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

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Submitted By,
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Chairman Sundquist and members of the Commission, I am pleased today to offer the following statement on behalf of the National Alliance on Mental Illness (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.

Earlier this afternoon you heard from Aaron Spencer of Houston, TX. Aaron spoke eloquently about the importance of Medicaid in his own recovery. Aaron referenced access to medications, Medicaid funding for peer provided services, continuation of Medicaid benefits during employment through initiatives such as Ticket to Work, and cultural competency. NAMI agrees with Aaron's comments on these important matters and encourages this Commission to give great weight to his testimony.

This afternoon, I want to comment on two themes that have emerged in recent, state initiated Medicaid reform and redesign. These two themes – participant cost-sharing and new waiver innovations such as defined contribution plans and tailored reforms – could potentially undermine the stronger elements of Medicaid that make the program successful for people living with mental illness. I also will comment on the importance of Medicaid investment in rehabilitative services.

Participant Cost-Sharing

Numerous studies have led to the same conclusion. Cost-sharing is more likely to delay access to needed care than dissuade inappropriate use of medical services. RAND has documented a 41% reduction of effective health services by poor people when cost-sharing was increased. Research from Quebec found that emergency department use increased by 88% after cost-sharing was imposed and other unintended consequences (increased hospitalization, institutionalization, and death) increased by 78%. Similar findings have played out repeatedly in states as access to needed services, especially pharmaceuticals, has been limited.

To understand the consequences of cost-sharing, it is important to put into context the impact even nominal copayments can have on an individual Medicaid participant's personal budget. Supplemental Security Income (SSI) is often the sole source of income for Medicaid participants. Nationally, the federal SSI payment amounts to $603 per month. If I were a resident of Dallas, Texas, it would take 125% of my SSI income to

afford a one-bedroom apartment, based upon the most recent rental trends. Even if I received reasonable housing subsidies, I would struggle to meet my dietary, clothing, and healthcare needs while paying my rent. For many of us, a co-payment of $3-$5 wouldn't cause us a second thought. However, for someone living on a fixed income of $603 per month, a co-pay of this amount may be unaffordable. This is particularly true because for many on Medicaid, addressing multiple illnesses is the norm. So we are not only talking about one $ 3 co-payment, we could be talking about 4, or 6 or even 10 or more. Cost sharing eats up a disproportionate amount of available income for people on Medicaid than it does for those benefiting from employer provided insurance. If I'm on SSI, trying to live in a decent apartment, feed myself and address my healthcare needs, I'm out of money before I even get started.

Expecting co-payments from Medicaid participants who are categorically eligible due to disability is both bad policy and unrealistic. NAMI encourages the Commission to look more intently at strategies such as disease management to address utilization as opposed to introducing restrictive barriers such as cost-sharing. In most cases, the beneficiary does not have the money to meet copayments and the system will be burdened by more costly care later when the beneficiary requires more expensive services than would have been required if the burden of cost-sharing had not discouraged early intervention.

Defined Contribution Plans and Tailoring Efforts

As exemplified in Florida's two county pilot, defined contribution plans – as opposed to the traditional defined benefit plans – have gained popularity in many Medicaid reform discussions. Defined contribution plans are akin to a "money follows the person" approach to healthcare. NAMI believes that consumer and family involvement in healthcare decision making is essential and a trademark of a recovery based system of care. However, in the context of the defined contribution model, people with mental illness are often significantly disabled and can require extensive assistance in navigating choices related to health plan enrollment and benefits selection.

Yet to be proven is the effectiveness of private plans in consistently and effectively serving the needs of persons with serious mental illness. Private plans have historically provided very limited mental health benefits. In addition, many states have attempted to use managed care to serve this constituency and the results have not been encouraging.

Another concern with the defined contribution model is the selection of an actuarially adjusted premium. Tough questions should be asked related to the consequences when a person, due to an unforeseen psychiatric event, requires services that exceed the actuarial projection. This will occur and questions remain as to whether or not policymakers have adequately planned for events such as this.

NAMI encourages the Commission to make recommendations that limit the exposure of individuals with disabilities to the defined contribution model. When defined contribution models are used, consideration should be given to strong staffing and support, including benefits counselors experienced with working with people with mental illness and "catastrophic coverage" that is readily available should an individual's cap be reached.

Our members have reported numerous challenges across the country in expecting private health plans to meet the needs of persons who have chronic mental illness. Any analysis of the current reforms should include careful monitoring of potential shortcomings in private sector mental health delivery, such as emergency department utilization and increased involvement of the criminal justice system.

We also urge further analysis of reforms that rely on a "lean benefits" design in states that "tailor" benefits design to meet the needs of specific populations. Idaho and Kentucky are two states that have elected to initiate reforms using this approach. NAMI applauds these states for recognizing the needs of people with disabilities and protecting this population from reform efforts. However, monitoring of these reform efforts must include tracking individuals that, at the initiation of the reform, receive the lean benefits package and then experience disabling mental illness. Individuals must have access to adequate mental health benefits, and, if appropriate, must be transitioned quickly to a Medicaid program that has a rich benefit design. Without appropriate forethought, disruptive transitions will cost Medicaid a lot of money and put people's lives at risk.

Overall, we are concerned that the current rush to reform Medicaid is based upon saving a few pennies today without considering the long term affects of the changes to the system of care. NAMI asks the commission to take steps to allow the current pilots and innovations to demonstrate their strengths and weaknesses before national reforms are allowed to take place.

Rehabilitation Services

A critical element of the service mix for Medicaid is the availability of rehabilitation services. Rehabilitation services can include important supports such as assertive community treatment (ACT), life skills training, and other skills development. These services are critical to recovery, self-sufficiency and independence.

Without ACT, intensive case management, and other rehabilitation services as part of the Medicaid mix, local communities will experience disastrous consequences, 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.

An essential premise of the offering of rehabilitative services is a commitment to the belief in recovery from mental illness. NAMI encourages the Commission to include the provision of long-term rehabilitative supports in its recommendations.

Thank you for this opportunity to testify on behalf of NAMI and our members. Access to Medicaid funded services is essential to people living with mental illness and their families. We look forward to continuing to work with the Commission as you develop your recommendations.

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