EDC
EATING DISORDERS COALITION
FOR RESEARCH, POLICY & ACTION

September 7, 2016

The Honorable Fred Upton
Chairman
House Energy & Commerce Committee
2183 Rayburn House Office Bldg.
Washington, DC 20515

The Honorable Frank Pallone
Ranking Member
House Energy & Commerce Committee
237 Cannon House Office Bldg.
Washington, DC 20515

The Honorable Joseph Pitts
Chairman
House Energy & Commerce Committee, Health Subcommittee
420 Cannon House Office Bldg.
Washington, DC 20515

The Honorable Gene Green
Ranking Member
House Energy & Commerce Committee, Health Subcommittee
2470 Rayburn House Office Bldg.
Washington, DC 20515

Dear Chairman Upton, Subcommittee Chair Pitts, Ranking Member Pallone, and Subcommittee Ranking Member Green:

On behalf of the Eating Disorders Coalition for Research, Policy, and Action, we want to thank you for holding a hearing examining Federal Mental Health Parity Laws and Regulations, as well as for your support of the Helping Families in Mental Health Crisis Act of 2016 (H.R. 2646), which includes provisions from the Anna Westin Act of 2015 (H.R. 2515) intended to clarify the availability of eating disorder benefits, including residential treatment (Section 808), in our nation's parity laws. The Eating Disorders Coalition is a Washington, DC-based nonprofit organization comprised of eating disorder treatment providers, advocacy organizations, and patient advocates across the nation, devoted to improving federal policies to help better the lives of people experiencing eating disorders.

Eating disorders are classified as mental disorders in standard medical manuals including the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5), and include specific disorders such as anorexia nervosa, bulimia nervosa, and binge-eating disorder.

Eating disorders affect the lives of over 30 million Americans during their lifetimes and are among the most lethal of all psychiatric illnesses. Despite the high prevalence and severity of these mental disorders, persons with eating disorders frequently face remarkable barriers in pursuit of life-saving treatment. These vulnerable citizens are too often the victims of imprudent treatment denials by health insurance companies—casualties of payors' violations of the Paul Wellstone and Pete Domenici Federal Mental Health Parity and Addictions Equity Act of 2008 (Parity Act). Many people—be they adults or children—are affected by Parity Act noncompliance. with mental illness and/or addictions. The Act requires fairness—or, as its name implies, parity—between mental health and substance use benefits on the one hand and medical/surgical benefits on the other. The Parity Act was a groundbreaking piece of legislation aimed at ending ongoing discriminatory practices by insurance companies against those suffering from eating disorders, as well as all mental health issues.

We encourage the Energy and Commerce Committee to look into noncompliance issues related to medical necessity, chronicity, and transparency from health insurance plans on top of other related noncompliance issues. Below provides some detailed information on the specific concerns within these topic areas as it relates to eating disorders:

A. Medical Necessity

The place providers run into the most trouble is the accessibility of the medical necessity standards that insurance companies use. Difficulties arise when providers and reviewers disagree on interpretation of medical necessity. What occurs is that the providers will be working in-person with the consumer and their family and the provider believes it is the best interest of a consumer to receive a particular level of care. However, upon discussion with the health plan reviewer, who has never met or interacted with the consumer and their family, the reviewer believes it is in the best interest of the consumer to not receive that level of care. While this doesn't always happen, it is particularly distressing when it does. The provider is then left to tell the consumer and family, "We believe you need this level of care, yet your insurance company disagrees and will not authorize the care. You can choose to have your loved one in this level of care at your own expense."

Medical necessity criteria used by insurance companies are often only available online and are often difficult to locate. When providers ask some insurance company representatives to explain the criteria, they are often unable or unwilling to do so. Enrollers can try to access the criteria online, but the criteria are

confusing and often impossible to meet. Denial letters are confusing and are not tied to the standard of care in the community or insurance company criteria.

B. Chronicity

Some insurance companies speak often about "chronic" eating disorders, despite the fact that there is no standard in the field of eating disorders that defines "chronic". There is no agreed upon definition and no treatment guidelines that say that providers should definitively treat those with an eating disorder for a long time period differently than those with a short time of illness. In this way, there are some insurance companies that are essentially creating a requirement to determine something that cannot be determined.

Anecdotally, our provider Members have had clients who have been told at the age of 17, after having anorexia for under 2 years, that they are "chronic" and treatment should focus on helping them adapt to this chronic illness and facilitate return to "baseline level of functioning" at this “chronic” place rather than providing coverage for treatment that would support and facilitate full recovery, which we know to be possible.

C. Transparency

A frustrating element for treatment providers, consumers and their families is the limited information health plans and insurance companies provide to providers and consumers when coverage for their eating disorders benefit is denied. Oftentimes the information is so limited that both the provider and consumer are not able to determine the exact reason that a benefit was denied- i.e. medical necessity.

Denial letters are confusing and are not tied to the American Psychiatric Association Guideline for the Treatment of Eating Disorders, which is the standard of care in the industry. Even when insurers use their own guidelines, they often do not cite to those guidelines in the denial letters. Often insurers use template denial sentences which are not individualized to the patient’s condition. Insurers often do not accurately reflect the information provided by the treating experts, and sometimes do not even consult with the experts before making life and death decisions about treatment.

Recently, a large insurer in Iowa provided written authorization to families for treatment at the residential level of care. After the family member finished their treatment, families got letters stating that the care was not authorized and would not be paid for. Denial letters included reasons for denial as lack of medical

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necessity, despite prior authorization based on medical necessity, and incomplete documentation, despite thorough documentation submitted to the company. Families are left with enormous bills that they believed would be covered by their insurance company.

In conclusion, we applaud the Energy and Commerce Health Subcommittee for opening this dialogue on mental health parity, and going forward, the Eating Disorders Coalition would love to continue this dialogue and work with you to better help the coverage provided by Federal mental health parity, particularly as it pertains to eating disorders. We welcome the opportunity to provide further insight on noncompliance for people with eating disorders as you continue this dialogue.

Sincerely,

Katrina Velasquez, Esq.
Policy Director
Eating Disorders Coalition