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to the Federal Medicaid Commission

Presented On Behalf of the National Alliance on Mental Illness and the National Council for Community Behavioral HealthCare

September 7, 2006

Arlington, VA

Chairman Sundquist and Members of the Commission,

Thank you for allowing me to offer this statement, which I am submitting on behalf of the National Alliance on Mental Illness (NAMI) and the National Council for Community Behavioral Healthcare (NCCBH). I have been a community psychiatrist practicing in public sector settings for the past 15 years. My work has been mostly with people who have chronic and disabling mental illness and who are poor.

My current position is with the Sheppard Pratt Health System. I practice in Frederick, Maryland and most of my patients are supported by and live in homes operated by a psychiatric rehabilitation program (PRP) called Way Station, Inc.

Almost all of my patients rely on public medical insurance to access mental and physical health care. About 60% of them are dually eligible for Medicare and Medicaid in Maryland. Reformation of Medicaid will deeply affect most of the patients whom I treat.

In Maryland, in addition to paying for medical and psychiatric treatment, Medicaid funds psychiatric rehabilitation services, which provide the care that helps people with severe mental illnesses remain in the community and avoid costly hospitalizations. In addition, the support of psychiatric rehabilitation programs gives patients access to programs like "Ticket to Work" which, while they are designed to help people achieve self-sufficiency, have requirements and paperwork which are so complex that most of my patients are not able to use them without support and encouragement.

I would like to offer my thoughts about several reform measures that are being proposed and those that have already been implemented in several states. I will focus my comments regarding the influence of reforms on the doctor-patient relationship and on cost sharing proposals.

Member agreements and requirements of compliance.

In 2003, the President's New Freedom Commission on Mental Health produced a report calling for the nation's mental health care system to fundamentally transform itself into one that more effectively assists patients and families with recovery from mental illness.

> ***Recovery*** *refers to the process in which people are able to live, work, learn, and participate fully in their communities. For some individuals, recovery is the ability to live a fulfilling and productive life despite a disability. For others, recovery implies the reduction or complete remission of symptoms. Science has shown that having hope plays an integral role in an individual's recovery. (New Freedom Commission Final report at page 5)*

One goal of recovery-focused treatment is the management of symptoms so that major complications and relapses are avoided. When hospitalizations and severe relapses are avoided, people are then able to achieve goals like employment and more independent living and to sustain these gains over time. In other words, to help patients "put the illness

in its place," so that it doesn't take over a patient's life and all of their hopes for their recovery. The process of the patient and doctor coming to a shared understanding of the goals of recovery focused treatment requires a high level of trust, honesty and a willingness to stay in the relationship despite setbacks.

Because cures are not usually possible with our current state of knowledge, the treatment of psychiatric conditions such as schizophrenia and bipolar disorder has much in common with the clinical management of chronic medical illnesses like hypertension, diabetes and heart disease. In the treatment of chronic illness, finding effective and well-tolerated treatment is frequently a process of trial and error.

Because recovery is more likely when patients and doctors work together to establish achievable goals, I have concerns about plans that focus more on compliance rather than collaboration and punish participants for non-compliance by reducing the availability of needed services. These plans may inadvertently encourage an authoritarian model of care that I believe is not effective for the treatment of most chronic illnesses.

I hope this clinical example will help illustrate this point. Over the years, I've learned to ask this question when I meet people for the first time: "What else is important for me to know about you today to be your doctor?"

In 2004, I asked this of a 20 year old young man who came to me after he had been though six years of repeated admissions, multiple failures of medication treatment, one serious suicide attempt and a long state hospital stay while he waited for appropriate placement in a community program. He said, "I like to be part of decisions about my medications." He then began to talk about the side effects of his medications and his wish to make changes. I had to explain to him that it's not my usual practice to make major medication changes on the first visit and especially with someone who had suffered through so many setbacks in his treatment. I was able to convince him that I too hoped that our relationship would be collaborative, that I was willing to listen to his complaints about the medication and that my goal was to help him find the most effective and tolerable regimen. Somehow, he was able to trust that I did mean those words even if I wasn't in agreement with his wish to change his medications on that first day. We're still working together and were able to make many of the changes he first requested. He has not been re-hospitalized, has moved into a lower level of supervised housing and has been able to take classes at the local college.

I have concerns about approaches that focus on compliance and adherence such as found in the West Virginia plan. These types of reforms fail to appreciate the need for negotiation and re-negotiation of treatment options. The outcome for the patient described above could have been very different if we had been required to focus on his compliance rather than his goals and his level of comfort with his symptoms and side effects.

Studies on treatment adherence often produce troubling results which indicate that a large number of people do not follow the treatment recommendations to which they have

agreed. (Osterberg L. and Blaschke T., "Adherence to Medication," New England Journal of Medicine, 353:487-97, August 2005) While every physician including myself wants to believe that these findings don't apply to them and their patients, I often have to face the fact that my patients do not always follow our treatment agreements. The reasons for this are many and are often related to symptoms of the illnesses that we're trying to treat. There is widespread recognition in the field that lack of insight about symptoms can be a core feature of schizophrenia and other severe mental illnesses. This lack of insight often leads to a refusal to take medications or agree to other types of treatment. Overcoming this obstacle and being able to find mutually agreeable goals requires an atmosphere of honest communication between doctor and patient. If honesty on the part of patients jeopardizes access to treatment, the therapeutic relationship between doctor and patient could be seriously compromised.

I recall one man who recently told me that he believed that the same people who could hear his thoughts and were listening to all his conversations in his apartment were influencing me. He also believed that the program staff was involved in the conspiracy. Based on these delusional beliefs, he had considered stopping his medication. Because he was able to share his delusional fears with me, I was able to help him recall together our long treatment relationship and our goals for his recovery. He was then able to acknowledge that he hadn't ever been harmed by anything I'd recommended. He now reports that the delusional beliefs are less intense and I believe he is taking medications more accurately with the help of nurses in our program.

When he comes to my office, he also visits with a nurse in the PRP who reviews his medication regimen, discusses his symptoms, and helps him organize his medications. Instead of opening multiple bottles of pills, he keeps all of his medications in one pillbox with a slot for each dose he takes. This is an illustration of how some additional support and $2.00 technology can make a positive difference. This is also an example of using a variety of services in a flexible mix in order to achieve a good outcome. Once I am satisfied that he is receiving maximal benefit from his medication regimen, I will be able to see him less often knowing that he will be seen weekly to receive help taking his medications and any exacerbations will be quickly brought to my attention.

It is important also to recognize that people with mental illnesses often have serious physical health problems in addition to the psychiatric diagnoses. They need access to effective medical care for these problems but have several inherent barriers to actually using the services. Someone with schizophrenia who is in treatment for diabetes has the same challenges to overcome when they are trying to comply with their medical doctor's recommendations as they do with the recommendations of their psychiatrist. Most of my patients would not be able to receive adequate medical care without the support of psychiatric rehabilitation program staff that usually make and attend appointments with them, help them remember what treatment was recommended and help them adhere to these recommendations.

Some Medicaid proposals have suggested penalizing non-compliant individuals by "bumping" them from an enhanced plan to a basic plan. Any plan, basic or enhanced,

must include mental health benefits. Mental illnesses are as real as other medical illnesses. We would never consider excluding treatments for heart disease, cancer or diabetes from a medical plan. In the absence of a treatment system available to provide mental health benefits, people will suffer needlessly, and likely will need higher and more expensive levels of care associated with emergency room treatment, inpatient hospitalizations and other inevitable consequences of lack of psychiatric treatment.

Like other physicians, I am not convinced that punishing people promotes healthy behaviors. (Bishop G. and Brodkey A.C., "Personal Responsibility and Physician Responsibility — West Virginia's Medicaid Plan**,"** New England Journal of Medicine, 355:8 756-758, August 2006) This is especially true for individuals are who ill and impoverished and may have difficulty complying with treatment, and yet are most vulnerable to suffering harm if they do not receive the help they need. I understand that individuals with disabilities who qualify for Medicaid by virtue of their eligibility for Supplemental Security Income (SSI) are not currently included in some reform plans. This exclusion will protect many of the most seriously mentally ill individuals if they have been able to secure disability benefits. There is much reason to be very concerned, however, for those with mental illnesses who are not currently covered by disability benefits or who are not currently eligible.

Cost sharing proposals

The introduction of cost sharing has been discussed in several of the proposals before the committee. At your hearing in Dallas, you heard from Steve Buck, NAMI's Director of State Policy about studies that concluded that "cost sharing is more likely to delay access to needed care than dissuade inappropriate use of medical services."

Medicaid beneficiaries are among our poorest citizens. They do not have much money. My experience with patients trying to live on SSI and SSDI benefits convinces me that even nominal co-pays will represent burdens and barriers to needed care.

Most of my patients in the housing program have a disposable monthly income of $102 which pays for shampoo, soap and other personal needs. If additional co-pays are imposed, this extra cost would either have to be covered by the housing provider or would come out of the personal needs allowance. For those not in PRP housing programs, the situation would be even more difficult.

Individuals who are disabled and receive Supplemental Security Income in Frederick County have monthly incomes of around $600. They rely on Medicaid solely to pay for healthcare. To put this level of income in the context of other living expenses, the median rent for an apartment in Frederick County was $613 in 2000.

In another shift from Federal Medicaid rules in the past, the Deficit Reduction Act 2005 allows for providers to deny services based on inability to pay co-pay fees. It also allows providers to waive these fees. Should I refuse to see a patient with schizophrenia or major depression because they didn't have $3.00? A system that consistently refuses to

see people because of their inability to make nominal co-payments will likely provoke the extremely negative and costly health and personal outcomes including homelessness, criminalization, hospitalization and emergency room visits that it is trying to prevent. I have seen this process occur regularly in my experience of working in homeless shelters and mobile treatment teams if people are denied access to care. I hope that states will carefully examine whether this flexibility to deny services is used to screen out those Medicaid beneficiaries who are perceived to be more difficult to treat.

Positive proposals for cost savings

There are ways to contain costs in Medicaid without compromising access to care or the quality of care received by Medicaid recipients.

For example, I would strongly support efforts towards rewarding providers whose practice patterns are supported by evidence of effectiveness. One set of examples are five evidence-based practices that have been supported by the Substance Abuse and Mental Health Services Administration (SAMHSA). These evidence-based practices include Illness Management and Recovery, Assertive Community Treatment, Family Psychoeducation, Supported Employment, and Integrated Dual Diagnosis Treatment. SAMHSA has produced toolkits that are available for free and are designed to help providers implement these practices in their usual clinical routines.

Disease management programs, if properly implemented, can also achieve greater efficiencies and quality in the provision of care for people with chronic illnesses. In my experience, flexible approaches to the provision of care can make all the difference. For example, home nursing visits and other strategies for educating and supporting compliance with treatment have proven effectiveness.

One area that has generated much interest in Medicaid reform are strategies to control the high costs of medications, especially atypical antipsychotics used to treat schizophrenia and bipolar disorder. I do not support excessively restrictive formularies or other cost-containment strategies that impede access to needed medications. However, I urge the commission to look at efforts that have taken place in Missouri, Massachusetts and Pennsylvania that incorporate quality management strategies so that less expensive care does not become less effective care. (Ning A., Dublin W., and Parks J., "State Mental Health Policy: Pharmacy Costs: Finding a Role for Quality," Psychiatric Services, 65:909, August 2005)

Doctors in the US have recently gained experience with the implementation of widespread utilization review for prescriptions with Medicare Part D. This brought about rapid changes in the way that prescriptions are covered for my dually eligible patients. Medicare Part D has been helpful in some ways but quite problematic in others. Providing information about less expensive alternatives and having to justify more costly alternatives has been useful. However, utilization review methods that are merely time consuming and inconvenient, but have no discernible monetary savings, do not enhance the quality of care. For example, why should a separate process be needed to receive

authorization for two different pill sizes of the same medication i.e. if a patient takes a 5 mg pill and a 10 mg pill of the same drug together? Another aspect that has been difficult is the number of different plans that have been approved. One system with one set of rules would have been easier to implement and not have involved the chaos that occurred with Part D when it was initiated this January.

Advancing the use of information technology will help physicians provide more efficient and effective medical care. As examples, I would urge the commission to support reforms that help providers, including pharmacists, communicate with each other, those that help identify duplications of services and alert physicians to potentially harmful combinations of medications.

Conclusion

Medicaid is by far the single largest program financing public sector mental health services in America today. Changes to this important program must be made carefully, driven by the desire to improve quality and efficiency, not merely to contain costs. Thank you for this opportunity to speak with you today.

Respectfully Submitted,

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