U.S. House of Representatives Committee on Energy and Commerce Subcommittee on Oversight and Investigations

Hearings on the Substance Abuse and Mental health Services Administration

Examining SAMHSA's Role in Delivering Services to the Severely Mentally Ill

Testimony of Sally Satel, MD

May 22, 2013

Representatives Murphy, DeGette, and other members of the Subcommittee:

Thank you for inviting me to testify today. I am a psychiatrist trained at Yale University School of Medicine. I served on the faculty until 1993. Since leaving Yale I have continued clinical work, part time, in drug treatment clinics in Washington D.C., and, since 2001, I have been a resident scholar at the American Enterprise Institute.

From 2002 to 2006 I was a member of the National Advisory Council of the Center for Mental Health Services (CMHS), the agency within SAMHSA charged with funding services for individuals who are mentally ill. ¹ At that time, I expressed concerns privately to the head of SAMHSA, and publicly in published articles, that CMHS was failing to provide adequate federal leadership in the care of people with severe psychiatric disorders. By this term I refer to individuals afflicted by schizophrenia, bipolar disorder, severe depression (often with psychotic features), and related psychotic conditions.

In the time I have today, I first wish to describe what I believe are two major sources of SAMSHA's dereliction in attending to the sickest individuals. These are (1) its idiosyncratic interpretation of its very mission – one that fosters models of care that many chronically psychotic people are not capable of using, and (2) a dearth of psychiatrists in leadership position. These two dynamics have played a significant role in shaping the agency's overall orientation towards the severely mentally ill. Next, I will outline the

¹ To Fight Stigmas, Start With Treatment, *New York Times*, April 29, 2009 at http://www.nytimes.com/2009/04/21/health/21mind.html

Sane Mental Health Laws? Don't Hold Your Breath *The Weekly Standard* May 28, 2006 at http://www.sallysatelmd.com/html/a-ws8.html

Commission's Omission - The President's Mental-health Commission in Denial. *National Review* July 9, 2003 at http://mentalillnesspolicy.org/mentalhealth/new-freedom-commission.html

manifestation of SAMSHA's vision in the kinds of the programs it advances as models of care under its National Registry of Evidence-based Programs and Practices.

SAMHSA's Understanding of its Mission

The Recovery Model - SAMHSA's guiding philosophy of care for all mental disorders, no matter the severity, is the "recovery model." In 2004, the agency convened a conference at which the recovery model was formalized: "By definition, the recovery process must be self-directed by the individual, who defines his or her own life goals and designs a unique path toward those goals." A 2012 SAMHSA newsletter framed recovery as "A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential."

Many can benefit from the Recovery Model. But so many cannot, as I will discuss in a moment.

The recovery emphasis reflects a chief recommendation of the 2003 New Freedom Commission on Mental Illness in a report commissioned by President George Bush. The commission focused on people who are willing and able to make use of treatments, programs, and opportunities. Notably, the commission even prided itself on soliciting testimony from constituents, stating, "Nearly every consumer...expressed the need to fully participate in his or her plan for recovery." The commission suggested that sufficient therapy, housing options, and employment programs will enable people with schizophrenia or manic-depressive illness to take charge of their lives.

Now, I recognize that many patients who have been diagnosed with these disorders can lead lives that are much more fulfilling and productive than some clinicians ever imagined and that some clinicians don't pay enough attention to what a particular patient wants and to what he values in his or her life

The problem is that some patients are too sick to take advantage of treatment, to collaborate in creating a detailed life plan, or to determine their own "unique path." I am referring here to the fact that over half of all untreated people with a psychotic illness do not acknowledge there is anything wrong with them, a condition technically called anosognosia. This is a neurological problem caused by disruption of the mechanisms within the brain that mediate our capacity to reflect upon ourselves. They are the most vulnerable of CMHS' constituency, yet the agency invests not nearly enough in their wellbeing.

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 $^{^2\} http://www.samhsa.gov/samhsanewsletter/Volume_20_Number_3/Fall2012-volume-20-number-3.pdf$

Indeed, during its hearings, the Commission did not hear from the sickest silent minority that is languishing in back bedrooms, jail cells, and homeless shelters. They are too paranoid, oblivious, or lost in psychosis to attend hearings, let alone testify at one.

This is a good place to point out that SAMSHA, too, receives much of its input – intentionally and selectively so in my view -- from so-called "consumer-survivors" to claim to speak for all patients. This creates significant distortion: the agency asserts that it is responsive to its constituents when, in fact, its most impaired constituents cannot advocate for themselves. What's more, the views of other patients who would indeed able to participate more fully in their care, but also recognize the value of mainstream psychiatry and readily say they benefit from it, are not routinely, if at all, solicited. ³

The problem with the recovery vision is that it is a dangerously partial vision. The emphasis on recovery as a goal steers policy away from the needs of the most severely disabled. SAMHSA forthrightly acknowledges that it sees the "consumer" who can "fully participate in his plan for recovery" is its primary constituent, not the dependent patients who need quality psychiatric care. ⁴ This imbalance needs to be corrected.

Dearth of Professional Psychiatric Input at CMHS

SAMHSA makes an inadequate contribution to the treatment of individuals with severe psychiatric disorders because it is under-populated by staff with expertise in the nature of their treatment needs.

During my tenure on the CMHS National Advisory Council, I attempted to have some input into the CMHS decisions regarding what projects should be funded. Despite the fact that we were called an "advisory council," it was clear that CMHS did not want our advice. Rather than being able to see proposals ahead of time, we were presented with the approved proposals as a fait accompli at the time of the meeting. Thus SAMHSA not only had little

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³ http://phenomenologyofmadness.wordpress.com/2013/05/11/on-problems-inside-the-movement/ See also, http://www.treatmentadvocacycenter.org/resources/briefing-papers-and-fact-sheets/159/467

⁴ Interview with Kathryn Power, CMHS Director circa 2003 – 2008 http://www.accessmylibrary.com/coms2/summary_0286-35121827_ITM. Power is the Regional Administrator, Region One for the Substance Abuse and Mental Health Services Administration, where she continues to promote that philosophy.

in-house expertise on serious psychiatric disorders (I recall a single public mental health psychiatrist) it also failed to take advantage of the expertise on its own advisory council.

My colleague, Jeffrey Geller MD, Director of Public Sector Psychiatry at the University of Massachusetts Medical School, who served on the CMHS Advisory Council from 2004-2008, had a similar experience. "Most members who served during the years I served, gave up attempts for meaningful input and left in disgust," he notes. They had repeatedly asked then-CMHS director, Kathryn Power, that the grant proposals "be provided to Council members in advance of the meetings, [that we have] time and opportunity for meaningful exchange on the merits of a proposal at the meeting, and/or revisions and re-review of the proposals…We were rebuffed each and every time."

Unbalanced Compendium of Care

SAMHSA's National Registry of Evidence-based Programs and Practices (NREPP) is an online "registry of mental health and substance abuse interventions that have been reviewed and rated by independent reviewers. The purpose of this registry is to assist the public in identifying scientifically based approaches to preventing and treating mental and/or substance use disorders that can be readily disseminated to the field." When a program is certified as evidence-based by SAMHSA, state mental health departments are encouraged to use block grant money for them.

On its website, http://www.nrepp.samhsa.gov/ViewAll.aspx, SAMHSA lists 288 separate evidence based programs (ideally understood to mean demonstrated in clinical trials, subjected to peer review and successful replication). Among the almost 300 studies, are many sound programs to treat substance abusers and drug offenders (e.g., Motivational Enhancement Therapy; Moral Reconation Therapy, Oxford House), enhance parenting skills, support caregivers, prevent HIV, etc. Broad-focus programs such as "Enhance Wellness" (an exercise and education program for adults with physical illnesses) and "Coping Cat" (to help children recognizes symptoms or anxiety) may well be useful if well executed, but, crucially, like the vast majority of programs listed in the Registry, these are not intended for the sickest of individuals.

The striking nature of the NREPP repertoire of programs is its imbalance.

Programs for the Mentally III -- Of the 288 programs listed, four by my count, specifically designated people with severe illness as their recipients (Compeer, Critical Time Intervention, Housing First, and Psychiatric

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⁵ Personal communication, May 12, 2013

⁶ http://www.nrepp.samhsa.gov/ViewAll.aspx

Rehabilitation Process Model). Among those, the Rehab Process Model is "client" centered and aimed at "encouraging self-determination," again the recovery agenda with its intrinsic limitations, while Compeer is aimed at reducing isolation (a most noble aim, but, by design, not about treatment itself). Housing First is an excellent program for people who need minimal supervision and can comply with rules. Critical Time Intervention provides time-limited case management, under supervision of a psychiatrist or psychologist, to prevent homelessness and other adverse outcomes in people with serious mental illness following discharge from hospitals, shelters, prisons and other institutions. This program is notable as is it most narrowly aimed at a highly vulnerable subpopulation.

A handful of other programs (Modified Therapeutic Community, and International Center for Club House Development, Wellness Recovery Action Planning, WRAP) do not specifically mention severe mental illness in their description, but presumably serve those patients as well. WRAP, in particular, is only eight weeks long. It is "designed to create a safe, nonjudgmental autonomy supportive environment in which people feel motivated to manage their mental health issues." Again, it is a program aimed at patients whose psychotic symptoms are in check. Worth noting as well, a recent assessment contains no measures of re-hospitalization, incarceration, or homelessness. 8

Even if I missed some programs in my review of the synopses of all 288 programs listed, it is abundantly clear that services aimed specifically at the most desperately ill – or, more precisely, those in the most intense phase of their psychotic illness – represent only a small minority of the NREPP programs.

Furthermore – and remarkably -- NREPP neglects one of the most effective and best-studied programs for individuals with severe mental illnesses: Assisted Outpatient Therapy (AOT). AOT is a form of civil court-ordered community treatment, which is often necessary for those who have a reliable pattern of falling into a spiral of self-destruction or dangerousness when off medication. To date, studies have shown that it reduces hospitalizations; homelessness; both arrest and victimization of mentally ill people, and violent behavior. ⁹ Two studies document that AOT saves money. ¹⁰The Department of Justice has certified AOT as an effective crime prevention program¹¹ Despite numerous attempts by

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⁷ http://www.mentalhealthrecovery.com/wrap/documents/SchizophrBull-2011-Cook-schbul_sbr012.pdf ⁸ ibid

⁹ http://mentalillnesspolicy.org/kendras-law/research/kendras-law-studies.html; http://www.treatmentadvocacycenter.org/about-us/our-reports-and-studies/471

¹⁰ http://www.treatmentadvocacycenter.org/storage/documents/aot_saves_money.pdf

¹¹ http://www.crimesolutions.gov/ProgramDetails.aspx?ID=228

families of people with mental illness to raise the profile of AOT at the agency, such programs remain unrecognized by NREPP. 12

<u>Primary Prevention Agenda of Block Grant Not Relevant to Severe Mental</u> Illness

SAMHSA focuses heavily on the prevention of mental illness and substance abuse.

Prevention and severe mental illness is a puzzling concept because we know little about the biological causes of conditions such as schizophrenia and bipolar disorder. These are primarily diseases of the brain but our understanding of the underlying brain mechanisms is still in the early stages. Absent this knowledge, prevention is not possible. Therefore, SAMHSA's focus on prevention has virtually nothing to contribute to the well-being of individuals with severe mental illnesses.

Clearly, SAMSHA's net is wide: In its instructions to the states on how the federal block grant funds should be spent, SAMHSA instructs them to "make general prevention and primary prevention priorities." States are also told that: "The focus is about everyone, not just those illness or disease, but whole population. The focus is on prevention and wellness activities." ¹³Inclusive as it is mission is, the agency makes relatively minimal room for the most needy.

Conclusion and Recommendations

In summary, SAMHSA is the federal agency created by Congress in 1992 to provide leadership on severe illness (among other aspects of mental health), yet little leadership is to be found within its walls. That CMHS does not have any psychiatrists in a leadership position is, frankly, astounding. Imagine the National Institute of Mental Health employing no neuroscientists in key roles. "Home, health, purpose, and community," SAMHSA's stated priorities, are supremely laudable goals but only – and this is a critical point – only for people who are motivated to to attain them and able to make use of help.

Unfortunately, the Center for Mental Health Services has a skewed understanding of its constituency—no surprise, really, as its mission is refracted through the lens of the "recovery model." The agency's guiding ideology leads it to overlook millions of people with long-term psychotic disorders. Very few SAMHSA programs help reduce the impact of mental illness on the communities – that is, on rates of incarceration,

¹² http://feedback.samhsa.gov/forums/148531-closed-help-samhsa-highlight-advances-of-the-beh/suggestions/2580341-implementation-of-assisted-outpatient-treatment and http://feedback.samhsa.gov/forums/148531-closed-help-samhsa-highlight-advances-of-the-beh/suggestions/2586918-court-ordered-outpatient-treatment; http://feedback.samhsa.gov/forums/77283-closed-samhsa-s-strategic-initiatives/suggestions/1155179-increase-use-of-assisted-outpatient-treatment

http://www.samhsa.gov/grants/blockgrant/docs/BGapplication-100312.pdf p 39

homelessness, and dangerousness.

The agency's relative neglect of those with severe mental illness is only part of the problem. As the testimony of other panelists will make clear, the agency also supports activities that actively sabotage their welfare. This is strong language, I am aware. I refer here to CMHS's seemingly uncritical support of both "consumer" groups and legal aide workers (though its Protection and Advocacy, PAIMI, program) who either condemn the use medications or are hostile to formal psychiatric care. The efforts of these advocates have been decidedly harmful to patients with schizophrenia and other psychotic illnesses.

I respectfully recommend that:

Consider directing the Secretary of HSS to commission demonstration projects of Assisted Outpatient Treatment (e.g. Kendra's Law in New York, Laura's Law in California) throughout the country.

Consider directing the Secretary to commission an independent review of the scientific soundness of NREPP programs, paying particular attention to effective programs for severe mental illness that should be included in the NREPP.

Consider directing the Secretary to review personnel hiring policies at SAMHSA with the goal of introducing more psychiatrists and psychologists who have direct clinical expertise in delivering publicly funded care to people with severe psychiatric disorders.

Consider redefining the goals of PAIMI by limiting its role to protection and disallowing lobbying of state legislatures on commitment laws

It is my hope that today that this Congressional Subcommittee can begin to address these shortcomings I've outlined in my remarks.

Thank you for your attention.