



March 31, 1998

## NAMI STATEMENT ON THE PATIENTS' BILL OF RIGHTS ACT OF 1998

The nation's leading national organization representing people with serious brain disorders and their families today joined forces today with a broad-based coalition of groups representing health care consumers in support of comprehensive consumer protection legislation for people enrolled in managed care plans. The National Alliance for the Mentally Ill (NAMI) is pleased to be able to support efforts in Congress to make health plans more accountable to the needs of people living with brain disorders such as schizophrenia, bipolar disorder (manic-depressive illness), major depression, obsessive-compulsive disorder, and severe anxiety disorders.

The shift toward managed care is now having a profound impact on access to treatment for severe mental illnesses. For millions of people living with these illnesses and their families, managed care has made it harder for them to get the treatment they need, including hospitalization, new advanced medications and outpatient services. In addition, managed care is also restricting the ability of families and consumers to get the information they need about the benefits in their health plan and their right to appeal denials of care.

The Patients' Bill of Rights Act of 1998 is an important step forward for NAMI's 172,000 members. The bill establishes minimum standards for health plans in the areas of access to prescription drugs and clinical trials for new treatments for serious brain disorders such as schizophrenia, bipolar disorder and major depression. This legislation, introduced today by Senators Tom Daschle (D-SD) and Edward M. Kennedy (D-MA) and Representatives Richard Gephardt (D-MO) and John D. Dingell (D-MI), would establish new standards for internal and external grievance procedures for adverse treatment decisions, and set up state "ombudsman" programs to assist vulnerable populations in dealing with the ever-growing complexity of our nation's health care system.

NAMI supports these efforts and urges the Congress to move forward on managed care consumer protection legislation in 1998. Without minimum standards for the managed care industry, more and more consumers and families are likely to slip through the cracks of our health care system. People with serious brain disorders and their families are especially vulnerable in private sector managed care plans that seek first to satisfy the interests of corporate profits and shareholders. Enforceable standards are critical to ensuring that treatment decisions are made by consumers, family members and their doctors on the basis of medical need, rather than on a health plan's financial bottom line.

NAMI looks forward to continuing our work with Congress to further these objectives. We believe that every American, regardless of their illness, should be guaranteed equal health care protections under law.

*With more than 172,000 members, NAMI is the nation's leading grassroots organization solely dedicated to improving the lives of persons with severe mental illnesses including schizophrenia, bipolar disorder (manic-depressive illness), major depression, obsessive-compulsive disorder, and anxiety disorders. NAMI's efforts focus on support to persons with serious brain disorders and to their families; advocacy for nondiscriminatory and equitable federal, state, and private-sector policies; research into the causes, symptoms and treatment for brain disorders; and education to eliminate the pervasive stigma surrounding severe mental illness. NAMI has more than 1,140 state and local affiliates in all 50 states, the District of Columbia, Puerto Rico, and Canada.*

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