, because they know I have the right to an impartial hearing.

Placements that have been offered so far by OPWDD to my brother have not even had a board-certified behavior analyst on staff.

The placements OPWDD proposed did not provide intensive positive-behavioral interventions, functional-communication tokens, or aversive therapy.

An independent expert who visited the placements has stated that my brother's life would be in danger at these facilities.

My family only wants to make sure my brother is safe and can function.

The State made the right decision 25 -- until -- for the past 25 years, to keep him in a

place where he can be safe and function, until they could develop a place in New York that he could be safe and function.

Given that the current state of support and services in New York for individuals like my brother is so clearly inadequate, we are gravely concerned.

Moreover, it is an inherent conflict of interest for a funding agency; in this case, it's OPWDD, to unilaterally decide what is appropriate.

We are only asking for the same due-process rights that all disabled individuals in New York have, and which everyone with a disability under the age of 21 has.

If S-7374/A-9729, which I'm so grateful that you sponsored, is signed by the Governor, my brother will have those rights.

He was only placed outside of New York to begin with because no place in New York would accept him.

And, again, we only want my brother to live, function, and have a quality of life.

That's all we're asking for.

I have a statement from the JRC Parents Association. If anyone is interested, they could pick it up.

SENATOR CARLUCCI: Great.

Well, thank you so much for your testimony.

We really appreciate it.

Thank you.

ASSEMBLYWOMAN JAFFEE: Thank you for sharing.

ILANA SLAFF-GALATAN: You're welcome.

[Applause.]

SENATOR CARLUCCI: And our next speaker is Susan Kent, who's the president of the Public Employees Federation.

SUSAN KENT: Good afternoon now, isn't it?

Good afternoon, Senator Carlucci.

Good afternoon, Assemblywoman Jaffee.

SENATOR CARLUCCI: Good afternoon.

SUSAN KENT: So, I was told I was long-winded last time, so I won't be long-winded today.

Thank you for holding this hearing.

I have brought testimony with me too.

SENATOR CARLUCCI: Great.

SUSAN KENT: Additional testimony.

So, you've said who I am.

I'm Susan Kent, and I'm very proud to represent the members of the Public Employees Federation.

We are 54,000 members' strong, and we are the

professionals that provide the services in the state of New York, including services to individuals living with mental-health issues.

I want to thank you for your leadership in ensuring in this year's state budget --

And this was no small feat on your part, and I can't stress enough, our thanks.

-- that any savings resulting from Governor Cuomo's proposed mental-health-facility closures, should be, must be, reinvested in community mental-health-care services, to follow the patients prior to any closing of any facilities.

As we have seen far too often, when public facilities close, the savings from those closures rarely make it into the community, and the results are disastrous.

Patients, with nowhere to go, do not receive the care or treatment they need.

Many end up in costly emergency rooms, on the streets, in jail or prison, or, even worse, God forbid.

As you may be aware, the Treatment Advocacy Center is a national not-profit organization dedicated to eliminating barriers to the timely and effective treatment of severe mental illness.

According to an April 2014 report by the Treatment Advocacy Center, there are 10 times as many persons living with mental illness in jail or prison as there are receiving the necessary treatment in psychiatric inpatient facilities.

Jails and prisons have become the new alternative to inpatient psychiatric facilities in our society because the money saved from closing facilities was never reinvested into community mental-health-care programs.

We absolutely need to remain steadfast that this does not occur again.

That is why it was crucial to push a requirement to reinvest those savings into the community at the beginning of the process, and before, any actual facility closures took place.

Again, your leadership in sponsoring legislation in the Senate and in the Assembly is vital for both of the patients and for my members.

Last month, OMH began releasing funding for various community-based programs, totaling $6.6 million around New York State.

Just last week, OMH announced that the Hudson Valley would receive $2.25 million, for several counties, including $449,668 for

Rockland County, and 225,000 for Sullivan County.

As an initial investment for community-based services, these dollars are a good and positive step forward.

If such investments can better manage mental-health care so those in need remain active and healthy persons in the community, that is what we all want to achieve.

Those individuals most at risk of emergency room visits and hospitalizations must have competent mental-health-care treatment available to them in the community now more than ever.

Unlike a system that had the ability to refer a serious mental illness that is occurring in an individual to inpatient services, that option will be limited, based on the Governor's plan to limit access to inpatient services.

Therefore, it is absolutely imperative that the expert professionals who presently provide such care in facilities must also be available in the community.

State-provided services are necessary; they are crucial.

We seek your help during this transition, to make sure we are included in the ongoing process of

development and implementation of the plans as these services are transitioned into the community.

It is so important that we work together and utilize all of the expertise available to us, which includes my members, in forging a plan that protects the patients, serves the needs of our communities, and continues the high-quality of care provided by mental-health professionals whose expertise, knowledge, and dedication is invaluable.

In an effort to suspend certain passage of legislation that would have placed a moratorium on facility closures, the Governor agreed, with the Senate and the Assembly, to a number of conditions, including the formation of a workgroup, with union representatives, to put together a long-term plan on how we will provide mental-health and developmental-disability services in the future.

Although PEF did appoint representatives who served on the Regional Centers of Excellence committees, to date, I am sorry to report to you, we have not been included in any such workgroup; nor, have we gotten any kind of call back from the Governor's staff about this.

And I must also say to you, that after Primary Day, I spoke personally with the Governor,

who did not seem to be aware that this workgroup was to be formed, and, did not speak very positively about whether or not he would ensure that we would be included.

I know this is a strong statement, but it's a truthful statement.

And I'm telling you, because, when you put your reputations on the line, to form an agreement, I'm sure that you want to make sure that the agreement that you entered into is going to be followed through with.

And, so, I need you to know what has not happened.

And we need to be wary that we are going into another budget session, and after election day, maybe we will continue this year's legislative session, and you need to be aware that what was promised to you, has not happened.

Again, I want though thank you for your leadership about requiring a detailed plan for the savings from the closing of inpatient psychiatric facilities, that they would be reinvested into community-base mental-health-care services prior to the commencement of the closing of these facilities is absolutely crucial to ensure not only that the

necessary care is provided, but is provided by experts.

This is crucial, because the inpatient mental-health-care-facility closures have historically led to a deplorable lack of mental-health-care services, homelessness, suicides, crimes, incarceration, of people living with mental illness.

In addition, too many individuals with mental illness, having no place to go, fall victims themselves to violent crimes, and many are unable to manage chronic-health illnesses, such as asthma and diabetes, which result in unnecessary hospitalizations.

As I mentioned, recently, OMH has delivered additional funding for community-based mental-health-care services throughout the state.

And, as we continue to review these reinvestments, it is important to determine which, if any, of these services can deliver the necessary care and support that patients would otherwise need, and to receive, as they transition from psychiatric facilities to the community.

We must be a major stakeholder in the process, moving forward. We have the experience and

expertise in the delivery of mental-health-care services that must, must, must be included in any plan.

Our members know their patients, they know the mental illness they're living with, they know what the best practices are in the various settings, and are always developing informed and creative methods in providing quality care to our patients.

While there have been indications that PEF members and other public employes will eventually be shifted to community-based treatment services, along with the patients, no details of this process have yet to be provided.

We stand by our earlier statements, that closing inpatient psychiatric facilities will result in a multitude of problems for patients, and, will have a negative economic effect on the communities these facilities serve.

We fear dangerous patients will fall through the cracks, many of whom will become victims of violence, while others may harm others.

With so many mental illness in jails and prison, we remain worried that New York will follow a similar path witnessed in other states that close too many state psychiatric inpatient facilities, as

reported in the Treatment Advocacy Center report released last April.

PEF represents nearly 7,000 OMH employees. They are invested in the communities, and possess the clinical expertise that provides an important piece of the safety net for New York's most vulnerable citizens.

Please, please, help us to ensure that these critical services for people living with mental illness are maintained.

Thank you so very much for your time, and thank you for the work that you do.

[Applause.]

SENATOR CARLUCCI: Thank you, Susan.

We look forward to working with you in the upcoming legislative session.

SUSAN KENT: Thank you.

And I wish you both very well.

ASSEMBLYWOMAN JAFFEE: I'll start making some calls tomorrow.

SUSAN KENT: Thank you. Thank you, both.

ASSEMBLYWOMAN JAFFEE: Maybe we'll find out what's happening.

SENATOR CARLUCCI: So we have, our last speaker, is Diana Siegel, who is representing

NAMI Familya.

DIANA SIEGEL: After hearing Susan Kent, who I had never met, I am a member of a different union, but you make me proud to be a union member.

And Susan has described the condition so well in Rockland County.

I did put up two poster-boards there, with articles from local newspapers, "New York Times," et cetera, written by people who are very concerned with the dire situation of people with mental illness, in the country, in our state, and, in our county.

I represent NAMI of Rockland.

We are an organization, largely voluntary, that offers support, education, and advocacy for people with mental illness.

And we are so grateful to you, Senator Carlucci, and to you, Representative Jaffee, for taking so great an interest in our community.

Particularly, we are in the process of receiving a grant that will enable us to expand our services to people with mental illness and their families in our community.

There are some specific needs which have been generally addressed, but I will try to point them

out, with some emphasis; and that is:

We desperately need a central place of access for evaluation and reform, since the disillusion of the Pomona Complex.

Nyack Hospital has a different kind of program, different kind of emphasis.

And, at present, there is no central place where people in crisis can go when they need help.

NAMI has a hotline. We are, very often, the first point of contact.

We have services within our voluntary organization that provides education to families.

But, there must be a place that people are aware of, that people know they can go to, when they need help.

There was a partial hospitalization program which was a wonderful facility up at Pomona. It was one of the first programs that was closed.

Because, when people who have been hospitalized return to the community, they are not ready to access what the community has to offer. They need supportive help to transition.

And that partial-hospitalization program, which I know of personally, provided that help.

So, I would like you to consider that kind of

a facility.

We also need mobile crisis 24/7.

So if you would, please, consider that.

In the disillusion of Pomona, organizations, the Mental Health Association, and Jawonio, have picked up services, largely, for people who are ready to move into the community.

But, people with, you've heard the term today, "persistent, serious mental illness," have been cut out. We used to have day-treatment centers, a place where someone could get up to go.

They have been disparaged, but they provided a service, where you meet people, where you get support from professionals, where there's a place to eat and socialize, rather than hanging around in front of a television set at home.

So please consider restoring places for people with persistent, serious mental illness to go.

We are appreciative of the current mental-health alternatives for incarceration.

Please expand it, continue it. Don't let it go.

It's so important, as you heard from that excellent panel today.

CIT training, we need that.

We need more children's services.

And I thank you.

I won't keep you any longer.

You have been wonderful to us, and we are so appreciative.

Thank you.

SENATOR CARLUCCI: Thank you very much.

ASSEMBLYWOMAN JAFFEE: I have just one question, regarding the children's services.

Specifically, you're discussing a site where families could bring children to be with each other.

What kind of service? Mental-health-specific? Mental-health psychologists?

What --

DIANA SIEGEL: This kind of information I have received from the person who does our family-basics program.

When the families finish, it's a six-week program, where we help to train families to deal with children and adolescents with mental illness.

And, we have been told by Ann Arias (ph.), who runs this program, that after the program's over, there's no place to take the children.

There just aren't -- psychiatrists and psychologists in the county do not accept Medicaid or Medicare. Some don't even accept insurance. You need to, you know, pay, pay, pay, cash.

So I would say, all of the above, yes.

We need places for the children to go, where there are professionals, where they can receive services. We need professionals who will accept Medicare and Medicaid.

Yes.

Thank you very much.

SENATOR CARLUCCI: Thank you.

Well, we really just want to thank everyone for coming here today; for sharing your stories, your experiences.

If there is additional information you would like to provide to us, we'll accept written testimonies so we have it on the record.

This is extremely important for us, to make sure that this dialogue is had, that we can share these stories with our colleagues in the Legislature, and make sure that these issues are being addressed.

So we covered a wide range today.

And I really, again, want to thank all of you

for the work that you're doing. For standing up, and sharing your experiences, your troubles that you've have had, the problems you've encountered, but ideas that you have for future on how to fix them.

So, thank you so much for being with us today.

And, with that, our Committee meeting is adjourned.

Thank you.

ASSEMBLYWOMAN JAFFEE: Thank you.

(Whereupon, at approximately 1:40 p.m., the public hearing held before the New York State Senate Standing Committee on Mental Health and Developmental Disabilities concluded, and adjourned.)

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