To: The Office of the Health Care Advocate, State of Connecticut
From: Margo Maine, PhD, FAED, CEDS
Re: Testimony for Public Hearing:
Mental Health and Substance Use: Access to Prevention, Treatment, and Coverage
October 17, 2012

Today I represent the National Eating Disorders Association, having been a founding member, a longtime board member and now a senior advisor to the board. I am also a local psychologist, having specialized in the treatment of eating disorders in CT for over 3 decades. When we first started seeing girls with these problems at Newington Children's Hospital, my supervisors and mentors advised not to specialize in eating disorders, as they were just a "fad." I wish that had been true. Instead, eating disorders have become a major public health problem in the US and across the globe, although they remain largely unrecognized, misunderstood, and undertreated in the health care system. Today, minimally, a total of 30 million people suffer from anorexia nervosa, bulimia nervosa, and related eating disorders. Although 90% of these are women, these are equal opportunity diseases, occurring in every race, ethnicity, socio-economic class, and increasingly in adult women, young children, and males.

The fact is that eating disorders are the 3rd most common chronic illness among female adolescents in the US, behind asthma and diabetes. Young women who develop Anorexia Nervosa suffer a mortality rate 12 times higher than the death rate of all other causes of death. The mortality rate is 3 times greater than in depression, schizophrenia, or alcoholism. The mortality rates associated with Bulimia Nervosa and with Eating Disorders Not Otherwise Specified are unknown due to serious gaps in research, but are likely to be as high or higher, as sufferers are identified and treated later in the illness process, if at all.

Eating disorders are multidetermined conditions, and although they are classified as psychiatric, they affect every system in the body. Medical complications can occur quickly, despite long-term medical stability and normal laboratory values, and can result in sudden death. Some of the most common medical issues are:

- Cardiac- slow rate, arrhythmias, CHF, impaired structure and function, arrest
- Cognitive dysfunction affecting concentration, memory, thought processes and affect regulation; brain tissue loss
- Electrolyte imbalances
- Dehydration
- Kidney failure
- Hypothermia

- GI problems- gasteroparesis; acid indigestion; increased risk of esophageal pre-cancers, cancers; bleeding; constipation; diarrhea
- Aspiration
- Dental cavities, loss of enamel and teeth
- Compromised immune system
- Endocrine dysfunction- menstrual irregularities; decreased bone mineral density; increased risk for osteopenia and osteoporosis; fertility issues
- Musculoskeletal system- stress fractures; aches/pains; weakness
- Psychomotor slowing
- Seizures, coma, sudden death

Despite these facts, most who suffer from eating disorders are untreated or undertreated. Only one-third of people with anorexia and only 6% of those with bulimia receive mental health services. Furthermore, as many as 80% of those who access care for their eating disorders do not get the intensity of treatment they need to achieve recovery. They may not have access to specialists or to the appropriate level of care. If hospitalized, they are often sent home weeks earlier than the recommended stay. In fact, despite a strong correlation between length of stay and treatment outcome, research tells us that the length of hospitalization for eating disorders has decreased 95% since 1984. A 2009 study tells us that delayed, inadequate, and truncated care has contributed to rates of recidivism (both relapse and re-hospitalization) that range from 25-50%. Another study shows that more than half of patients with anorexia nervosa who were underweight at the time of discharge required re-hospitalization, but fewer than 10% of the patients discharged at normalized weight sought additional inpatient treatment. Both research and clinical experience tell us that specialized treatment for eating disorders is preferable and cost effective, and that recovery takes place over a long period of time.

The good news is that people can get better from eating disorders. 76% of one group studied for 10-15 years after admission met criteria for full recovery, but time to recovery ranged from 5 to 7 years. Another10% met criteria for partial recovery. Patients with bulimia nervosa demonstrate a better recovery rate if they receive treatment early in their illness. When treated within the first 5 years, the recovery rate is 80%. For those who are not treated till after 15 years of symptoms, recovery falls to 20%.

The bad news is that, without treatment, up to 20% of people with serious eating disorders die. With treatment, that number falls to 2-3%. The mortality rate increases with the duration of symptoms. Eating disorders require prompt, comprehensive and specialized care, at the intensity and duration determined by the individual's condition. When I talk to insurance reviewers to pre-certify care or refer to a higher level of care, they talk like we are "making a deal," instead of dealing with life and death issues of seriously ill patients.

People suffering from these potentially life-threatening conditions need help early and often. Insurance and health maintenance organizations must provide coverage and reimbursement for the level of care the individual needs. For example, although much of recovery takes place in outpatient settings, little or limited reimbursement is available for this, so patients often get worse and need a more intense and expensive level of care, that can range as high as $2,000/day. The average cost for a month of inpatient treatment is $30,000. Many individuals with eating disorders need anywhere from 3 – 6 months of inpatient care. Treating patients in the community at an early stage of their illness not only can save lives but also saves parents from bankruptcy and insurers (and ultimately tax payers) from paying far more than they otherwise would have if the insurance companies had paid for the cost of early treatment in the community. The reality is that families are too often forced to choose between bankruptcy and their loved one's life. This is not a choice anyone should have to face.

Because I treat people with eating disorders, I have met some of the finest and most trustworthy and responsible people on this earth. But, as one mom described, when the eating disorder enters their lives, "they go dark." The problems develop due to a deep sense of personal inadequacy, so when an insurance company denies care, people suffering with eating disorders only feel worse about themselves, more worthless and hopeless, and undeserving of anything. They believe they are not "sick enough" or that their eating disorder is "not good enough" to deserve care. They often give up. Suicide is a frequent outcome of their despair. Today we have clear standards for the treatment of eating disorders provided by the American Psychiatric Association. Relative to other accepted medical interventions, the treatment of eating disorders has been shown to be cost-effective and, in fact, quite reasonable. We have more and more evidence of the effectiveness of treatment but few have access to comprehensive care.

The American people understand much of what I have said. In fact, a national study by a major global market research group commissioned by the National Eating Disorders Association found that:

* 3 out of 4 Americans believe eating disorders should be covered by insurance companies just like any other illness.

* Americans believe that government should require insurance companies to cover the treatment of eating disorders.

We need the insurance companies and the health care system to have the same common sense that the American people have. Eating disorders are not lifestyle choices- they are debilitating and life threatening illnesses. Connecticut needs to do a better job to prevent these problems,

to identify cases earlier, and to provide appropriate care to patients and families. Time is of the essence: we cannot lose another life.

*Dr. Margo Maine, cofounder of the Maine & Weinstein Specialty Group, is a clinical psychologist who has specialized in eating disorders and related issues for over 30 years. Author of :***Treatment of Eating Disorders: Bridging the Research- Practice Gap,** *co-edited withBeth McGilley and Doug Bunnell (Elsevier,2010);* ***Effective Clinical Practice in the Treatment of Eating Disorders: The Heart of the Matter,*** *co-edited with William Davis and Jane Shure (Routledge , 2009);* ***The Body Myth: Adult Women and the Pressure to Be Perfect*** *(with Joe Kelly, John Wiley, 2005);* ***Father Hunger: Fathers, Daughters and the Pursuit of Thinness*** *(Gurze, 2004); and* ***Body Wars: Making Peace With Women's Bodies*** *(Gurze, 2000), she is a senior editor of* ***Eating Disorders: The Journal of Treatment and Prevention****. Dr. Maine was a founding member and longtime board member and vice president of the Eating Disorders Coalition for Research, Policy, and Action. A Founding Member and Fellow of the Academy for Eating Disorders and a member of the Founder's Council and past president of the National Eating Disorders Association, she is a member of the psychiatry departments at the Institute of Living/Hartford Hospital's Mental Health Network and at Connecticut Children's Medical Center, having previously directed their eating disorder programs. Dr Maine is the 2007 recipient of The Lori Irving Award for Excellence in Eating Disorders Awareness and Prevention, given by the National Eating Disorders Association. She lectures nationally and internationally on topics related to the treatment and prevention of eating disorders, female development, and women's health. Dr. Maine devotes much time and energy to addressing federal policy related to eating disorders through her work for the National Eating Disorders Association and the Eating Disorders Coalition for Research, Policy, and Action, having chaired the policy section of the FREED Act (Federal Response to Eliminate Eating Disorders), which was introduced into Congress by Representative Patrick Kennedy in February, 2009 and by Senator Harkin in 2010.*