The Emily Program

Real help for eating disorders

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

June 22, 2018

Department of Health and Human Services
Room 445-G, Hubert Humphrey Building
200 Independence Avenue, SW
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Internal Revenue Service
Department of Treasury
1111 Constitution Avenue, Northwest
Washington, DC 20224

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

RE: The Emily Program 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 Emily Program, 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 multistate eating disorders treatment center with facilities including Como, St. Paul, MN; Toogood, St. Paul, MN; Anna Westin House Adult, St. Paul, MN; Anna Westin House Adolescent and Young Adult, St. Paul MN; St. Louis Park, MN; Woodbury, MN; Duluth, MN; Cleveland, OH; Cleveland Residential, Cleveland, OH; Pittsburgh, PA; Seattle, WA; Seattle Residential, Seattle, WA; Spokane WA, and South Sound, WA.. The Emily Program is a specialty eating disorder treatment program, providing comprehensive, community-based, patient centered specialized care for eating disorders through evidence-based treatments and a multidisciplinary approach.

Our treatment centers are in the business of treating people affected by the serious mental illness of eating disorders and co-occurring conditions associated with the disorder, including substance use disorder. 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

[1] Swanson, S., Crow, S., Le Grange, D., Swendsen, J., Merikangas, K. Prevalence and Correlates of Eating Disorders in Adolescents: Results from the National Comorbidity Survey Replication Adolescent Supplement. Arch Gen Psychiatry 2011; 68:714-23.

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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 use 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]

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

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[2] Hudson, J. I., Hiripi, E., Pope, H. G., & Kessler, R. C. (2007). The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. *Biological Psychiatry*, 61(3), 348-358.
[3] Le Grange, D., Swanson, S. A., Crow, S. J., & Merikangas, K. R. (2012). Eating disorder not otherwise specified presentation in the US population. *International Journal of Eating Disorders*, 45(5), 711-718.
[4] American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5.* Washington, D.C: American Psychiatric Association.
[5] National Center on Addiction and Substance Abuse at Columbia University. (2003). *Food for thought: substance abuse and eating disorders* http://www.centeronaddiction.org/addiction-research/reports/food-thought-substance-abuse-and-eating-disorders
[6] Westmoreland, P., Krantz, M. J., & Mehler, P. S. (2016). Medical complications of anorexia nervosa and bulimia. *Am J Med*, 129(1), 30–37.
[7] Thornton, L. M., Watson, H. J., Jangmo, A., Welch, E., Wiklund, C., von Hausswolff-Juhlin, Y., . . . Bulik, C. M. (2017). Binge-eating disorder in the Swedish national registers: somatic comorbidity. *Int J Eat Disord*, 50(1), 58-65.
[8] Hudson, J. I., Hiripi, E., Pope, H. G., & Kessler, R. C. (2007). The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. Biological Psychiatry, 61(3), 348-358.
[9] Le Grange, D., Swanson, S. A., Crow, S. J., & Merikangas, K. R. (2012). Eating disorder not otherwise specified presentation in the US population. International Journal of Eating Disorders, 45(5), 711-718.
[10] Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies. Archives of General Psychiatry, 68(7), 724-731.
[11] American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders: DSM-5. Washington, D.C: American Psychiatric Association.

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, narrow networks, and limited guidance on what constitutes inpatient treatment versus outpatient treatment all affect a patient's ability to receive adequate care.

The Emily Program 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.

D. Miller

Dirk Miller, PhD

Founder and Executive Chairman

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[12] American Psychiatric Association. (2006). Practice guideline for the treatment of patients with eating disorders (3rd ed). Washington, DC: American Psychiatric Association.

[13] American Psychiatric Association. (2006). Practice guideline for the treatment of patients with eating disorders (3rd ed). Washington, DC: American Psychiatric Association.

[14] Brewerton, T. D. & Costin, C. (2011). Treatment results of anorexia nervosa and bulimia nervosa in a residential treatment program. Eating Disorders, 19(2), 117-131.

[15] Koman, S. (n.d). A "continuum of care" approach to eating disorders. Walden Behavioral Care. Retrieved from: http://www.waldenbehavioralcare.com/pdfs/ContinuumOfCare.pdf.

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 Emily Program 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
    - Q9: Eating disorders and residential treatment centers
    - 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 categorize 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.

In some plans, treatments for Binge Eating Disorder, when it is a primary diagnosis, are specifically excluded. Binge eating disorder might be covered, if there is another mental health diagnosis, such as anxiety or depression, but not if binge eating disorder is considered primary – or the presenting problem. While some plans make exceptions in some of the states in which we operate, specifically Minnesota, such exceptions as the example below, specifically excluding binge eating disorder, preclude people from getting care for a mental health condition with high physical health co-morbidities. https://www.providerexpress.com/content/dam/opeprovexpr/us/pdfs/clinResourcesMain/guidelines/cdg/bingeEating.pdf. It is difficult to explain to a patient why the problem they came in to get treatment for isn't a significant enough problem to be covered by their insurance, but one they might have, but didn't come in to get treatment for could be.

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.

An example of the damage that fail-first policies have on patients can be seen in Seattle where a young woman was seeking residential treatment. Her insurance carrier, Kaiser Permanente, required her to go into a partial hospitalization program (PHP) before residential treatment would be considered as an option for authorization. She went into PHP but did poorly and felt like she was not able to progress. As a result, she left treatment entirely and the severity of her disorder heightened.

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 a 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.

For example, in some markets in which we operate, narrow networks present challenges to patients when trying to access care. Eating disorder providers try to become in-network, only to be told that the network is full – yet patients trying to access the providers in the network are told by those providers that they are full or no longer accepting the reimbursement of that network because the rates are untenable. New providers can not join these "full" networks, patients cannot access adequate care, and providers that try to stay in-network end up having to load balance the work they do with those networks to stay in business.

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 9: Eating Disorders and Residential Treatment-* ***Of Highest Concern***

Support: We are supportive of the current FAQ 9 as it relates to analyzing an exclusion of eating disorders residential treatment, and the Departments clarification that eating disorders are mental health benefits. We applaud for Departments for taking these clarifying steps.

Issue: The current language of FAQ 9 reads to potentially permit plans to cover residential treatment for eating disorders as either an inpatient in-network, inpatient out-of-network, outpatient in-network or outpatient out-of-network benefit within the six classifications of benefits under the MHPAEA. This multiple classification continues to be a point of confusion for insurers, providers, and patients alike and threatens to limit life-saving treatment needed for people with the severe mental illness of eating disorders.

Recommendation: As seen with Medicare Part A's hospital coverage component of the program, inpatient hospital treatment coverage includes skilled nursing facility care, nursing home care, hospice and home health services.[16] Additionally, similar to Medicare Part A requirements for inpatient benefits, residential treatment for eating disorders requires treatment provider authorized, 24-hour supervised, multidisciplinary care that lasts for two or more midnights of medically necessary hospital care (typically for the ~5% of consumers with severe eating disorders requiring residential treatment, industry standards require an average of 30-60 midnights to medically treat a patient at this level). In turn, residential treatment should be classified as a sub-category of inpatient benefits for the purposes of MHPAEA compliance just as skilled nursing facilities, nursing home care, and hospice are considered sub-categories of inpatient care under Medicare Part A. Given the complexity of the severe mental illness of eating disorders, within industry standards and guidelines, you will not find less than two midnights to be sufficient for medically necessitated residential treatment for eating disorders that could be categorized as outpatient benefits. The current bifurcation of residential treatment as inpatient and/or outpatient curtails the number of individuals who can seek treatment for this deadly illness.

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

> **"Q9: My health plan generally covers medically appropriate treatments. The plan covers inpatient, out-of-network treatment outside of a hospital setting for medical/surgical conditions if the prescribing physician obtains authorization from the plan and the treatment is medically appropriate for the individual, based on clinically appropriate standards of care. The plan provides benefits for the treatment of eating disorders but excludes all inpatient, out-of-network treatment outside of a hospital setting for eating disorders, including residential treatment (which it regards as an inpatient benefit). Is this permissible under MHPAEA?**
>
> No. The Departments' regulations implementing MHPAEA define "mental health benefits" as benefits with respect to items or services for mental health conditions, as defined under the terms of the plan or health insurance coverage and in accordance with applicable Federal and State law.
>
> Section 13007 of the 21st Century Cures Act clarified that if a group health plan or health insurance issuer provides coverage for eating disorder benefits, including residential treatment those benefits must be offered consistent with the requirements of MHPAEA. Accordingly, the Departments have clarified that eating disorders are mental health conditions and, therefore, treatment of an eating disorder is a "mental health benefit" within the meaning of that term as defined by MHPAEA. Plan or coverage restrictions based on facility type are NQTLs under MHPAEA. A plan may impose an NQTL if, under the terms of the plan as written and in operation, the processes, strategies,

[16] Medicare.gov. (n.d.) "What Part A covers." Centers for Medicare and Medicaid Services. Retrieved from https://www.medicare.gov/what-medicare-covers/part-a/what-part-a-covers.html

evidentiary standards, and other factors considered by the plan in implementing its exclusion with respect to MH/SUD benefits are comparable to and applied no more stringently than, those used in applying the NQTL to medical/surgical benefits in the same classification. In evaluating an exclusion of an intermediate level of care, including residential treatment, it must be initially determined if the intermediate level of care is assigned to the six-benefit classifications in the same way for both medical/surgical and MH/SUD benefits. If so, then the basis for the exclusion (in this case, residential treatment) in the classification must be reviewed to determine if the processes, strategies, evidentiary standards and other factors that are the basis for the exclusion of MH/SUD benefits are comparable to and applied no more stringently than the processes, strategies, evidentiary standards and other factors used in applying the NQTL to medical/surgical benefits in the same classification. Following this analysis, if a plan can articulate factors that are comparable to and applied no more stringently than to support excluding residential treatment in certain circumstances, the plan may be able to demonstrate that the exclusion is consistent with parity standards will meet its obligation with respect to this limitation under MHPAEA. However, in this example, the plan provides inpatient, out-of-network treatment outside of a hospital for medical/surgical conditions so long as a prescribing physician obtains prior authorization from the plan and the treatment is medically appropriate for the individual, while the plan unequivocally excludes all inpatient, out-of-network treatment outside of a hospital (in this case, residential treatment) for eating disorders. This restriction on residential treatment for eating disorders is not comparable to this plan's coverage restrictions for inpatient treatment outside of a hospital for medical/surgical conditions, which are less stringent. This exclusion does not comply with MHPAEA. **Additionally, the Departments clarify that for the purposes of MHPAEA compliance, MH/SUD residential treatment is a category of inpatient benefit under the six-benefit classification."**

E. *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.[17] 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.

One example includes a young woman in Minnesota who was requesting 14 additional days of residential eating disorders treatment, per the medical determination from her treatment team. During the insurance review discussion with her treatment team, the treatment team explained the reasons outlined in the documentation, including the patient needing to restore approximately 15 pounds to reach the bottom end of her goal weight range. The insurance reviewer questioned the goal weight range, despite the range being set from the patient's growth charts and multiple other markers of success not being attained, including a recent incident of self-harm. The insurance reviewer responded that a doctor needed to review this claim, since the patient had been in residential treatment for six weeks. The treatment team requested a meeting

[17] 29 CFR §2590.712 (c)(4); 45 CFR §146.136 (c)(4); 26 CFR §54.9812–1 (c)(4)

with the doctor reviewing the claim to see if he had any questions before a decision was made. An additional week was authorized, but they needed a peer-to-peer conversation to do anything further. After a few days had passed and minimal updates had been communicated to the treatment team, the insurance representative stated that the doctors on the treatment team offering to discuss the treatment with the reviewing doctor was not sufficient. The reviewing doctor would only communicate with an MD, not a PhD. The treatment team then offered an MD on the treatment team to speak with, however, scheduling had not worked out for communicating with the doctor reviewing the request, and consequentially the patient was denied additional time in residential treatment.

Recommendation: While there is currently an ERISA regulation stating that an insurance plan may offer Medical Guidelines upon request,[18] 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.[19] 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.

F. *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*

[18] 29 CFR § 2560.03-1(g)(1)(v)(A)
[19] https://www.hhs.gov/sites/default/files/mental-health-substance-use-disorder-parity-task-force-final-report.pdf

- *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.

- *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*
  - *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.

  - *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*
  - *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?

As an example, one utilization reviewer reviewing the case of a patient receiving residential eating disorder treatment had worked in the area of eating disorders 20 years ago, but not since then. Based on their experience in that setting, they would not authorize on going care because the patient was not receiving a 12-step intervention; the reviewer's idea of standard of care in the field. This is in no way the current standard of care in the field of eating disorders. Another reviewer deemed a 16 year old female with an eating disorder "chronic" and therefore not in need of intensive treatment because she had had the eating disorder for more than 2 years. At 16 years old, the reviewer was willing to relegate her to a status of "untreatable". There is no accepted definition of "chronic" in the field of eating disorder and research is clear that people can recover from an eating disorder after a much longer period of time with the disorder. No standard of care in the field deems a two year history of an eating disorder as "untreatable".

- *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.*
  - 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.

  - *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

- *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.

- *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

- *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.

- *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 Emily Program. 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.