June 24, 2013

Brittany Havens
Legislative Clerk
Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, DC 20515

Dear Ms. Havens:

As a follow up to the questions from Rep. Waxman in regard to the Subcommittee on Oversight and Investigations Hearing on "Examining SAMHSA's Role in Delivering Services to the Severely Mentally Ill," please find attached my responses to each question for Rep. Waxman's consideration.

I appreciate the opportunity very much to respond to these critically important questions, as it helps to further expand on my written and oral testimony provided at the May 22 Oversight Sub-committee hearing on SAMHSA's initiatives.

I would be pleased to respond to any follow up questions based on the enclosed additional remarks, or additional questions that may arise during your deliberations.

Thank you again for inviting me to testify at the May 22 Oversight Hearing, and the opportunity to address further queries through this written submission.

Sincerely,

Joseph Parks, M.D.
[redacted]

Responses to Rep. Waxman's Follow-Up Questions

Can you explain how SAMHSA's Co-Occurring State Incentive Grants (COSIG) helped your state improve the ability of community mental health centers and substance abuse treatment agencies to promptly and effectively serve people who have both mental illness and substance abuse conditions simultaneously? Is this program still in effect? What steps can Congress take?

The COSIG grants improved the ability of both community mental health centers and substance abuse provider agencies, to serve persons that had both mental illness and substance abuse concurrently. Prior to these grants it would be common for a person who had both serious mental illness and addiction to be told by the community mental health center that they could not be treated for their serious mental illness until their addiction was treated and substance abuse treatment agencies would not treat them until their serious mental illness was stable. COSIG provided training and technical assistance so that both Community Mental Health Centers and Substance Abuse Treatment Agencies became competent and comfortable working with patients who have co-occurring Mental illness and addiction.

Since the COSIG grants have been in place, there is truly "a no wrong door" approach by community mental health centers and substance abuse treatment provider agencies in both welcoming the person needing treatment and engaging them immediately. This is a particularly important improvement with respect to reducing violence by persons with mental illness. The presence or absence of a substance use disorder is the major predictive factor of whether or not a person with mental illness will be more violent than a person without mental illness. In addition, integrated treatment of substance abuse and mental illness is more effective than treating only one condition and more efficient than treating the conditions simultaneously through using two different clinics or programs.

The COSIG grant program has ended, but further progress is needed. Congress should provide funding to SAMHSA for a new round of COSIG grants.

How do you anticipate the Affordable Care Act will impact services for people living with mental illness in your state?

Much of the impact of the ACA in Missouri hinges on whether or not Missouri expands Medicaid. If Missouri chooses to expand Medicaid to 138% of poverty, THE Department of Mental Health (DMH) prevalence estimates and utilization trends tell us that nearly 50,000 of the 300,000 newly eligible Missourians will obtain treatment annually through DMH: 65% for substance abuse – 35% for serious mental illness. Most will not be new to DMH. About 34,000 of those individuals – now indigent – who would qualify under Medicaid expansion would seek DMH services annually anyway, whether or not the state expands Medicaid coverage. Services for these indigent clients are now covered fully by state or block grant funds, or through charity care delivered by DMH's contracted community behavioral health providers. Without insurance or Medicaid coverage, indigent care services are limited and crisis focused. Today, the average annual cost for individuals receiving DMH behavioral health services is about $2,800. The cost of adding 50,000 consumers is about $140 million. The 10% state match ultimately required by Medicaid expansion is $14 million and can be

fully funded from cost offsets in DMH's core budget as indigent our consumers become Medicaid eligible. Missouri's mental health system is now largely focused on Medicaid eligible individuals to maximize limited funding. Most of its community program dollars serve people who are categorically Medicaid eligible by disability determination, and for their ancillary services that Medicaid doesn't cover. Unfortunately, only a small percentage of Missourians with substance use disorders now qualify for Medicaid. And young adults, in early stages of serious mental illness, only become Medicaid-eligible after being determined disabled, usually through a lengthy federal eligibility process that is extremely difficult to navigate for people with mental illnesses.

DMH's behavioral health system turns away 100,000 Missourians annually. What this means, in real-world terms, is that most young adults, beginning to experience mental illnesses, like Schizophrenia or Bipolar Disorder, will go for years with inadequate treatment, or none at all. As their illnesses progress, they move from crisis to crisis, appearing frequently in hospital ERs. Some are involuntarily committed by courts to short-term, episodic inpatient treatment. Some commit law violations, mostly minor nuisance violations, but that ultimately ensnares them in the criminal justice system.

Many, if not most of these individuals, initially fight outpatient mental health treatment and fail to take their medications, either because they don't think they need treatment, or because of the detrimental side effects of the powerful psychotropic medications they are prescribed, or because they feel stigmatized by the their mental illness. And their desperate families don't know where to turn for help. The sad outcome of all this is that thousands of confused, vulnerable young people decompensate and become long-term victims of poverty, poor health care, crime and abuse long before they ever enter DMH's services continuum. When they do enter our system, they are older and their conditions have deteriorated to the point that they require more expensive services. Most develop serious, chronic medical conditions, like hypertension, diabetes, heart disease, and COPD. On average, they will die between the ages of 50-60 years old. Eight of ten will die from their chronic medical condition.

Although people with mental illness are far more likely to be victims of crime than perpetrators, a small number strike out at society. We hear about them in local, state and national news, and we mourn their actions. The ACA Medicaid expansion can change this. New services can be tailored to young people in earlier stages of mental illness without the need for stigmatizing disability labels. This would be of immeasurable value to vulnerable consumers and their exhausted families, and would represent a long overdue "sea change" toward early intervention for mental health. There is also a major Missouri mental health system downside to not accepting Medicaid expansion.

Under ACA, Missouri's community hospitals, some of whom now do all of the acute psychiatric inpatient care in our state, will lose about $250 million in federal disproportionate share (DSH) funding for the indigent patients they serve because it is assumed that hospitals will receive Medicaid reimbursement for these patients once the Medicaid expansion occurs. It is critical to understand that the percentage of indigent care patients is much higher on psychiatric units than on general medical units in these hospitals. For example, Cox Medical Center in Springfield has an overall patient mix of only 7% indigent patients, but 22% of its psychiatric patients are indigent. When hospitals incur the DSH cuts, they will first be forced to close psychiatric units serving indigent adult patients under age 65.

Currently, there are only 1,170 acute psychiatric beds for adult, non-geriatric patients left in Missouri. We have lost 1,400 psychiatric beds in this state since 1990. We now have one acute psychiatric bed for every 2,800 Missourians. In comparison, we have one medical hospital bed for every 300 Missourians. This has placed an incredible strain on the system, and it has affected county and city law enforcement units, who must transport these patients longer distances and remain with them as

they are processed by community hospital emergency rooms and ultimately transferred to a psychiatric bed, if available. If not, the individual often winds up in a county jail. Not expanding Medicaid guarantees the further elimination of adult psychiatric beds in Missouri and will ultimately put pressure on the state to reopen acute psychiatric beds.

We closed our acute care beds in Kansas City, St. Louis, Columbia and Farmington in FY 2010-2011 due to budget cuts. A state-operated acute inpatient psychiatric bed will cost roughly $900 per day, or about $33 million per year for each 100 beds, not counting capital costs. The state will receive no Medicaid reimbursement because the federal government prohibits it, and will receive dramatically reduced DSH funding. County and city jails, already stressed with untreated mentally ill individuals, will initially feel the brunt of the loss of more beds. Corrections will also feel it. Now, over 16% of all inmates incarcerated in DOC are treated for a serious mental illness. That number and percentage will grow. For mental health services in Missouri, the decision to expand or not to expand Medicaid will create a sea change for Missouri, either way it goes. If it is not accepted, I believe that the resulting sea change downward is even more threatening than the sea change up if expansion occurs.

Aside from Medicaid expansion the ACA will provide life changing and life saving benefits to people in Missouri with mental illness. The combination of requiring community rating, parity with medical benefits, and prohibiting the exclusion of pre-existing conditions from coverage will give people with mental illness access to decent affordable health insurance. The numerous programs and incentives to integrate mental health care and medical care in the ACA, particularly the Medicaid Health Homes for Persons with Chronic Conditions (Section 2703) are bringing transformative improvements to care that are saving both lives and money.

In 2008, the Mental Health Parity Addiction and Equity Act was enacted. Many of the Committee members co-sponsored and voted for this legislation. How does the mental health parity law impact people living with mental illness in your state?

The Mental Health Parity Addiction Equity Act has significantly improved access to mental health treatment particularly in the area of quantitative limits. Persons with mental illness are no longer faced with arbitrary limitations on the number of treatment visits they can have with their mental health clinician and no longer have to pay higher co-pays and deductibles that are paid for the treatment of medical illnesses. There has not been as much progress in achieving the parity goals of the act in the area of qualitative limits. For instance many plans that allow for a period of several weeks of more intensive rehabilitation services following a stroke or a heart attack are still not providing the same period of intensive rehabilitation services following a hospital admission for a psychotic episode or suicide attempt. Congress should make funding available to assist patients work through the administratively complicated appeals process laid out in the legislation. Persons with mental illness commonly have impairments of concentration, memory, attention, and difficulties with organization and persistence, all of which are required to successfully avail themselves of their appeal rights. Providing funding to assist mentally ill persons with the appeal process and including such assistance as one of the functions of existing funded advocacy and rights programs is necessary to achieve full implementation of the Mental Health Parity Addiction and Equity Act.

Dr. Parks, what next steps can Congress take to provide the best treatment for those living with mental health issues?

My Recommendations are:

1) **Increase the Resources Available through SAMHSA MENTAL HEALTH Block Grant (MHBG) and Discretionary Grants.**

SAMHSA resources have not kept pace with either the general rate of inflation in the cost of care or with the markedly increased demand for mental health services that has occurred in the last 10 years. THE MHBG and discretionary provide important tools to states and communities for improving the treatment of serious mental illness and providing the early interventions that will be the most effective means of reducing violence involving persons with serious mental illness.

2) Develop a National Approach for Increasing the Psychiatric Workforce

The demand for psychiatric services is far outstripping the ability of the available workforce to supply them this is increasingly severely restricting access to essential treatment services for persons with serious mental illness. According to a University of North Carolina (UNC) 2008 study commissioned by Health Resources and Services Administration (HRSA) the United States have a significant shortage of mental health professionals, especially "prescribers". The current supply of psychiatrists is at least 30,000 short of what is needed.

The projected demand for all physicians continues to rise outstripping the projected increase in physicians. For psychiatry, the anticipated demand has risen dramatically. The number of people seeking psychiatric services has increased because of the growing and aging population, mental health parity and anti-stigma efforts.

The number of psychiatric problems has increased because of the economic downturn and the psychological toll of two wars. Other factors increasing the demand for psychiatrists are direct marketing of psychiatric medications to the public and an increase in the number of black box warnings causing primary care clinicians to be reluctant to prescribe psychotropic medications. This is occurring at the same time that the projected supply of psychiatrists is flat.

Psychiatrists are not increasing in number because retirements are outnumbering those entering the workforce through training. Currently 55% of psychiatrists are older than age 55. In a recent projection using a similar methodology to the UNC study, the deficit has increased to 45,000. Patients often have to wait months to see a psychiatrist because clinics cannot find enough psychiatrists to hire to provide service. Hospitals have closed their psychiatric units due to difficulties recruiting psychiatrists to staff them. Current national shortages in mental health professionals specifically psychiatrists will continue to exacerbate. All projections estimate the gap between unmet need and supply will widen substantially over the next 20 years.

3) Specific Discretionary Grant Recommendations

a. **Grants Funding Mental Health First Aid (MHFA)** – Early identification and treatment can prevent a mental illness from developing into a disability or leading to suicide or violence against others. Mental Health First Aid is a groundbreaking public education program that helps the public identify, understand, and respond to signs of mental illnesses and substance use disorders.

The idea behind MHFA is no different than that of traditional first aid: to create an environment where people know how to help someone in emergency situations. But instead of learning how to give CPR or how to treat a broken bone, the program teaches people how to recognize the signs and

symptoms of mental health problems and how to provide initial aid before guiding a person toward appropriate professional help.

Mental Health First Aid is offered in the form of an interactive 8-hour course that is presented by instructors who have been certified through intensive 5-day training. The course presents an overview of mental illness and substance use disorders in the U.S. and introduces participants to risk factors and warning signs of mental health problems, builds understanding of their impact, and overviews common treatments. Those who take the course to certify as Mental Health First Aiders learn an action plan encompassing the skills, resources and knowledge to help an individual in crisis connect with appropriate professional, peer, social, and self-help care. Since its introduction in the U.S. four years ago, more than 50,000 people have been trained in 47 states and the District of Columbia. Mental Health First Aid can create community environments more alert, and prepared, to intervene in the mental distress that leads to suicide and violence against others.

b. **Grants to Implement and Improve the Integrated Treatment of Substance Abuse Disorders and Mental Disorders in Persons with SMI**

The presence of substance abuse is the strongest protector that persons with SMI will commit violence. We can do better addressing substance abuse disorders in people with SMI.

c. Grants Supporting Effective Early Treatment of Psychotic Illness. –

Our nation's approach to helping people with psychotic illnesses like schizophrenia is shameful. Usually, young people slip into psychotic illnesses for several years while these individuals—or their families—get no help. When they have a "first psychotic break," they usually are briefly hospitalized. Almost always, medications take the worst of the symptoms away—within days or weeks. So then they are discharged with a referral to care and maybe a recommendation of a support group. This is woefully deficient.

Having symptoms reduced is not a cure. When people feel better, and especially since the drugs have significant side effects, they often stop taking them. Relapse is likely. Usually the second break is worse. And then the revolving door begins. Often after decades people figure out how to manage their illness, but by then they are often on permanent disability status, unemployed, and in terrible health.

Some have suggested that the solution to this problem is in going backward—not forward—to days when stays in mental hospitals were measured in months and years. This is not the approach I would advocate. There is no research to suggest it is effective. It is terribly expensive. Hospitals cannot be run (as the old asylums were) on unpaid patient labor. And a civilized society cannot detain people on a vague hope they will get better.

So we should not turn the clock back on mental health care. But we do need a modern approach to care for people with psychotic disorders, one that replaces both the asylum and the revolving door with continuous team treatment like that we provide for people with chronic medical problems. Teams delivering First Episode Psychosis (FEP) care have figured out how to do this work. It is person-centered, family driven, collaborative and recovery oriented. Staying in school or work is encouraged—though adaptations may be needed. It is time to implement this approach, as both Australia and Great Britain have done. We need not lag behind other nations in this area. Our country needs to make modest investments now to develop FEP teams so that families anywhere in the state struggling with a young adult who is slipping away from sanity can get good care reasonably close to home. The Committee's attention to this issue could have an enormous positive effect.

4) Make HIPAA Work as it was Originally Intended

Although HIPAA explicitly allows health care providers and providers of healthcare related services to share protected health information absent patient consent for the purposes of treatment, which includes care coordination, many health care providers continue to insist that they can only share protected health information with patient consent. Adding additional groups with whom health care providers are allowed to share information, such as family members who are directly supporting the persons coordination of care, is unlikely to be successful when health care providers routinely interpret HIPAA as prohibiting sharing protected health information absent patient consent even between other health care providers when in fact that is what HIPAA explicitly allows. These health care providers are taking an inappropriately restrictive interpretation of HIPAA in an attempt to reduce their personal and organizational liability as opposed to taking an interpretation that maximizes the patient's best interests in receiving coordinated care. In short their primary goal is not what is best for the patient but rather how best to limit their own liability risks. This is both clinically dangerous for patients because it results in information not being shared that would improve care decisions and economically wasteful for the health care system in that it results in unnecessary repetition of assessments, tests, and hospitalizations.

There is a need for a national initiative to retrain health care providers to error on the side of sharing protected health information when it would benefit the individual receiving treatment. There is a need for a national strategy to make the perceived liability risk of not sharing information when it could have been shared, and the lack of sharing information, results in patient harm as great as or greater than the perceived risk of sharing information absent patient consent.

5) **Increase Federal Support for Mental Health Courts**

I have been involved in providing mandatory treatment through different modalities including inpatient and outpatient civil commitment, guardianship, not guilty by reason of insanity processes, probate court order and both mental health and drug courts in Ohio, Illinois, and Missouri. All three states have outpatient commitment laws and in all three states they are difficult to implement and only used rarely. The major barrier has been the unwillingness of police and sheriff departments to commit resources to enforcing violations of commitment orders. Local law enforcement almost uniformly state that they do not have the resources in terms of officers available to assist with mental health treatment in this manner and that crimes the have been committed or are being committed are a higher priority for community safety.

Please ensure departments are usually effective in persuading the local judges to make orders for outpatient commitment rarely if at all. There has been much more success nationally in implementing mental health courts were a person is required to accept treatment for their mental illness as a condition of probation or parole. This is more acceptable local law enforcement because it helps keep mentally ill people out of their jails, more acceptable to the courts because it provides them with an additional option or disposition of the case, and more acceptable to mentally ill person who is usually more ready to admit they have committed a crime then they are so sick that they must have treatment is a civil probate requirement because they might do something dangerous in the future. There is been much more federal support available for implementing drug courts and there has been for mental health courts.

The best current strategy for increasing the in availability of mandatory treatment for persons with serious mental illness would be to increase federal support for mental health courts which are easier

to implement and more acceptable to both local law enforcement and the persons being mandated in to treatment.

6) Treat the Appalling Rate of Premature Death Among Persons with Serious Mental Illness in the Public Mental Health System like the National Epidemic It Is

It has been over 10 years now since research showed that persons in the public mental health system most of whom have serious mental illness are dying on average 25 years younger than the general population. This is a higher death rate than experienced currently by persons with HIV and on a par with sub-Saharan Africa. Over 80% of the premature deaths and years of life lost are due to chronic medical conditions, not suicide or accidents. There is no federal agency that is routinely and systematically tracking this epidemic let alone addressing it.

a. Persons with serious mental illness should be federally designated as a distinct at risk health disparities population
b. The CDC and SAMHSA should develop, implement, and fund national annual surveillance of the mortality rates and causes of death in persons with serious mental illness.
c. HHS and SAMHSA should develop, implement, and fund a national strategy specifically for reducing premature death among persons with serious mental illness by promoting the integration of behavioral health care and general medical care.

What is the value of the HIPAA law? Why is patient privacy important with regard to treating those with mental illnesses?

HIPAA as written in statute provides both reasonable protections to patient privacy and reasonable access to health information when it is necessary for individual treatment and efficient healthcare delivery.

Can you explain how HIPAA is impacting the coordination of care among mental health care providers?

Persons with serious mental illness are much more likely than the general population to have multiple chronic medical problems in addition to their mental illness. It is common for persons with serious mental illness to see 20 or more different health care providers in a single year and take 20 or more different medications prescribed by multiple physicians. HIPAA as written in statute allows health care providers to communicate to coordinate care even without patient consent. This is essential since it is not possible to anticipate what providers an individual will see in the future, and it is not reasonable to expect anyone and especially persons with mental illness to remember all every provider they have seen in all the details of their care.

Patients cannot provide consent unless they remember all the providers that they have seen. In my career, I have seen many more patients harmed when information was not appropriately shared, compared to patients harmed when information was inappropriately released. When health care organizations implement HIPAA as written there is administratively efficient sharing of critical individual clinical information that is life saving and health enhancing.

HIPAA allows disclosures to share and discuss medical information with family, friends, and individuals involved with a patient's care in appropriate circumstances. Have you encountered health care providers taking an inappropriately restrictive interpretation of HIPAA privacy rules?

Unfortunately it is quite common for health care organizations to impose many more restrictions on sharing individual health information for treatment and coordination of care is required under HIPAA. I commonly encounter health care organization privacy officers, risk managers, and general counsels who have not actually read HIPAA or advise their organizations to be more restrictive "just to be safe". They appear to believe that this will somehow reduce their organization's legal liability and believe that that is more important to reduce their organizations potential liability from sharing information than it is to prevent harm from occurring due to information not being appropriately shared.

There is another inappropriate and burdensome restriction to sharing patient information for coordination of care and treatment in the case of persons receiving treatment for alcoholism and drug addiction. A separate federal statute and regulation commonly referred to as 42CFR puts much greater restriction on any information related to the treatment of alcoholism and substance abuse disorders that occur under HIPAA. This impacts persons with mental illness since many of them also suffer from alcoholism and addictions. Since co-occurring substance abuse and alcoholism is the major factor associated with violence by persons with mental illness 42CFR actually prevents clinicians treating persons with mental illness from accurately assessing risk of violence and intervening to reduce the risk of violence.

Under 42CFR, information cannot be shared without explicit and specific patient consent and that consent must be time-limited with an automatic expiration date. Persons with alcoholism and addictions commonly have multiple chronic medical problems and are frequently prescribed more medications than persons without these disorders. Mental health clinicians need the restricted information to accurately diagnose, assess risk of violence and treat persons with co-occurring substance abuse and alcoholism. Persons with alcoholism and addiction need the support and encouragement of all their healthcare providers in achieving and maintaining sobriety not just their substance abuse treatment programs. 42CFR actually discriminates against persons with alcoholism and addictions because they cannot get the same level of coordination of care for all their health care conditions that are available to patients with other conditions. Treating alcoholism and addictions differently from other conditions under the privacy laws promotes and keeps alive the stigma that these conditions are somehow intrinsically different and less worthy of good clinical care than other healthcare conditions. Separate is never equal. Congress should repeal 42CFR.

Do you have any suggestions on how we can address the problems with the mistaken way HIPAA is often applied?

Congress should mandate and fund a substantial HIPAA re-education initiative targeted at health organization's privacy officers, risk managers, general counsels, and CEOs. In particular HHS should assert and require that health organization's privacy officers, risk managers, general counsels, and CEOs acknowledge that they understand that:

HIPAA allows sharing healthcare information between providers directly involved in treatment absent patient consent.

a) HIPAA allows sharing health care information between providers directly involved in treatment even when the patient requests information not be shared.
b) Neglect has occurred if a patient comes to harm due to health care information not being shared when it could have been and should have been shared in order to coordinate care and provide the best possible treatment outcomes.
c) The failure to appropriately share health care information for coordination of care and to provide the best possible treatment outcomes is substandard care and outside of the acceptable community standard of treatment.
d) A simple and clear statement that the appropriate sharing of health care information for coordination of care and to provide the best possible treatment outcomes – is a requirement for adequate care on a par with having infection control procedures – will go a very long way to ending the inappropriate and self-serving restrictions on the flow of information necessary for good clinical care.