MEMORANDUM

Date: November 7, 2016

TO: Carole Johnson, Office of Domestic Policy, The White House

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FROM: Katrina Velasquez, Esq., Policy Director, Eating Disorders Coalition

RE: White House Roundtable on Eating Disorders– Early Identification and Training

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Executive Summary:
20% of Americans struggle with mental health disorders, with more than 30 million Americans suffering from eating disorders in their lifetime. Eating disorders have the highest mortality rate of any psychiatric illness and affect women at a higher rate than men. Every 62 minutes someone dies from an eating disorder in the United States, and less than half of Americans receive treatment for their eating disorder.[1]

On September 14, 2016, the White House Office of Domestic Policy in coordination with the Eating Disorders Coalition gathered experts from the eating disorders community and the federal government to discuss issues related to mental health parity compliance, early identification of eating disorders, and research. The White House, SAMHSA, and HRSA requested follow-up information to help inform their work regarding the early identification of eating disorders for health professionals, school personnel, and identification amongst minorities. Within this memorandum you will find the follow-up recommendations for early identification of eating disorders including the following: (1) Early Identification Trainings for Health Professionals, (2) School-based

[1] 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. http://doi.org/10.1016/j.biopsych.2006.03.040

Eating Disorder Screening Tools, and (3) Early Identification and Awareness Amongst Underserved and Marginalized Communities.

We hope that the provided information can be used to better educate health professionals and school personnel and improve the early identification of eating disorders. We welcome the opportunity to discuss the issues both now and in the transition to the new administration.

Please feel free to reach out to the Eating Disorders Coalition Policy Director Katrina Velasquez, Esq. at kvelasquez@eatingdisorderscoalition.org or 202-808-8857 with any questions, comments or meeting requests.

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I. Early Identification Trainings for Health Professionals

Every 62 minutes someone dies as a direct result of suffering an eating disorder.[2] Eating disorders are brain-based, biological illnesses with a strong genetic component and psychosocial influences. They do not discriminate. Eating disorders can affect individuals of all ages, genders, ethnicities, socioeconomic backgrounds, and with a variety of body shapes, weights and sizes. The feeding and eating disorders covered by the DSM-V[3] are:

Anorexia Nervosa (AN)

- Restriction of energy intake relative to an individual's requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory and health status. Disturbance of body image, an intense fear of gaining weight, lack of recognition of the seriousness of the illness and/or behaviors that interfere with weight gain are also present.

Bulimia Nervosa (BN)

- Binge eating (eating a large amount of food in a relatively short period of time with a concomitant sense of loss of control) with compensatory behavior once a week or more for at least three months. Disturbance of body image, an intense fear of gaining weight and lack of recognition of the seriousness of the illness may also be present.

Binge-Eating Disorder (BED)

- Binge eating, in the absence of compensatory behavior, once a week for at least three months. Binge eating episodes are associated with eating: rapidly, when not hungry, until extreme fullness, and/or associated with depression, shame or guilt.

Avoidant/Restrictive Food Intake Disorder (ARFID)

- Significant weight loss, nutritional deficiency, dependence on nutritional supplement or marked interference with psychosocial functioning due to caloric and/or nutrient restriction, but without weight or shape concerns.

Other Specified Feeding or Eating Disorders (OSFED)

- An eating disorder that does not meet full criteria for one of the above categories, but has specific disordered eating behaviors such as restricting intake, purging and/or binge eating as key features.

[2] 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
[3] American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.).

Atypical Anorexia

- All criteria for Anorexia Nervosa are met except, despite significant weight loss the individual's weight is within or above the normal range.

Purging Disorder

- Recurrent purging behavior to influence weight or shape in the absence of binge eating.

Chewing and Spitting Disorder

- A condition in which a person chews up food, usually sweet or high-calorie, then spits it out.

Attached you will find a PowerPoint, developed by The Alliance for Eating Disorders Awareness, that we suggest as essential training on identification and assessment of eating disorders for the medical community. This training has been used at Eglin Air Force Base for their medical residents, the University of Florida School of Medicine, Florida Atlantic University School of Medicine, LSU/Tulane Psychiatry Residents, New York Medical College, UnityPoint Health, Jupiter Medical Center, Jackson Memorial Hospital, and St. Mary's Hospital.

The Alliance for Eating Disorders Awareness was created as a source of community outreach, education, awareness, and prevention of the various eating disorders currently plaguing our nation. Since its inception, The Alliance for Eating Disorders Awareness has offered presentations on eating disorders and their prevention to more than 150,000 individuals nationwide and internationally. For information about The Alliance for Eating Disorders Awareness, please contact them at (866) 662-1235 or at www.allianceforeatingdisorders.com.

The Academy for Eating Disorders (AED) also published a guide for medical professionals who are not experts in eating disorders to provide them with information on how to recognize early signs of eating disorders and make referrals to appropriate specialist evaluation and care if needed. The guide is titled "Eating Disorders: Critical Points for Early Recognition and Medical Risk Management in the Care of Individuals with Eating Disorders" and you can download it for free from the AED website at: http://www.aedweb.org/index.php/education/eating-disorder-information/eating-disorder-information-13

To complement the guide, AED funded the development and testing of a brief online training module for medical professionals who are not eating disorders specialists to increase knowledge and skills in early detection and referral for eating disorder symptoms in patients in their practice. The module was developed and tested in a study[4] led by Dr. Holly Gooding, MD, MS, Assistant Professor in Pediatrics at Harvard Medical School

[4] http://www.harvardmacy.org/index.php/hmi/transforming-case-method-teaching-for-online-platforms

and expert in both eating disorders and effective methods for medical education. Dr. Gooding is also medical research faculty based at Boston Children's Hospital in the Division of Adolescent and Young Adult Medicine.

The Academy for Eating Disorders is a global professional association committed to leadership in eating disorders research, education, treatment, and prevention. More information can be found at http://www.aedweb.org.

II. School-based Eating Disorder Screening Tools

Many states have mandatory screening in schools for scoliosis, asthma, and other conditions. No states currently screen for eating disorders, despite the fact that they are the third most common chronic illness among adolescents[5] and possess the highest mortality rate of any mental illness. Screenings are important and effective tools in early intervention efforts and could potentially prevent serious, chronic eating disorders.

All too frequently, eating disorders are diagnosed once the illness is entrenched and patients have suffered irreversible physical harm. Studies have demonstrated a link between early intervention and better treatment outcomes for many psychiatric conditions.[6] If we can identify young people of all genders, races, ethnicities, and socioeconomic statuses as they are beginning to exhibit symptoms of disordered eating, we can reduce the incidence of full-syndrome eating disorders and the serious secondary health conditions they cause.

Research conducted by Wright et al. demonstrated that screening for eating disorders in a school setting is likely to be highly cost-effective, with positive effects on accessing treatment and attaining recovery.[7] Given the cost-effectiveness and the benefit to students, as well as the current school screening practices for other health conditions, school-based eating disorder screening programs should be implemented across the country in order to combat these potentially life-threatening illnesses.

Currently, the three major screening tools are the Eating Attitudes Test (EAT), the SCOFF questionnaire, and the Eating Disorder Screen for Primary care (ESP). They can be administered quickly and have shown validity in nonclinical populations.[8,9] Each of these screenings have advantages, however there are some concerns that they miss signifiers from non-female-identified students and those experiencing binge-eating disorder. Additional research would be beneficial to ensure these screening instruments will be more appropriate for diverse populations, males, and people with binge eating symptoms. The scoring of these screening tools does not require clinical expertise and is intended to show a potential presence of an eating disorder, not to diagnose one.

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[5] Kalisvaart, J. L., & Hergenroeder, A. C. (2007). Hospitalization of patients with eating disorders on adolescent medical units is threatened by current reimbursement systems. International Journal of Adolescent Medicine and Health, 19(2), 155-165.
[6] Greenfield, S. F. & Shore, M. F. (1995). Prevention of psychiatric disorders. Harvard Review of Psychiatry 3(3), 115-129.
[7] Wright, D. R., Austin, S. B., Noh, H. L., Jiang, Y., & Sonneville, K. R. (2014). The cost-effectiveness of school-based eating disorder screening. American Journal of Public Health, 104(9), 1774-1782.
[8] Morgan, J. F., Reid, F., & Lacey, J. H. (1999). The SCOFF questionnaire: assessment of a new screening tool for eating disorders. BMJ (Clinical Research ed.), 319(7223), 1467-1468.
[9] Cotton, M. A., Ball, C., & Robinson, P. H. (2003). Four simple questions can help screen for eating disorders. Journal of General Internal Medicine, 18(1), 53-56.

A. Eating Attitudes Test (EAT)

- The EAT is a twenty-six-question standardized self-report screening designed for adolescents and adults that measures symptoms and concerns characteristic of eating disorders. The screening can be administered by various individuals, such as school counselors, coaches, or camp counselors, in a clinical or nonclinical setting, and individually or in a group. The goal of the screening is not to diagnose eating disorders, but to identify individuals who should be referred to a specialist for a comprehensive eating disorder assessment. The EAT is well-suited for settings like schools, athletic programs, and general medical practices.[10]

B. The SCOFF

- The SCOFF is a five-question screening tool to evaluate the core features of anorexia nervosa and bulimia nervosa. The questions are in a yes/no format, with each affirmative answer receiving one point.
- The questions as listed in Kagan & Melrose[11] are:
    - Do you make yourself Sick because you feel uncomfortably full?
    - Do you worry that you have lost Control over how much you eat?
    - Have you recently lost more than One stone (14 lbs) in a 3-month period?
    - Do you believe yourself to be Fat when others say you are too thin?
    - Would you say that Food dominates your life?
- A score greater than or equal to two indicates a possible case of anorexia or bulimia. The SCOFF has been tested with clinical and college student populations and was able to identify 100% of clinical eating disorders with a false positive rate of 12.5%.[12] In a later study in primary care and university settings, the SCOFF was shown to have a sensitivity rate of 78% and a specificity of 88%.[13]

[10] EAT-26 Self-Test: Screening. (n.d.). Retrieved October 26, 2016, from http://www.eat-26.com/screening.php
[11] Kagan, S. & Melrose, C. (2003). The SCOFF questionnaire was less sensitive but more specific than the ESP for detecting eating disorders. Evidence-Based Nursing, 6(4), 118.
[12] Morgan, J. F., Reid, F., & Lacey, J. H. (1999). The SCOFF questionnaire: assessment of a new screening tool for eating disorders. BMJ (Clinical Research ed.), 319(7223), 1467-1468.
[13] Cotton, M. A., Ball, C., & Robinson, P. H. (2003). Four simple questions can help screen for eating disorders. Journal of General Internal Medicine, 18(1), 53-56.

C. Eating Disorder Screen for Primary Care (ESP)

- The ESP is a four-question screening tool for eating disorders. Like the SCOFF, questions are in a yes/no format, with two or more abnormal responses (a no response to question one, and a yes to two through five) indicating the presence of an eating disorder. The four questions are:
  - Are you satisfied with your eating patterns?
  - Do you ever eat in secret?
  - Does your weight affect the way you feel about yourself?
  - Do you currently suffer with or have you ever suffered in the past with an eating disorder?
- In a study comparing the ESP to the SCOFF, the ESP yielded a sensitivity of 100% and a specificity of 71%.[14] In their commentary on the comparison study of the SCOFF and the ESP, Kagan and Melrose[15] note that the ESP questions are "less invasive" than the SCOFF, and may be less likely to provoke evasive or defensive responses than a question about self-induced vomiting.

D. Considering eating disorder triggers within current practice of BMI testing in schools

Several states currently mandate that school systems conduct 'body mass index' (BMI) screenings of their students. BMI is a measure of body weight (weight/height^2) that is used as a tool to categorize individuals as underweight, normal weight, overweight, or obese based on the amount of tissue mass (muscle, fat, and bone) the individual possesses. While we applaud the Administration's work towards ending childhood obesity, we do recommend taking into consideration the triggering effects of the current practice of testing BMI within schools. Studies show that BMI offers an inaccurate measure of an individual's health, especially when evaluating growing children and adolescents, and there are significant concerns with the current practices of BMI testing in schools.[16]

BMI screenings were introduced to address growing concerns over childhood obesity. However, as noted by the CDC, BMI alone does not signify an increased health risk, as it does not account for differences in body composition.[17] The American Academy of Pediatrics agreeing with

[14] Cotton, M. A., Ball, C., & Robinson, P. H. (2003). Four simple questions can help screen for eating disorders. Journal of General Internal Medicine, 18(1), 53-56.
[15] Kagan, S. & Melrose, C. (2003). The SCOFF questionnaire was less sensitive but more specific than the ESP for detecting eating disorders. Evidence-Based Nursing, 6(4), 118.
[16] Tomiyama, A., Hunger, J., Nguyen-Cuu, J., and Wells, C. (2016) Misclassification of cardiometabolic health when using body mass index categories in NHANES 2005-2012. International Journal of Obesity. 40(5):883-6. doi: 10.1038/ijo.2016.17.
[17] Centers for Disease Control. (2012). Prevalence of obesity among children and adolescents: United States, trends 1963-1965 through 2009-2010. Retrieved October,

the CDC states "clinical judgment must be used in applying [BMI] criteria to a patient, because obesity refers to excess adiposity rather than excess weight, and BMI is a surrogate for adiposity."[18]

As part of the screenings, many school systems also send letters (or BMI report cards) to parents informing them into which category of weight their child's BMI falls. While BMI screenings do not cause eating disorders — as these are complex, multifactorial disorders — individuals at an increased risk for eating disorders may be triggered by the receipt of a BMI report card.[19]

25, 2016, from http://www.cdc.gov/nchs/data/hestat/obesity_child_09_10/obesity_child_09_10.pdf

[18] American Academy of Pediatrics. (2003). Prevention of pediatric overweight and obesity. Pediatrics: Official Journal of the American Academy of Pediatrics, 112(2), 424-430.

[19] Cogan, J. C., Smith, J. P., & Maine, M. (2007). The risks of a quick fix: a case against mandatory body mass index reporting laws. Eating Disorders, 16(1), 2-13.

III. Early Identification and Awareness Amongst Underserved and Marginalized Communities

We have a growing understanding as a field that eating disorders are serious, deadly illnesses that can and do affect people of all ethnicities, colors, nationalities, incomes, gender identities, sexuality, ages, or sizes. Misunderstandings and myths about who suffers from eating disorders exist among healthcare professionals as well as the general public and these misunderstandings are rooted in outdated beliefs about the nature of eating disorders, as well as reflective of existing stigma about mental illnesses.

Eating disorders are syndromes resulting from a complex interplay of genetic predisposition, biologic vulnerabilities, and other epigenetic factors. Among such risk factors, a history of macro- and micro-aggressions, discrimination and marginalization, and the well-documented confluence of stressors associated with minority status put people from marginalized communities at particularly high risk for the development of eating disorders.[20,21,22]

A. Relative Prevalence of Eating Disorders in Marginalized Communities

- Eating disorders in communities of color[23]:
  - Research demonstrates that there do not appear to be any significant differences in rates of Anorexia Nervosa across all ethnic groups in the United States.
  - Rates of Bulimia Nervosa appear to be significantly higher in Latino and African-American groups than compared to Caucasians.
  - Rates of Binge-Eating Disorder are significantly higher in all ethnic groups in the United States.

- Eating Disorders in the LGBTQ community[20,21,22]:
  - Overall rates of eating disorders and disordered eating behaviors appear to be significantly higher in the LGBTQ community as compared to heterosexual women and men.

[20] Austin, S. B., Nelson, L. A., Birkett, M. A., Calzo, J. P., & Everett, B. (2013). Eating Disorder Symptoms and Obesity at the Intersections of Gender, Ethnicity and Sexual Orientation in U.S. High School Students. American Journal of Public Health, 103(2), e16–e22.

[21] Feldman, M. B., & Meyer, I. H. (2007). Eating Disorders in Diverse Lesbian, Gay, and Bisexual Populations. The International Journal of Eating Disorders,40(3), 218–226.

[22] Diemer, E. W., Grant, J. D., Munn-Chernoff, M. A., Patterson, D. A., & Duncan, A. E. (2015). Gender identity, sexual orientation, and eating-related pathology in a national sample of college students. Journal of Adolescent Health, 57(2), 144-149.

[23] Marques, L., Alegria, M., Becker, A. E., Chen, C., Fang, A., Chosak, A., & Diniz, J. B. (2011). Comparative Prevalence, Correlates of Impairment, and Service Utilization for Eating Disorders across U.S. Ethnic Groups: Implications for Reducing Ethnic Disparities in Health Care Access for Eating Disorders. The International Journal of Eating Disorders, 44(5), 412–420.

- The transgender population appears to have an alarmingly elevated risk of eating disorders as compared to other groups.

B. Treatment Utilization[22]:

Despite rates of eating disorders being the same or higher in these groups, there remains a tremendous disparity in who receives services and who remains under-identified by professionals, thereby not receiving much needed treatment and care.

- The already low rates of treatment utilization among people with eating disorders are even lower for people in marginalized communities.
- People in ethnic minority groups with a lifetime history of any eating disorders were significantly less likely to have received and utilized mental health services than non-Latino Whites.
- There are significant economic barriers for many people in marginalized communities that result in lack of or difficulty in accessing much needed care.

C. Recommendations for addressing the specific needs of marginalized communities:

- Inclusion of questions about discrimination, macro- and micro-aggressions, and minority stress into screening assessments and prevention programs.
- Cultural competency training integrated into training on eating disorders for professionals.
- Development of specific prevention and educational programming targeting these at-risk groups.
- Development of culturally specific treatment programs and training programs for eating disorder specialists.