June 22, 2018

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Office of Regulations and Interpretations, Room N-5655
Employee Benefits Security Administration
Department of Labor
200 Constitution Avenue, NW
Washington, DC 20210

Department of Health and Human Services
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Department of Treasury
111 Constitution Avenue, Northwest
Washington, DC 20224

Submitted electronically to: E-OHPSCA-FAQ39@dol.gov

RE: Eating Disorders Coalition Comments on Proposed FAQs Part 39, Self-Compliance Toolkit, and Request for Information/Model Disclosure Form in Response to April 23, 2018 Release

Dear Director Turner, Director Verma, and Acting Commissioner Kautter,

On behalf of The Center for Eating Disorders at Sheppard Pratt, please accept the written comments below on the mental health parity Proposed FAQs Part 39, self-compliance toolkit, and model disclosure form in response to the April 23, 2018 release. We are a 34-bed inpatient eating disorders treatment center in Baltimore, Maryland with additional partial hospital programs, an intensive outpatient program as well as a specialized child and adolescent program and comprehensive outpatient services. Our program stands as one of the largest and most respected eating disorder programs in an acute freestanding psychiatric setting in the United States and has been in existence since 1989. As part of Sheppard Pratt Health System, the largest provider of behavioral health services in our state, we work to offer the highest quality treatment available for all types of eating disorders and co-occurring physical and mental illness. Our multi-disciplinary staff of more than 150 licensed treatment professionals is committed to the provision of evidence-based care for individuals of all ages and genders as well as their families throughout the many stages of the recovery process.
Eating disorders are complex, biologically-based serious mental illnesses, having the highest mortality rate of any psychiatric illness—with one person losing their life every 62 minutes as a direct result of an eating disorder.\(^1\) Over 30 million Americans experience a clinically significant eating disorder during their lifetime\(^2\), affecting individuals of all ages, races, genders, ethnicities, socioeconomic backgrounds, body sizes, and sexual orientations.\(^3\) Under the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders: DSM-5, eating disorders include the specific disorders of anorexia nervosa, bulimia nervosa, binge eating disorder, avoidant/restrictive food intake disorder, and other specified feeding or eating disorders.\(^4\) These disorders are unique in that they co-occur and can lead to several mental health and medical complications. For example, half of people experiencing an eating disorder have a co-occurring substance abuse disorder.\(^5\) Additionally, eating disorders are associated with a range of medical complications including cardiac disability, starvation, hepatitis, refeeding syndrome, cognitive dysfunction, kidney failure, esophageal cancer, osteoporosis, fractures (hip, back, etc.), hypoglycemic seizures, amenorrhea, infertility, high and low blood pressure, Type II diabetes mellitus, edema (swelling), high cholesterol levels, gall bladder disease, decalcification of teeth, severe dehydration, chronically inflamed sore throat, and inflammation and possible rupture of the esophagus.\(^6\), \(^7\)

To end discrimination against individuals and families who seek services for the serious mental illness of eating disorders, we have advocated for the last two decades in support of mental health parity legislation and the enforcement of corresponding regulations. We are committed to helping this Administration effectively implement and enforce the Mental Health Parity and Addiction Equity Act (MHPAEA), and we submit the below comments and recommendations as outlined in the April 23, 2018 “FAQS About Mental Health and Substance Use Disorder Parity Implementation and the 21st Century Cures Act Part XX” and corresponding solicitation for comments.

I. Disclosure and Treatment for Eating Disorders, Including Request for Comments

Eating disorders are a serious mental illness that affects over 30 million Americans during their lifetime\(^8\), including people of all ages, races, sizes, sexual orientations, ethnicities, and socioeconomic statuses.\(^9\) These disorders have the highest mortality rate of any psychiatric illness.\(^10\)

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Eating disorders are complex, biologically-based illnesses including the specific disorders of anorexia nervosa, bulimia nervosa, binge-eating disorder, avoidant/restrictive food intake disorder, and other specified feeding or eating disorders (OSFED). 11 Eating disorders can be successfully treated with interventions at the appropriate durations and levels-of-care, however, only one-third of those with eating disorders receive any medical, psychiatric, and/or therapeutic care. 12 According to the American Psychiatric Association (APA): Practice Guidelines for the Treatment of Patients with Eating Disorders, the best practice for treating eating disorders includes patients, their families, and a comprehensive team of professionals such as social workers, mental health counselors, primary care practitioners, psychiatrists, psychologists, dietitians, and other specialty providers. 13 Successful treatment of eating disorders may include treatment at all evidence-based levels of care including inpatient, residential treatment, 14 partial hospitalization, day program, intensive outpatient program, and outpatient treatment. 15

Given the complexity of treatment throughout a patient’s recovery, access to all levels of treatment is critical for a successful recovery. It is important to emphasize that access to treatment is only as comprehensive as the coverage a payer provides. Treatment limitations, lack of disclosure from payers and narrow networks, all affect a patient’s ability to receive adequate care.

The Center for Eating Disorders at Sheppard Pratt remains committed to working with the Administration and its Agencies to enforce the Mental Health Parity and Addiction Equity Act (MHPAEA) and submit for your consideration the following comments and recommendations below to continue strengthening enforcement of mental health parity for people affected by eating disorders.

Sincerely,

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The Center for Eating Disorders at Sheppard Pratt

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Co-Director
The Center for Eating Disorders at Sheppard Pratt

II. Initial Analysis of Proposed FAQs and Related Documents

On April 23, 2018, the U.S. Department of Labor (DOL), U.S. Department of Health and Human Services (HHS), and the U.S. Department of Treasury (together, the Departments) released Proposed FAQs 39 and proposed guidance regarding nonquantitative treatment limitations and disclosure requirements in connection with the Mental Health Parity and Addiction Equity Act (MHPAEA). This proposed guidance is in response to the September 13, 2017 Proposed FAQ 38 comment submission.

As defined in the MHPAEA, financial requirements and treatment limitations imposed on mental health or substance use disorder (MH/SUD) benefits cannot be more restrictive than the financial requirements and treatment limitations applied to medical/surgical benefits. As it relates to nonquantitative treatment limitation (NQTL), the final MHPAEA regulations posit that a group health plan or health insurance issuer may not impose an NQTL on a MH/SUD benefit in any classification unless, under the terms of the plan are comparable to medical/surgical benefits in the same classification.

In the most recent release of the proposed guidance on April 23, 2018, The Center for Eating Disorders at Sheppard Pratt was pleased to see that eating disorders issues were addressed in the majority of the documents. However, we have strong concerns that the proposed changes may cause unintended consequences in coverage for the serious mental illness of eating disorders. In analyzing the proposal, we would like to provide commentary and recommendations for:

- Proposed FAQ Questions:
  - Q5: General exclusions for specific disease states
  - Q6: Fail-first policies
  - Q7: Provider Reimbursement Rates
  - Q10: Disclosure
- Self-Compliance Toolkit
- Model Disclosure Form

The EDC has also provided comment related to provider network adequacy and Freedom of Information Requests (FOIR).
III. Commentary & Recommendations to Proposed FAQs

A. FAQ 5: General Exclusions for disease specific items and services

*Issue:* As written, an exclusion of benefits (i.e. prescription drugs) for a condition or disorder is not considered a treatment limitation for the purposes of the definition of “treatment limitations” in the MHPAEA regulations. We have a particular concern regarding the generalizability of the language as written in Q5, in that this type of an exclusion is more of the exception than the rule. Particularly under the current framework, if a patient/provider sees this FAQ, they may automatically assume their condition/diagnosis is excluded and not attempt to appeal.

In the field when we see eating disorders covered, often the sub-group of eating disorders like binge-eating disorder are not covered, with payers often categorizing this disorder as “weight-loss” treatment. This practice represents current stigma and discrimination with some insurance policies, as you would not see the same types of calculated exclusion on the medical/surgical benefits side. In turn, it is critical that when eating disorders are covered under a plan, that the sub-categories of eating disorders including: anorexia nervosa, bulimia nervosa, binge-eating disorder, avoidant/restrictive food intake disorder, and other specified feeding or eating disorders (OSFED) are treated equally to mitigate potential loopholes from payers to deny coverage. Mis-categorizing a severe mental illness against industry standards of care is dangerous and leads to increased risk of medical complications and death.

We see countless examples each year where insurers have little understanding of the variations in eating disorder diagnoses and routinely deny services that should be covered. This requires significant unnecessary burden on providers and patients through the appeal process.

*Recommendation:* Current mental health parity regulations are unclear on whether an insurance provider can cover a type of mental illness (i.e. eating disorders) but exclude a sub-type of the disorder (i.e. binge-eating disorder). We recommend revising this general Q5 answer for the sake of patients and providers to provide clear guidance and show that a sub-disorder exclusion may not be permissible and provide a thorough explanation of some potential exclusions to give the general public a clearer understanding of the types of exclusions permissible.

Our suggested revised FAQ statement is as follows, with changes in bolded red as follows:

"Q5: My large group health plan or large group insurance coverage provides benefits for prescription drugs to treat both medical/surgical and MH/SUD conditions but contains a general exclusion for items and services to treat bipolar disorder, including prescription drugs. Is this permissible under MHPAEA?

Yes, although if the plan is insured, it would depend on whether State law permits such an exclusion for large group insurance coverage. Generally, MHPAEA requires that treatment limitations imposed on MH/SUD benefits cannot be more restrictive than treatment limitations that apply to medical and surgical benefits. An exclusion of all benefits for a particular condition or disorder, however, is not a treatment limitation for purposes of the definition of “treatment limitations” in the MHPAEA regulations. Small employer group health insurance coverage and individual health insurance coverage are subject to the requirement to provide essential health benefits, and the determination of whether certain benefits must be covered under the requirements for essential health benefits depends on the benefits in the applicable State’s EHB benchmark plan. **However, MH/SUD is an essential health benefit under these plans, and unless the plan can demonstrate that evidentiary standards or other factors were utilized comparably to develop and apply a**
sub-category exclusion for a mental illness as they would for a medical/surgical sub-category exclusion, this practice would not be compliant with the MHPAEA.”

B. FAQ 6: Fail-First Policies

Issue: The eating disorders community is fraught with stories of fail-first policies, which require an eating disorder patient to fail at a lower level of care before a higher level of care will be authorized. Although prohibited under the MHPAEA, it remains unclear whether the onus to appeal lies with the insurance plan, the provider, or the patient. Given the lack of disclosure from many insurance plans, proving a non-compliant fail-first policy is extremely difficult for a patient/provider or if the patient/provider has the means, their attorney.

We have had multiple cases where, despite a patient being significantly and morbidly ill, insurers will routinely deny care stating that the patient has “not had an appropriate trial of outpatient treatment”. This may occur even when it is not medically safe for the patient to be treated on an outpatient basis. Often in the appeal process, reviewers will still not authorize care to patients meeting appropriate criteria for higher levels of care. This creates a risk to patients and a burden to providers.

Recommendation:

1. Although the FAQs state that a fail-first policy is an example of an NQTL and “regulations require that the processes, strategies, evidentiary standards, or other factors used in applying an NQTL to MH/SUD benefits must be comparable to and applied no more stringently than medical/surgical benefits”, the statement fails to address how unlikely it is that an insurance plan that engages in these practices can be MHPAEA compliant. We recommend providing clarifying language to demonstrate the difficulty of a fail-first policy being compliant to encourage patients to advocate for their rights under MHPAEA.

2. Additionally, given the disclosure issues that remain in the insurance industry, we recommend clarifying that the burden of proof lies with the insurer to prove that there was or was not a fail-first policy within the corresponding medical/surgical side and within a timely manner.

Our suggested revised FAQ statement is as follows, with changes in bolded red as follows:

"Q6: My health plan requires step therapy for both medical/surgical and MH/SUD inpatient, in-network benefits. The plan requires a participant to have two unsuccessful attempts at outpatient treatment in the past 12 months to be eligible for certain inpatient in-network SUD benefits. However, the plan only requires one unsuccessful attempt at outpatient treatment in the past 12 months to be eligible for inpatient, in-network medical/surgical benefits. Is this permissible under MHPAEA?

Probably not. Refusing to pay for a higher-cost therapy until it is shown that a lower-cost therapy is not effective (commonly known as “step therapy protocols” or “fail-first policies”) is an NQTL. The Departments’ regulations require that the processes, strategies, evidentiary standards, or other factors used in applying an NQTL to MH/SUD benefits must be comparable to and applied no more stringently than the processes, strategies, evidentiary standards, or other factors used in applying the NQTL to treat medical/surgical conditions. Although the same NQTL – step therapy – is applied to both MH/SUD benefits and medical/surgical benefits for eligibility for inpatient, in-network services, the requirement for two attempts at outpatient treatment to be eligible for inpatient, in-network SUD benefits is more stringent application of the NQTL than the requirement for one attempt at outpatient treatment to be eligible for inpatient, in-network medical/surgical benefits. Unless the plan can demonstrate that evidentiary standards or other factors were utilized
comparably to develop and apply the differing step therapy requirements for these MH/SUD and medical/surgical benefits, which has traditionally been uncommon for a plan to demonstrate, this NQTL does not comply with MHPAEA. The Departments place the burden of proof on the insurance plan to demonstrate that the evidentiary standards or other factors were utilized comparably to develop and apply the differing step therapy or fail-first policies for MH/SUD and medical/surgical benefits."

C. FAQ 7: Provider Reimbursement Rates

Issue: As FAQ 7 notes, while a plan is not required to pay identical provider reimbursement rates for medical/surgical and MH/SUD providers, a plan’s standards for admitting a provider to participate in a network (including the plan’s reimbursement rates for providers) is an NQTL. A plan may impose an NQTL if under the terms of the plan as written and in operation, the processes, strategies, evidentiary standards, and other factors considered by the plan in implementing its NQTL with respect to MH/SUD services are comparable to and applied no more stringently than those used in applying the NQTL with respect to medical/surgical benefits in the same classification. While this statement does prove to be helpful, the statement within the FAQ is too narrow to encompass the larger problem of provider network adequacy.

Given the current structure of reimbursement, MH/SUD providers are disincentivized to join networks that have low reimbursement rates. This has the effect of smaller or less adequate MH/SUD provider networks within plans, which leave patients with few options to access care.

Several insurers in our region are insisting that certain patients be hospitalized at specific programs that they have developed contracts with, sometimes far from the patient’s home. This is despite the local availability of excellent eating disorder treatment. This creates a hurdle for the patient and the family and often is an impediment to good clinical care.

Recommendation: To address the issue of limited provider networks for MH/SUD, we recommend providing additional guidance on what happens if a network is not broad enough to provide MH/SUD treatment at various levels of care for a specific disorder. For example, providing an additional FAQ on when a plan does not have enough in-network providers to cover all the levels of care for eating disorders (i.e. inpatient, RTC, PHP, IOP, outpatient), that the plan will trigger in-network coverage for out-of-network providers at no additional cost to the patient.

D. FAQ 10: Disclosure

Issue: The MHPAEA Final Rules state that when your processes, strategies, and evidentiary standards are not the same on the medical/surgical side as the MH/SUD side, these standards are noncompliant. In practice, the utilization review process between the medical/surgical side and MH/SUD side are often very different given the complexity of treating MH/SUD and difference in disclosure. Often there will be no utilization review or minimal utilization review on the medical/surgical side, while having an extensive required review on the MH/SUD. Additionally, utilization review is often used on the MH/SUD side versus the medical/surgical due to a lack of disclosure of Medical Guidelines for MH/SUD in comparison to medical/surgical. For example, some Medical Guidelines are very clear that certain illnesses/treatments are not covered, like bone marrow cancer and drills down into specifics. However, the MH/SUD guidelines are not disclosed or available to providers.

In our program, we have seen many patients who meet reasonable criteria for higher levels of eating disorder treatment denied care under the pretense that they do not meet the medical eligibility criteria of the insurer.

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16 29 CFR §2590.712 (c)(4); 45 CFR §146.136 (c)(4); 26 CFR §54.9812–1 (c)(4)
In some cases, insurers are reticent to share their criteria, and sometimes when they do, they have set up vague criteria that fosters denial of medically necessary care. In other cases, even if initial authorization is provided, continued length of stay criteria are similarly vague and limit critical time for patients to make adequate changes and achieve medical stability. This frequently establishes a risk for relapse and a revolving door readmission pattern that significant increases amount of treatment, lifetime costs and fosters a sense of hopelessness in the patient.

**Recommendation:** While there is currently an ERISA regulation stating that an insurance plan may offer Medical Guidelines upon request,\(^\text{17}\) in practice it has become an empty offer as insurers do not willingly disclose this information claiming it is proprietary. We recommend providing additional guidance, requiring that medical guidelines and medical necessity criteria be automatically provided to providers and patients’ agents upon request within 7 business days.

Additionally, we applaud the Department of Labor’s 1,515 investigations of mental health parity non-compliance, resulting in 171 cited cases of non-compliance between October 2010 to October 2016.\(^\text{18}\) However, being on the ground with consumers, providers, and representatives, we know that there are at minimum 171 instances of non-compliance for eating disorders parity every year. Currently, one of the largest barriers is that consumers do not know their rights under current law, and there are limited outlets to help hold plans accountable. We encourage the further enactment of a consumer protection portal that can be used by patients, providers, and representatives to submit mental health parity non-compliance complaints. The 2016 BETA tested version was a good start; however, we encourage the enactment of an enforcement mechanism like the Consumer Financial Protection Bureau, as well as public service announcements to help consumers understand their rights under mental health parity.

### E. Further Recommendations for Consideration and Integration

- **Freedom of Information Requests (FOIR) Availability for Pending MHAPEA Investigations**
  - **Issue:** Over the years it has become increasingly difficult to receive FOIR requests for pending MHPAEA non-compliance investigations, as these investigations often taken years before resolution is reached. Understandably, the details of these investigations would need to remain confidential; however, the basic information regarding the plan involved and non-compliance complaint submitted would provide a great benefit to patient’s choice in determining which plan to select for MH/SUD benefits and other pending appeals claims.

  - **Recommendation:** We recommend increased cooperation from DOL/HHS in sharing information related to MHPAEA non-compliance investigations (even before the case is resolved) to help providers, attorneys, and patients better determine common issues arising from mental parity enforcement and selecting future plans will benefit all. Redacted information could mean the difference of coverage or non-coverage of MH/SUD benefits for many patients as the details of plans and medical necessity are often not easily disclosed by plans.

- **Enhanced Federal Agency Guidance on Standards of Care**
  - **Issue:** It is difficult for payers to stay up-to-date on evidence-based quality standards and accreditation/certification requirements for complex diseases such as eating disorders.

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\(^\text{17}\) 29 CFR § 2560.03-1(g)(1)(v)(A)

• **Recommendation:** We encourage the Departments to provide further guidance on current evidence-based industry standards of care and certification/accreditation standards for treating eating disorders to ensure insurers are current in the science and relevant certification. The detrimental effects of this lack of guidance can be seen for dietitian visits for nutrition counseling for a patient’s eating disorder diagnosis. The medical/surgical side often rejects the claim, stating it is the responsibility of the MH/SUD benefit side. However, the MH/SUD side rejects the claim stating coverage is only for “mental health professionals”, usually meaning psychiatrists, psychologists, licensed counselors, social workers, and nurse practitioners. However, industry standards include nutrition counseling within the successful treatment of eating disorders. In a study conducted by The International Federation of Eating Disorder Dietitians (IFEDD), 30% of patients with eating disorders said their nutrition counseling claims were denied (J. Setnick, personal communication, May 31, 2018), underscoring the critical need for federal agency guidance on standards of care.

The APA Clinical Practice Guidelines for Patients with Eating Disorders have published practice guidelines that support the multidisciplinary treatment model (therapy, nutrition, medical and psychiatric personnel, plus others) as a best practice approach to treating these illnesses. Specifically, we recommend providing specific accreditation guidance for The Joint Commission (TJC) and Commission on Accreditation of Rehabilitation Facilities (CARF) within your recommendations as well as industry standards of care, which includes guidance on evidence-based quality standards.

• **Pre-authorization Guidance**
  
  o **Issue:** As the number of specialized eating disorders treatment centers providing intermediate levels of care are limited in the U.S., it is not uncommon for patients to travel long distances (sometimes flying across the country) to receive in-person pre-authorization. This practice creates a huge financial burden on patients and families and is a direct violation of mental health parity.

  o **Recommendation:** We recommend providing guidance on pre-authorization examinations for eating disorders to be permitted by the local provider, or for self-refer patients, allow examinations to occur telephonically or virtually by the specialty provider.

• **Insurance Reviewer Education**
  
  o **Issue:** Some insurance companies only require its utilization review doctor to be “board certified”, have five years of practice in the last ten years, and have an unrestricted and active license in one state. Reviewers can have a general behavioral health background, but there is no requirement that they have experience or knowledge about the treatment of eating disorders. The question in turn remains on how a utilization reviewer can provide a non-biased basis for the industry standard of care, if they were never trained in the industry standard of care?

  We have repeatedly been confronted with trying to justify medically necessary care to reviewers who have little experience with the treatment of eating disorders, and limited understanding of the basic principles of eating disorder care.
o **Recommendation:** We strongly recommend providing guidance that insurance reviewers receive some type of continuing education for the diseases/disorder areas in which they’re reviewing. The education should be evidence-based and utilize industry standards of care for medical practice for the disease/disorder.

- **Expedited resolutions for Parity Challenges.**
  o **Issue:** Patients are at a strict disadvantage when they challenge plans’ parity compliance, as the patient must make the decision to continue with the doctor-recommended treatment, which could lead to high out-of-pocket costs if they lose the challenge. In turn, it often takes patients years before they are ever reimbursed for the parity non-compliance, when it was the plan that was in violation. The high cost of escalating a parity non-compliance case often leads patients to not challenge denials and/or not receive treatment they need.

  o **Recommendation:** We recommend creating a new policy that if a parity challenge to a plan with a specific limitation violates parity, the insurance company should have to pay for the treatment while the appeal is pending. In turn, this process should be expedited so that both parties do not have to wait to go through the timely and costly ERISA litigation.

IV. **Self-Compliance Toolkit Improvements**

  o **Issue:** As it is now designed, the self-compliance toolkit would be beneficial for plans to help with compliance, however, would likely not be helpful to providers or patients in determining if their plan is MHPAEA compliant.

  o **Recommendation:** We recommend either creating a compliance toolkit for providers/consumers or removing the legalese, so it can be readily utilized for a variety of stakeholders—patients, families, providers, etc. Alternatively, creating separate self-compliance toolkits for different stakeholder groups would be another option to ensure the toolkit can be used by as many individuals as possible. Separate toolkits could be most effective as different stakeholder groups will have different concerns and questions regarding parity. For example, many patients are told by insurers they’re not required to provide information regarding their plan exclusions as it is proprietary information and/or has commercial value. However, MHPAEA prohibits insurers from claiming this rationale for withholding information from patients and would be a critical piece of information to highlight in the toolkit.

V. **Request for Information/Model Disclosure Form**

  o **Issue:** Overall, the model disclosure form is found to be very helpful. The only concern we have is that the guidance found in the Proposed FAQ 39 may not be viewed by all stakeholders if the model disclosure form and information on the Proposed FAQ 39 remain separate.

  o **Recommendation:** We recommend putting the disclosure form into the FAQ and the FAQ information into the form. Many patients and families will not know how to look for the model disclosure form and embedding it within the FAQs will help mitigate some of that oversight. We encourage the Departments to not make any further substantive edits to the
disclosure form at the risk of watering down its substance.

VI. Conclusion

Access and parity to comprehensive MH/SUD treatment is of critical importance to the work we do at The Center for Eating Disorders at Sheppard Pratt. We are pleased at the progress that has been made with the inclusion of eating disorders in many of the documents but know that further improvements can be made to strengthen the enforcement of the MHPAEA and the promise it holds for so many patients and providers.

We thank the Departments for the opportunity to provide feedback and recommendations on this important issue. We look forward to reviewing the revisions and continuing to work together to improve the access and parity to health care for all Americans.