

January 31, 2012

The Honorable Kathleen Sebelius
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Essential Health Benefits Bulletin

Dear Secretary Sebelius:

The Eating Disorders Coalition for Research, Policy & Action is a coalition of more than 35 organizations in the eating disorders education, prevention, and treatment communities. We represent millions of people suffering from eating disorders and their families, providers, researchers and advocates. We appreciate the opportunity to comment on the Essential Health Benefits Bulletin released by the Health and Human Services (HHS) on December 16, 2011.

The design of the Essential Health Benefits (EHB) will have a direct impact on the health of over 70 million Americans. As a central component of the Patient Protection and Affordable Care Act (ACA), the design and implementation of the EHB may have tremendous impact across our health care system. As such the EHB is an important opportunity to address the health needs of more than 11 million Americans suffering from eating disorders.

We were optimistic that with the passage of the ACA and the inclusion of mental health as a specific EHB category, the continued and widespread insurance discrimination experienced by people with eating disorders would come to an end. We ask you to capitalize on this moment in history and consider incorporating the following four recommendations so that people with eating disorders will finally have access to the life saving treatment they are often denied.

1. We ask the Secretary to replace the sizeable flexibility given to the states with national uniform standards for the EHB categories.

We continue to believe that a comprehensive federal EHB with the flexibility for States to go above and beyond national uniform standards is the optimal approach. When Congress passed the ACA and created the EHB they intended to create a *uniform* minimum benefit standard that would apply to all States in order to correct existing disparities. We applaud Congress for recognizing that mental illness and substance abuse are underserved health issues and therefore need to be part of a minimum benefit package. We ask that the Secretary protect this intent by explicitly defining the mental health benefit including eating disorders treatment.

People with eating disorders experience discrimination in accessing proper treatment and this is a serious obstacle to recovery. That was a prevailing message of more than 200 people who wrote to you during the last open comment period. People from across the country urged HHS to hear and address the challenges they are facing daily in accessing life saving care. Their experience is not unique. According to a 2003 epidemiological study of more than 2000 women, only 1 in 4

white women and 1 in 20 black women who had a diagnosable eating disorder ever received any treatment for their eating disorder.

Providing national standards that include the treatment of eating disorders would guarantee uniformity across states. Unfortunately the federal parity law is not necessarily improving access to care for people with eating disorders since the law did not require insurers to cover any specific mental illness and many people with eating disorders are being denied coverage. When left to the states, the options for eating disorders treatment are highly variable meaning that people receive care (or not) based on where they live. A state such as Rhode Island with a comprehensive state parity law requires insurance companies to provide eating disorder treatment so that individuals in that state have options for care. Contrast this with states like Wyoming and Arkansas that have no parity law and no eating disorder treatment available within the state, yet based on national prevalence data, these two states alone likely have over 75,000 individuals with eating disorders within their borders.

Consequences of not receiving necessary health insurance coverage include financial ruin for families paying out of pocket, a lack of life saving care, which leads to the worsening of symptoms and in some cases death. Anorexia has the highest mortality rate of all mental illnesses, upwards of 20%. Individuals with anorexia nervosa are 11 times more likely to die than their peers and they are 57 times more likely to die of suicide. Mortality rates are also higher for people with bulimia nervosa (3.9%), and eating disorder not otherwise specified (5.2%).

States differ widely on their support for the ACA, which in turn influences their commitment to effectively implement and enforce the law. In the absence of a uniform standard, we believe there is a significant risk that eating disorders will continue to be inadequately covered in many States. We urge HHS to offer concrete language defining the EHB for mental health that requires the coverage of eating disorders.

2. We ask the Secretary to offer a federal definition of medical necessity that is broad and inclusive.

The degree to which Americans enjoy full access to covered services within the ten EHB categories will depend, to a large degree, on the medical necessity standards that plans use to determine whether a service within these categories is covered.

Few regulations address the definition of medical necessity: there is no federal definition, and only about one-third of states have any regulatory standards for medical necessity. Consequently, the definition of “medical necessity” is most commonly found in individual insurance contracts that are defined by the insurer. *As a result, the standard of medical necessity is most often controlled by the insurer, not the treating professional.*

This has dire consequences for people suffering from eating disorders who are often discharged from treatment or denied treatment based on erroneous and shifting definitions of medical necessity, per insurers. After a year of pushing her insurance company to authorize proper treatment for her bulimia and anorexia Kari Lynn DeVries was given nine days of partial

hospitalization at a facility that did not specialize in eating disorders. Despite losing weight while in treatment and having suicidal ideations upon discharge, when her case was reviewed on May 3, 2005, the insurance company determined that she "did not meet medical necessity criteria for further treatment". Kari died in her sleep on May 20, 2005. Her autopsy indicated that Kari had been in potentially reversible heart failure and died from "normal complications of anorexia".

Unfortunately this experience is not simply an anomaly. A survey of 109 eating disorder specialists around the country, representing most inpatient eating disorders program in the United States found that nearly all specialists (96.7%) believe their patients with anorexia nervosa are put in life threatening situations because of early discharge mandated by health insurance companies refusing to cover treatment; And one in five specialists believe that insurance company policies are indirectly responsible for the death of at least one of their patients.

Most people with eating disorders who try to use their insurance benefits towards treatment get only a small percentage of the care that is optimally needed in order to recover. The result is a "revolving door" patient who repeatedly needs treatment, because they don't get the proper amount of treatment upfront. One study found that readmissions of patients with eating disorders between 1985 and 1998 increased steadily as length of stay became briefer. Research also shows that people with long term appropriate care including more days of treatment are more likely to recover.

In the summer of 2011 an insurer in North Carolina justified the discharge of a patient from treatment though she had reached only 65% of her ideal body weight. Their rationale was that inpatient treatment was not "medically necessary" according to their guidelines. Yet this is significantly lower than that recommended by the well-respected American Psychiatric Association (APA) Guidelines for the Treatment of Eating Disorders. These guidelines are based on clinical expertise and used by mental health professionals across the United States to assist in determining the best treatment approach for the patient's circumstances. Although these guidelines are widely accepted as defining the appropriate standard of care, insurance companies rarely use them. Instead insurers use arbitrary and non-transparent guidelines that allow them to limit and withhold treatment.

We urge HHS to offer a federal definition of medical necessity that 1) is broad enough to include all clinically necessary levels of care for eating disorders and 2) requires insurers to use well respected, clinically proven or evidence based criteria for the effective treatment of mental illness.

3. We ask the Secretary to ensure that health insurance plans do not discriminate on the basis of sex in the implementation of the essential health benefits.

We would like to underscore and build upon the point made by the National Women's Law Center that Section 1557 of the ACA prohibits discrimination on the basis of race, color, national origin, sex, age and disability in health programs. Given that eating disorders disproportionately affect girls and women, health insurance limitations disproportionately impact females. Recent national prevalence estimates indicate that three times as many women as men are affected by

anorexia nervosa and bulimia nervosa. Twice as many women as men are affected by binge eating disorder.

Insurance companies have routinely denied women coverage of vital health services including contraception, maternity care, and a range of treatment for substance abuse and mental health disorders, including treatment for eating disorders. The EHB package is the major tool in the ACA that is intended to correct these coverage gaps. It is necessary that the EHB package be sufficiently comprehensive if women are to have access to the full range of health care services they need.

We urge HHS to correct this sex discrimination against people suffering from eating disorders and ensure that eating disorders treatment is included in the essential health benefit package derived from a state's proposed benchmark plan.

4. We ask the Secretary to limit any further flexibility to the benefit design and eliminate any disease specific exclusions.

The Bulletin explains that HHS is considering permitting substitutions across benefit categories as well as within them. We are concerned that any further flexibility could result in eating disorders being specifically excluded as part of the mental health benefit.

Exclusion of eating disorders is all too common on the part of insurers seeking to limit interventions deemed non-essential. Despite being biologically based mental illnesses with potentially severe physical health ramifications, including death, eating disorders are all too often found on lists of benefit exclusions. One plan denied eating disorders treatment along with interventions such as therapeutic recreational camping, treatment for caffeine-related disorders, and elective cosmetic surgery. The Secretary must end this discrimination against individuals with eating disorders and ensure that eating disorders are not excluded from the mental health EHB.

Thank you for considering incorporating these recommendations so that people with eating disorders have access to more life saving treatment they are often denied. We look forward to a proposed regulation that further specifies the Secretary's approach for implementing the EHB.

Sincerely,

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