STATEMENT TO THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES MEDICAID REFORM COMMISSION

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Submitted By,
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National Alliance for the Mentally Ill

Chairman Sundquist and members of the Commission, I am pleased today to offer the following statement on behalf of the National Alliance for the Mentally Ill (NAMI). NAMI is the largest national organization representing children and adults living with severe mental illness. With over 210,000 members and 1,200 affiliates in all 50 states, NAMI is engaged in advocacy, education and support for people living with illnesses such as schizophrenia, bipolar disorder, major depression and severe anxiety disorders.

NAMI has an enormous stake in the work this Commission is undertaking, both in terms of the short-term goal of assisting Congress in developing $10 billion in savings over the next 5 years, and in terms of long -term reforms. NAMI intends to submit to this Commission proposals for long-term reform at a later date. Today, NAMI would like to offer perspectives on some of the proposals under discussion for reaching the immediate goal of $10 billion in savings.

Medicaid -- A Critical Link in Public Mental Illness Treatment Services
As you know, Medicaid is by the largest and most important source of funding for public sector mental illness treatment services. This past year, Medicaid surpassed 50% of all public mental health expenditures. It is expected to reach 70% of public mental health expenditures by 2017. This upward trend in Medicaid as a source of public mental health spending is occurring as a result of a range of factors. Chief among them is reductions in state expenditures for public sector services and the push at the state level to maximize federal matching dollars.

A quick examination of the eligibility categories that individuals with severe mental illnesses fall into, and the specific mental illness treatment and support services financed by Medicaid, reveals several important trends. First, while both children and adults with mental illness fall into the mandatory and optional eligibility categories, mandatory eligibility is predominant. More than 30% of SSI beneficiaries qualify for benefits as a result of a mental impairment.

For these mandatory beneficiaries, most of the mental illness treatment and support services they receive are deemed "optional." This includes coverage of prescription drugs, as well as intensive case management and assertive community treatment (ACT). While federal policy may deem these services to be "optional," NAMI can assure you that for these disabled and vulnerable Medicaid recipients, medication and intensive case management are not "optional" for their most basic health care needs.

Despite this, many NAMI affiliates across the nation are witnessing unprecedented efforts on the part of states to impose reductions and restrictions on these critically important mental illness treatment services. In some instances, states are imposing strict limits on the number of prescriptions per month. In other cases, states are placing restrictions on access to the newest and most effective treatments for schizophrenia and bipolar disorder through policies such as prior authorization, step therapy and "fail first." Finally, NAMI affiliates across the country are seeing states and localities eliminate access to evidence-based models such as assertive community treatment (ACT) programs.

These disturbing trends are occurring as this Commission and Congress develop proposals for achieving the goal of $10 billion in reductions over the next 5 years. NAMI understands that a range of options are currently on the table. As the largest organization representing Medicaid beneficiaries with severe mental illness, NAMI would like to offer the following input on some of those budget and policy options.

Increases in Beneficiary Co-Payments -- The bipartisan Medicaid proposal endorsed by the National Governors Association (NGA) recommended that states have the option to impose higher co-payment requirements on Medicaid beneficiaries for most health care services. State Medicaid programs typically allow -- and some cases require -- services to be rendered to beneficiaries that unable to meet even minimal co-payment requirements for services. This includes filling of prescriptions at a pharmacy counter (i.e., requiring dispensing if a Medicaid recipient is not able to pay).

NAMI is extremely concerned about the potential impact of such a proposal -- especially on children and adults living on SSI who are already at the bottom of the economic spectrum. A preliminary analysis by the Congressional Budget Office (CBO) suggests that most of the savings from such a proposal will come NOT as a result of increased revenues to state programs, but decreased utilization of health care services by Medicaid beneficiaries. In other words, the savings occur from vulnerable recipients -- including individuals with severe disabilities and chronic illnesses -- not receiving services they would otherwise access.

As you know, monthly SSI cash benefits in most states averages less than $600. For individuals with severe mental illnesses residing in supportive housing, board & care homes or other congregate living arrangements, most of their cash benefits are directed toward room and board -- with a minimal personal allowance that can be as low as $20 per week. Imposing higher co-payments on these most vulnerable beneficiaries, would

almost certainly result in their not being able to access the most basic treatment services including prescription drugs.

Changes in the Definition of Optional Rehabilitation Services -- A large number of states currently use the Medicaid Rehabilitation Option to finance assertive community treatment (ACT) services to adults with severe mental illness on SSI. This is specifically allowed -- and in fact -- was encouraged by HCFA back in 1999 in a Dear State Medicaid Director letter (see the attached). These services are typically provided by a Community Mental Health Center (CMHC) or a county mental health department and can often be integrated into other programs they offer. While they are based on treatment plans and typically involve established outcomes (e.g., keeping the individual client out of the hospital), they are not always clinical outcomes based on restoration of functioning (i.e., expecting the symptoms of schizophrenia to disappear is simply not a reasonable short-term expectation).

NAMI understands that the Bush Administration has submitted to this Commission and Congress a proposal to "clarify" the definition of Rehab services by imposing a limitation to services that are necessary for the "achievement of specific, measurable outcomes related to restoration of ... the best possible functional level ..." Further, the proposal would exclude services that are an intrinsic element of another program or routinely provided by a state or other entity without charge or as part of a fee schedule.

NAMI understands that this proposal was designed to curtail suspect practices at the state and local level that have been the subject of several examinations by the Government Accountability Office (GAO), this proposal appears to go much further. An examination of how intensive case management and ACT services are financed in the public mental health system raises a number of concerns. Services provided by CMHCs and public mental health agencies (including county governments) are typically provided to indigent clients without charge -- especially when treatment is provided on an involuntary basis through a court order or civil commitment. As a result, most CMHC and county mental health agencies are unlikely to maintain any kind of fee schedule.

NAMI is aware of no government audit or independent study demonstrating patterns of fraud and abuse with respect to states using the Medicaid Rehab Option to finance ACT services for either mandatory or optional populations. At the same time, this proposal appears to severely limit ACT services as part of the Rehab Option. By limiting services to specific measurable outcomes related to functioning, ACT would likely be excluded for individuals with the most severe and treatment resistant forms of cyclical and episodic illnesses such as schizophrenia and bipolar disorder. Likewise, eliminating from the Rehab Option governmental and non-profit providers (including CMHCs) that do not routinely charge clients in ACT programs would also severely curtail access to this highly effective evidence-based model.

Redefining Case Management Services -- The Administration's proposal also contains a clarification of case management that can be financed through Medicaid. As with the Rehab option, the proposal relates this back to: a) services that are distinct from other

services, b) services directed to specific measurable outcomes for specific individuals, c) not provided as an intrinsic element of another program, or d) routinely provided without charge or not through a fee schedule.

As with the Rehab Option proposal, this has enormous potential to wipe out Medicaid funding for ACT and intensive case management programs currently directed to the most vulnerable and disabled Medicaid recipients -- including mandatory beneficiaries. Intensive case management (the core of ACT) is all about helping the most severely impaired individuals with mental illness manage their disease. For this most severely ill population (most, if not all on SSI), ACT is what allows them to achieve treatment adherence (through medication management) and move toward recovery (no matter how slow and difficult that process). The reality is that a small, though significant, group of these most severely ill individuals endure episodes of their illness when they simply can not come voluntarily to treatment. This often occurs through lack of insight and sometimes through being unable to overcome auditory hallucinations or paranoid delusions that are part of an illness such as schizophrenia.

Eliminating ACT or intensive case management for these individuals is certain to have disastrous consequences for local communities, exacerbating the already high financial and personal costs associated with untreated mental illness: chronic homelessness, increased burden on the criminal justice system, higher rates of co-occurring substance abuse, and increased risk of suicide. Starting in 2006, this could also complicate the transition of many dual eligibles with mental illness transitioning into Medicare Part D.

Reductions in State Matching Rates for Targeted Case Management -- The Bush Administration is also proposing to curtail the matching rate provided to states for targeted case management services. Instead of paying states under the regular Medicaid match formula (each state has a different rate that varies from 50 cents to 80 cents on the dollar), all states would receive an administrative match of 50 cents. Such a proposal has potential to disproportionately impact poorer states that currently receive a higher match rate for targeted case management. As with the proposals to redefine Rehab services and case management, NAMI remains concerned about the impact of this proposal on states that are using targeted case management to finance ACT programs under Medicaid.

Changes to Pharmaceutical Pricing and Reductions on Pharmacy Dispensing Fees -- The Bush Administration proposed earlier this year to reform the way in which Medicaid pays for prescription drugs by shifting away from a system known as "Average Wholesale Price" (AWP) to "Average Sales Price" (ASP) or "Average Manufacturer's Price" (AMP). Such a proposal is designed to more accurately reflect actual prices paid on the market, rather than complex formulas that rarely reflect existing market conditions. This proposal also includes changing the fees paid to retail pharmacists for filling a prescription to a Medicaid recipient.

NAMI supports reforms that will create greater transparency and accountability in the pricing of medications in the Medicaid program. This transparency should help states

find the best price available and avoid gaming of current rules that result in AWP being commonly referred to by state officials as "Ain't What's Paid."

Increasing Supplemental Rebates -- NAMI wants to ensure that any changes to policies governing pricing of medications for state Medicaid programs not encourage states to seek to additional cost controls through supplemental rebates. Some advocates in Congress and elsewhere argue that supplemental rebates offer promise for large short-term savings for both state Medicaid programs and federal expenditures.

At the same time, NAMI remains extremely concerned that increases in supplemental rebates paid by manufacturers has enormous potential to limit access to medications for Medicaid beneficiaries. In states all across the country, supplemental rebates are routinely accompanied by very tight restrictions on access for specific products manufactured by companies that do not meet the highest rebate offered to a given state. As a result, states either exclude a specific medication from its Medicaid formulary, or impose an access restriction such as a prior authorization requirement, step therapy or "fail first." In the case of atypical anti-psychotic medications commonly used to treat schizophrenia and bipolar disorder, these policies can be disastrous given that these medications are simply not clinically interchangeable.

New Freedom Initiative (NFI) Proposals to Promote Community Integration for People With Disabilities -- NAMI supports the Bush Administration's New Freedom Initiative and the "Money Follows the Person" proposals to further the universally shared goals of transitioning people with disabilities out of institutional settings and into the mainstream of community life. Included among these proposals is an important 10-year demonstration program for community-based alternatives for psychiatric residential services for children. NAMI believes that these proposals should be included in this year's budget reconciliation package.

NAMI supports the goals and policy objectives of the entire NFI, namely reforming Medicaid to "eliminate institutional bias" and promote community-based options to nursing homes, ICF-MRs and psychiatric hospitals. However, in NAMI's view these efforts have historically fallen short in reaching non-elderly adults with severe mental illness because of the Medicaid Institutions for Mental Disease (IMD) exclusion. This fundamental discrimination in the Medicaid program results in non-elderly adults with mental illnesses being excluded from most home and community-based waiver programs.

Put simply, the IMD exclusion results in no money being available to "follow the person" into the community. Likewise, IMD sets aside a single category of services -- both long-term and acute psychiatric services -- being singled out for exclusion from Medicaid. Congress and the Bush Administration need to address this basic unfairness in Medicaid if the promises of recovery and community integration are to effectively reach non-elderly adults with severe mental illnesses. NAMI recognizes that long-term reform of IMD is not likely to be addressed as part of this year's budget reconciliation package. At the same time, this year's legislation does create an important opportunity to at least address the most egregious barriers with respect to acute psychiatric care. NAMI would

therefor commend to this Commission bipartisan legislation recently introduced by Senators Snowe and Conrad, the Medicaid Emergency Psychiatric Care Act (S 1592).

Extending Medicare Part D Access Protections to All Medicaid Beneficiaries -- The Part D drug benefit that goes into effect on January 1, 2006 provides important access protections for Medicare beneficiaries with mental illnesses -- including dual eligibles. Guidance provided to the drug plans that will administer the benefit requires them to cover "all or substantially all" medications in the classes of anti-psychotics, anti-depressants and anti-convulsants. In addition, these drug plans will be severely limited in their ability to impose access restrictions (prior authorization, step therapy, etc.) on these medications. NAMI is very supportive of these protections that CMS has developed after significant input from groups representing beneficiaries.

In NAMI's view, these important access protections contained in the Part D benefit for dual eligibles need to be extended to all Medicaid beneficiaries with severe mental illness. As noted above, in the past few years we have witnessed a proliferation of restrictive access policies in state Medicaid programs that increasingly being applied to medications to treat mental illness. These policies are -- in NAMI's view -- very costly to states over the long-term as immediate savings in pharmacy costs are more than offset by the higher costs associated with disrupting effective treatment (increased risk of hospitalization, chronic homelessness, family disruption, criminal justice, etc.). This is most acute in states that are now placing strict, inflexible limits on the number of prescriptions and states that are requiring beneficiaries to "fail first" on a single preferred drug. States should be pushed to ensure that the access protections contained in the Part D drug benefit are extended to all vulnerable Medicaid beneficiaries.

Encouraging Best Practices and Disease Management in State Medicaid Programs -- NAMI believes that disease management and adoption of best practices offers tremendous potential for states to improve quality of care and enhance treatment outcomes for people with severe mental illness. Disease management and pharmacy management programs are developing a strong record demonstrating improvements in quality of care and savings through reduced hospitalization and avoidance of many of the high costs associated with untreated mental illness (chronic homelessness, increased emergency room utilization, interaction with criminal justice, etc.). NAMI would be pleased to share with this Commission recent studies demonstrating the effectiveness of disease management in reaching these critical goals.

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DEPARTMENT OF HEALTH & HUMAN SERVICES
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June 7, 1999

Dear State Medicaid Director:

Mental illness affects millions of Americans, many of whom rely on Medicaid to cover their health and mental health care needs. In recognition of the White House Conference on Mental Health, I am writing to provide information about several issues related to mental health services.

Developments in Mental Health Treatment

Assertive Community Treatment (ACT) programs have been used to serve persons with serious and persistent mental illness for a number of years. Programs based on ACT principles employ interdisciplinary treatment teams, shared caseloads, 24-hour mobile crisis teams, assertive outreach for treatment in clients' own environments, individualized treatment, medication, rehabilitation and supportive services. Assertive Case Management (ACM) programs which incorporate shared caseloads also provide this array of individualized, community-based services.
The evidence base for a variety of treatment and service interventions for persons with schizophrenia, including ACT and ACM, has recently been reviewed by the Schizophrenia Patient Outcomes Research Team (PORT), with support from the Agency for Health Care Policy and Research and the National Institute of Mental Health. With respect to persons with schizophrenia who are at high risk for discontinuation of treatment or for repeated crises, the PORT team concluded that:

> "Randomized trials have demonstrated consistently the effectiveness of these programs [ACT and ACM] in reducing inpatient use among such high-risk patients. Several studies also support improvements in clinical and social outcomes. These studies suggest that both ACT and ACM are superior to conventional case management for high-risk cases (Schizophrenia Bulletin, 1998)."

States should consider this recommendation in their plans for comprehensive approaches to community-based mental health services. Programs based on ACT principles can be supported under existing Medicaid policies, and a number of States currently include ACT services as a component of their mental health service package. Consumer participation in program design and the development of operational policies is especially key in the successful implementation of ACT programs.

Consumer Directed Care

Advance directives are becoming an increasingly important tool for consumers of mental health services to articulate their decisions about treatment, and to guide treatment when they can not make these decisions themselves. Current Medicaid rules (42CFR 431.20, 434.20, and 489.100) require that States develop and provide current information about State laws that deal with

advance directives. We urge all State Medicaid programs to work with their State mental health authorities to ensure appropriate attention to mental health issues in their advance directives policies, and to consider how these policies are operationalized in Medicaid program services.

Pharmacy

Finally, I would like to underscore that Federal statutory requirements noted in my February 12, 1998 letter about new medications for schizophrenia apply to services that States carry out via contract. When there are prior authorization requirements for prescription medicines, including the new generation of drugs for schizophrenia, prescription requests must be responded to in 24 hours. In emergency situations, there must be provisions for dispensing at least a 72 hour supply of the requested drug.

I appreciate your attention to these important mental health updates. If you have questions or would like further information, please contact Peggy Clark (410-786-5321). If you are interested in finding out more about ACT programs, the mental health authority in your state would be a good resource. Additionally, consultation and technical assistance are available from the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (Michael English, 301-443-3606).

Sincerely,

Sally K. Richardson
Director

cc:
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