NATIONAL EATING DISORDERS ASSOCIATION COMMENTS FOR THE RECORD IN RESPONSE TO DEPARTMENT OF LABOR FAQS ABOUT MENTAL HEALTH AND SUBSTANCE USE DISORDER PARITY IMPLEMENTATION AND THE 21ST CENTURY CURES ACT PART 38

The National Eating Disorders Association wishes to be recorded in strong support of improving mental health parity benefits for eating disorders. As the leading organization dedicated to supporting individuals and families affected by eating disorders, we hear stories every day from people who are unable to receive treatment because their insurance companies deny their claims or cut off coverage prematurely, despite recommendations from their doctors. Eating disorders have the highest mortality rate of any mental illness and they can wreak havoc on all systems in the body. In addition to the severe psychological impacts of eating disorders, the physical side effects can include kidney damage, heart failure, osteoporosis, and gastrointestinal rupture.

30 million Americans will struggle with an eating disorder at some point in their lives yet roughly only one in three will receive the treatment they deserve. Despite the common myth that they can be cured if a patient simply “eats normally,” eating disorders are chronic illnesses that require comprehensive, specialized treatment. Treatment options are limited in many parts of the country and largely out of reach due to financial constraints. Because of the lack of parity in coverage, many families are forced to pay out of pocket for treatment, which can cost upwards of $30,000/month. Too often we hear of families that have to mortgage their homes to pay for care.

Our National Eating Disorders Helpline receives tens of thousands of contacts each year and problems with insurance are one of the most common concerns we hear about. Gathered from conversations with our Helpline volunteers, these testimonials speak to the dire need for parity in insurance coverage:

“Michael has been in contact with us several times and he expressed a variety of concerns from treatment options, insurance issues, getting involved, and his own personal struggles within 40 years of dealing with an eating disorder. He said he currently is facing issues with his insurance and feels as if he has slipped through the cracks. He has been denied certain levels of treatment by his health care providers and feels as if he has not been getting the proper care...he hopes that this does not continue on for more decades and that he can recover.”

“The caller was very upset, crying and asking for help. She kept repeating ‘Are poor people supposed to die!’ She has had no luck in finding a treatment facility (residential or inpatient) that accepts Medicaid in Manhattan. Sliding scale wasn’t an option for her because she didn’t have income. She tried joining support groups because they were free, but didn’t find them helpful since she really needed proper treatment.”

“This frustrated caller reported that her insurance is saying that eating disorders are an exclusion of the plan her employer provides. The employer’s corporate benefits team told her that the only thing excluded is residential treatment, but programs like partial hospitalization programs, intensive outpatient, and outpatient should be covered. She told this to the insurance company, but they are still denying it and saying any eating disorder treatment is excluded regardless. I’m really not sure how to proceed.”

Recommendation: Eating disorders are real, complex, and devastating conditions that can have serious consequences for health, productivity, and relationships. The earlier a person with an eating disorder begins treatment, the greater the likelihood of physical and emotional recovery. On behalf of families and individuals across the nation affected by eating disorders, we urge you to improve enforcement of these parity regulations to ensure that all individuals struggling with an eating disorder have access to the care that they need and deserve.

Sincerely,

Claire Mysko, CEO
National Eating Disorders Association