



New York Association of Psychiatric Rehabilitation Services, Inc.

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"Examining H.R. 2646, the Helping Families in Mental Health Crisis
Act."

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Good morning. Thanks so much for this opportunity to speak before you on issues of such critical importance to people with serious mental illnesses across our nation. I'm Harvey Rosenthal and I have served for the past 23 years as executive director of the New York Association of Psychiatric Rehabilitation Services (NYAPRS), a New York based coalition of recovering people and community providers who have been dedicated to improving services, social conditions and public policies to help people with serious mental health conditions to advance their recovery, rehabilitation, rights and full community inclusion.

I am also heavily involved in state mental health and healthcare policy, currently serving on New York's Medicaid Redesign Team, the Behavioral Health Work Group and our Most Integrated Setting Coordinating Council.

All of my 40 years of experience in the public mental health system as both a provider and an advocate has been aimed at supporting the needs of people with the most serious mental health conditions, partly because this is very personal to me as I am in long term recovery from a bipolar condition.

I want to thank the committee for inviting a person in recovery to testify today and I urge you to reach out to and include more input from the ultimate stakeholders, people with psychiatric disabilities.

My experience tells me that best way to fix a broken system isn't by forcing people into the exact same services that failed them in the past. It won't be achieved by reducing

privacy protections, limiting access to personal and systemic advocacy or by fostering a sharp swing to a more medical, biological bent in ways that could undo the extraordinary impact of the recovery and consumer focused approaches that have taken us decades to develop and proliferate.

While some have claimed that these recovery and rehabilitation services have abandoned the most seriously disabled and distressed, what is instead true is that tens of millions of Americans would be on the street, in prison or at risk for suicide, were it not for these services, most of which are relatively new and haven't been afforded yet the research to deem them as evidence based practices.

The focus on evidence based practices is essential but, unless this measure devotes substantive research funding to evaluate whether an entire new generation of recovery focused innovations meet those standards, they will be lost.

I'd like to share concerns we have about several provisions of this measure.

Assisted Outpatient Commitment: NYAPRS is joined by countless colleague groups in our state and nationally in our strong opposition to court mandated outpatient treatment.

Two major AOT studies have been conducted in New York comparing court mandated and voluntary approaches. A 1999 Bellevue study concluded that more and better

services made the difference, irrespective of whether individuals had court mandates.¹ A 2009 Duke University study ordered by the NYS legislature conceded that it was unable to compare the outcomes from roughly 8,000 court orders and 7,000 voluntary 'enhanced service packages,' adding that "it is difficult to assess whether the court order was a key ingredient in promoting engagement or whether comparable gains in engagement would have occurred over time with voluntary treatment alone."²

Why aren't we finding as much money to evaluate and expand voluntary outreach, engagement and rehabilitative approaches as we are in dedicating \$20 million for state or local AOT demonstration program expansions and in offering states that have or add AOT laws a 2% increase in their federal block grant allocations?

If I am interpreting the bill correctly, it will link block grant dollars with a demonstration that states have in effect active programs that while they may include AOT they may just as equally include a broad array of these voluntary approaches, to engage people with serious mental illnesses in comprehensive services. If this is so, we are very supportive of this approach.

Lifting the IMD Exclusion: States should use broad new Medicaid flexibility to quickly ramp up preventive, crisis and recovery community based alternatives instead of asking federal taxpayers to spending billions to bring federal share of Medicaid into state and private psychiatric hospitals.

¹ 2001 "Assessing the New York City Involuntary Outpatient Commitment Pilot Program" Steadman et al Psychiatric Services

² New York State Assisted Outpatient Treatment Program Evaluation June 30, 2009

Too often, the problem may not lie in a lack of beds but the lack of information about where open beds can be found. That's why we support the creation of real-time Internet-based acute psychiatric bed registries that identify available acute beds in public and private inpatient psychiatric facilities and public and private crisis stabilization units.

We are concerned that H.R. 2646 does not require full maintenance of efforts and reinvestment of savings to bolster our community systems of care, and that a study to track how savings were used won't take place until 2 years after this initiative is implemented. By then, tens of millions of dollars would have left cash poor state mental health service systems to be transferred to state general funds for other purposes entirely.

Protection and Advocacy for Individuals with Mental Illness: While we appreciate the Congressman has left PAIMI funding intact in this proposal, H.R. 2646 would eliminate critical functions that have made huge differences in the lives of people with psychiatric disabilities.

Under this proposal, P&As could no longer help the vet who is facing employment discrimination, the child who is being denied educational services or the individual who faces housing discrimination. And they could no longer protect individuals who are the victims of financial exploitation, abuse, and neglect by errant family members or guardians.

HIPAA: We very much share family members' outrage and heartbreak when community providers are unwilling to either listen to or share information about their loved one's status and greatly appreciate Congressman Murphy's prioritization of this issue.

All too often, this happens because providers don't understand the latitude and obligation they have under existing guidance, but sometimes providers simply hide behind HIPAA to avoid sharing an appropriate level of information.

We recommend codifying the recent guidance by the Federal Office of Civil Rights into law and conducting an aggressive stakeholder education program, as proposed by Congresswoman Matsui, with several inclusions:

- Individuals should be given **advanced notice** of the desire to share their information with family members or other caregivers and include an explanation of what information is to be shared and why it is clinically desirable to share such information.
- The use of **Psychiatric Advance Directives**, which are tools for designating in advance an individual's preferences concerning recipients of protected health or mental health information, should be promoted.
- H.R. 2646's provisions that sharing patient information may not include "friends' or those with documented histories of abuse be included in any final agreement.

SAMHSA has played a groundbreaking role in helping to promote the development of our entire field over the past two decades. It has helped fund and promote many of our most important innovations, including the concepts of recovery, rehabilitation, wellness, community integration, peer support and person centered and self-directed care. In recent years, SAMHSA has been accused of paying insufficient attention to the most needy. If so, the Health and Human Services Administration can increase its oversight role and report to Congress of necessary improvements in this area.

Peer Support: While we very much appreciate H.R. 2646's highlighting of peer support and its interest in conducting a survey and report of nationwide peer support programs, it would be inappropriate for Congress to then move to define these standards. We are not aware that it takes this level of involvement for the other disciplines. Congress should defer to CMS and state and national credentialing bodies to set such standards.

At the same time, I'd like to thank and congratulate Congressman Murphy for all that you have done over the past 3 years to put mental health issues on the front burner in Congress and across the nation.

H.R.2646 contains a number of critically important initiatives to help us sharpen, extend and make more effective and accountable the help we offer to them that include:

- mandating stronger federal oversight over enforcement of behavioral health care parity, which became law in New York State a decade ago thanks to the relentless persistence of then Assemblyman Paul Tonko.

- extending incentive payments to help behavioral health agencies to prepare for and to implement the use of electronic healthcare records
- raising the focus on the integration of primary and behavioral health care services and improved coordination between mental health and criminal justice systems
- bolstering of standards and guidelines for hospital discharge planning and follow up
- continued or new funding for numerous suicide prevention initiatives
- expanding first episode psychosis programs like RAISE
- the creation of an Interagency Serious Mental Illness Coordinating Committee we believe should include SAMHSA and the Centers for Medicare and Medicaid Services, which funds the vast majority of the nation's mental health programs

We also greatly appreciate the \$55 million allocation for specialized mental health education for law enforcement, corrections officers, paramedics and other first responders.

Thanks once again for this opportunity to speak before you today.