December 14, 2021

ADM Rachel Levine, USPHS, MD
Assistant Secretary for Health
Office of the Assistant Secretary for Health
United States Department of Health and Human Services
200 Independence Ave, SW
Washington, DC 20201

Dear Assistant Secretary Levine,

On behalf of the Eating Disorders Coalition for Research, Policy & Action, a coalition of national, state, and local eating disorders nonprofits, treatment providers, researchers, and individuals and families affected by the serious mental illness of eating disorders, we write to urge the Department of Health and Human Services (HHS) to take significant action to address the child and adolescent eating disorders crisis, which the COVID-19 pandemic has severely exacerbated. The community has seen 2-3 times increase in the eating disorders caseload at children’s hospitals across the county. Below we provide detailed recommendations for actions HHS can take under the agency’s current authority.

Executive Summary of Recommendations

National Institutes of Health (NIH)
Historically, NIH has been a primary funder of eating disorders research to address significant gaps in research, prevention, and treatment across multiple co-morbid conditions. However, within prevention, identification, treatment, recovery, intersectionality, and medication topics, there is much more research to be done to fully understand eating disorders. Our recommendations include:

1. Triple the funding for eating disorders research studies across the various Institutes and Centers, focusing on the gaps in eating disorders research and the effects of social media algorithms on youth at risk for an eating disorder.
2. Provide Congress the FY21 report on the status of eating disorders research, as was directed within the Consolidated Appropriations Act, 2021 (P.L. 116-260).
3. Create an Interagency Eating Disorders Coordinating Committee, like the Interagency Autism Coordinating Committee, to further facilitate activities, programs, policies, and research related to eating disorders.
4. Build a mental health promotion program within HHS focused on LGBTQ suicidal ideation as well as anxiety, depression, and disordered eating behaviors and integrate mental health promotion components into existing LGBTQ-targeted smoking cessation and sexual health programs.

Centers for Disease Control and Prevention (CDC)
Given CDC’s focus on nutrition, physical activity and obesity, the integration of eating disorders within these areas would advance public health interventions and efforts in youth and adults. Yet, the CDC has

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1 Otto, A; Jary, J; Sturza, J; Miller, C; Prohaska, N; Bravender, T & Jessica Van Huyssee. Medical admissions among adolescents with eating disorders during the covid-19 pandemic. Pediatrics 2021; 148; DOI: 10.1542/peds.2021-052201
conducted almost no research on eating disorders. Without this integration, current obesity interventions may present unintended consequences for individuals struggling with disordered eating. Additionally, the 21st Century Cures Act authorized HHS to expand public awareness and information on eating disorders, yet the CDC does not have a coordinating home for eating disorders within the agency. Our recommendations include:

1. Under the Prevention Research Centers, initiate study of the following activities:
   a. The effects of youth obesity prevention programs on youth at risk for disordered eating or an eating disorder.
   b. How school physical activity and nutrition promotion programs can be tailored to prevent eating disorders, disordered eating, weight stigma, and body dissatisfaction.
   c. Best mechanisms for prevention and early identification for historically underserved populations, including, but not limited to, persons of color and LBGTQ+.
2. Create a Translational Research Program, in coordination with NIH, to bring the science of eating disorders to practice.
3. Create a home for eating disorders, either within the Division of Nutrition, Physical Activity and Obesity or the Division of Population Health, School Health Branch.
4. Create a national awareness campaign.
5. Fund prevention programs for schools, like Be Real USA and Planet Health to increase eating disorders prevention and body positivity amongst youth and resources for school personnel, parents, and guardians.
6. Re-instate items measuring “Unhealthy Weight Control Practices” within the standard and/or national Youth Risk Behavior Surveillance Survey (YRBSS).

Agency for Healthcare Research and Quality (ARHQ)
The utilization of Body Mass Index (BMI) in medical and non-medical settings and in federal agencies does not account for individual differences in body composition (i.e., muscle, bone density, shape, etc.) and is extremely harmful to individuals, especially youth. Some of this suffering could be prevented if BMI screening were removed from medical and non-medical institutions (i.e., schools). We recommend:

1. Reevaluating the screening for obesity via BMI measurements in medical and non-medical settings.

HHS Office of the Assistant Secretary of Health (OASH)
Under the authorization of the 21st Century Cures Act, an informal interagency working group under the Office on Women’s Health was established to improve information and awareness around eating disorders as well as foster collaboration between subject matter experts in obesity and eating disorders. However, a formalized interagency task force is needed to strengthen eating disorder federal coordination. Further, the creation of an Advisory Committee on Eating Disorders is needed to advise FTC on solutions to address emerging threats such as the mental health impacts of social media use. We recommend:

1. Formally establish an interagency task force on eating disorders to advance federal leadership on the issue.
2. Create and fund an Advisory Committee on Eating Disorders as a part of the task force to inform the FTC of deceptive and unfair practices of social media companies.
Substance Abuse and Mental Health Service Administration (SAMHSA)

Under the 21st Century Cures Act authorization, SAMHSA created the National Center of Excellence for Eating Disorders (NCEED), which provides trainings for health professionals and recently created the first screening, brief intervention, and referral for treatment (SBIRT) training for primary care health professionals on adult eating disorders. We encourage SAMHSA to re-fund NCEED to create a similar training model for children and adolescents, military families, and marginalized populations. Additionally, recent evaluations of the National Suicide Lifeline found that crisis chat counselors lack training in eating disorders and are unable to adequately intervene and support clients with eating disorders. Finally, SAMHSA continues to classify eating disorders care as “specialized services” and therefore does not require Certified Community Behavioral Health Clinics (CCBHCs) to screen, assess, diagnose, or treat in-house, despite being required to do so for most other mental and behavioral health conditions. We recommend:

1. Increase NCEED funding to train more health professionals and expand their adult SBIRT program.
2. Create and fund a youth SBIRT program.
3. Formulate SBIRT training program to help marginalized populations including American Indians, LGBTQ+, persons of color, and people with disabilities.
4. Require the suicide lifeline to be trained on eating disorders and provide referrals to local care.
5. Create a nationally funded 24/7 eating disorders hotline to provide emotional support and referral for care to individuals affected by eating disorders.
6. Update requirements for CCBHCs to provide eating disorders screening, assessment, diagnosis, treatment planning, and outpatient services in-house, as required for other behavioral health conditions.
   a. At minimum, SAMHSA should furnish SBIRT trainings for eating disorders for all CCBHC staff providing direct care to fill existing gaps.
7. Designate eating disorders as a serious mental illness to enable individuals access to federal, state, and local support programs.

Indian Health Service (IHS)

There is limited research on the prevalence of eating disorders among American Indian and Alaska Native populations. One 1997 study found that nearly half of surveyed Native American girls were trying to lose weight – a rate higher than any other racial group. Rates of dieting among Native American boys also reached almost one-third. In a 2000 National Eating Disorders Screening Program, more African American, American Indian, Asian/Pacific Islander, and Latino boys reported symptoms of eating disorders than did white boys. Symptomatic boys may be overlooked by clinicians, school personnel, parents, and others because the prevalence of eating disorders in boys is commonly underestimated. But as can be seen from in the 2000 study, the American Indian population is affected, and further research must be done. We recommend:

1. Fund Indian Health Service to conduct:
   b. Coordinate with NCEED to formulate trainings on eating disorders screening, intervention, and referral for all Indian Health Service professionals who provide direct patient care.
Health Resources and Services Administration (HRSA)

Mental health and eating disorders support for children and adolescents, pregnant individuals, and others continue to see significant barriers in access to care. Many HRSA programs across maternal and school-based health care lack integration of eating disorders and mental health screening, identification, and referral. Additionally, caregivers spend up to six weeks paid time off helping their loved ones coordinate care, necessitating assistance to those caregivers and individuals to receive care. We recommend:

1. Integrate an eating disorders early identification program into Primary Care Training and Enhancement grants.
2. Integrate eating disorders early identification training into maternity care programs.
3. Require HRSA School Based Health Center funds to be contingent on the school incorporating mental health prevention, early intervention, and referral into existing procedures.
4. Create a funding mechanism for schools to facilitate tele-mental health appointments for students, particularly in Health Professional Shortage Areas.
5. Build a state-based care coordination program modeled after Head Start for mental health care that can be referred to on behalf of a primary care provider and help connect patients with care based on their insurance eligibility, coordinate provider waitlists, and create a structured care coordination plan to demonstrate improvement in their recovery process. Additionally, the program should coordinate to offer training and guidance to parents, caregivers, and guardians.

Centers for Medicare and Medicaid Services (CMS)

Particularly during the pandemic, telehealth services have become a critical mainstay for individuals in need of eating disorders treatment. The positive outcomes from delivering treatment via telehealth demonstrates that need for continued expansion of this modality. The codification of telehealth as a covered treatment modality and establishment of payment parity with in-person services would expand access to eating disorders care. Furthermore, Medicare does not currently cover residential, partial hospitalization (outside of a hospital), intensive outpatient treatment, registered dietitian services, an assessment from an eating disorder specialist, or the provision of mental health crisis services for eating disorders. Because Medicare historically sets the standard for broad service coverage, Medicare inadequacies have been replicated within TRICARE and the commercial market to the disservice of individuals and families with MH/SUD.

1. Expand telehealth under the ACA and institute parity in reimbursement to that of in-person services.
2. Create a pilot program to fund nutrition care services under Medicare under the Centers for Medicare & Medicaid Innovation (CMMI).
3. Build in coverage through Medicaid or another payment system for text counseling and other digital therapeutics.
4. Ensure that the CMS require eating disorders screening be included in Medicaid mandated EPSDT program and, if the PHQ-9 used, require follow up with clinical evaluation for a child if item #5 on dysregulation of eating behavior endorsed.
# Table of Contents

**Eating Disorders Background and the COVID-19 Public Health Emergency** ........................................... 6  
**Eating Disorder Research and Data Collection** .......................................................................................... 7  
  National Institutes of Health (NIH) ........................................................................................................ 8  
  NIH Recommendations ....................................................................................................................... 10  
  Centers for Disease Control and Prevention (CDC) ........................................................................... 11  
  CDC Recommendations ...................................................................................................................... 11  
**Awareness, Prevention, and Early Identification** ................................................................................. 11  
  Agency for Healthcare Research and Quality (ARHQ) ........................................................................ 11  
  ARHQ Recommendations ................................................................................................................... 12  
  HHS Office of the Secretary of Health (OASH) ............................................................................... 12  
  OASH Recommendations .................................................................................................................. 13  
  Centers for Disease Control and Prevention ..................................................................................... 13  
  CDC Recommendations ...................................................................................................................... 14  
  Substance Abuse and Mental Health Service Administration (SAMHSA) ...................................... 14  
  SAMHSA Recommendations ............................................................................................................. 15  
  Indian Health Service (IHS) ................................................................................................................ 15  
  IHS Recommendations ....................................................................................................................... 15  
  Health Resources and Services Administration (HRSA) ................................................................. 16  
  HRSA Recommendations ................................................................................................................... 17  
**Access to Care and Recovery** .............................................................................................................. 17  
  SAMHSA ................................................................................................................................................ 17  
  SAMHSA Recommendations ............................................................................................................. 18  
  Centers for Medicare and Medicaid Services (CMS) ....................................................................... 19  
  CMS Recommendation ....................................................................................................................... 21
Eating Disorders Background and the COVID-19 Public Health Emergency

Eating disorders are complex, serious mental illness with high rates of co-morbid conditions including depression, anxiety, substance use disorders, and other co-morbidities. Nearly 30 million Americans of all ages, races, ethnicities, genders, and sexualities will experience an eating disorder in their lifetime, and over 10,000 of them will die every year. This is equivalent to 1 death every 52 minutes as a direct result of an eating disorder. Specifically, people of color with eating disorders are half as likely as their white peers to be diagnosed or receive treatment; women are twice as likely as men to have an eating disorder; and a 2020 study of college students found women identifying as questioning and bisexual had about 1.4 times the odds of elevated ED risk than heterosexual women and among both men and women at elevated risk for an ED, sexual minorities overall were more likely to have received an ED diagnosis than their heterosexual peers. These troubling statistics have worsened with the COVID-19 pandemic because of increased isolation, stress, economic precarity, and food insecurity. As it relates to food insecurity, emerging research has consistently indicated that food insecurity elevates a person’s risk for eating disorders pathology and dietary restraint by as much as five times compared to food secure households. We also know that food insecurity is associated with a 257% higher risk of anxiety and 253% higher risk of depression. When families across the nation do not have access to mental health treatment at all levels of care and delivery modalities, they are not able to engage in lifesaving treatment. Studies show that when a person with a severe eating disorder does not receive comprehensive treatment, 41% of patients will relapse and are two times more likely to end up seeking care in the emergency room than someone without an eating disorder. Barriers to comprehensive treatment cost the U.S. economy $64.7 billion each year, with $17.7 billion shouldered by the federal government. There have been dozens of news and research articles documenting the rise in eating disorder diagnoses since the onset of the pandemic. An ongoing study from the National Center of Excellence for Eating

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2 Ibid.  
Disorders (NCEED)\(^{12}\) found in July 2020, 62% of people in the U.S. with anorexia experienced a worsening of symptoms as the pandemic hit, and nearly one-third of Americans with binge eating disorder, which is far more common, reported an increase in episodes.

Hospitals across the nation are reporting an inability to keep up with demand, with recent reports of hospitalizations for eating disorders doubling for children and adolescents. St. Louis Children’s Hospital in Missouri is seeing 8-15 kids per day for behavioral health issues including suicide attempts, eating disorders, anxiety, and psychosis.\(^{13}\) At C.S. Mott Children’s Hospital in Ann Arbor, Michigan, administrators found medical admissions among adolescents with eating disorders during the first 12 months of the pandemic more than doubled the mean for the previous 3 years.\(^{14,15}\)\(^{16}\) Arkansas Children’s Hospital CEO, Marcy Doderer\(^{17}\)\(^{18}\) The uptick in pediatric mental health conditions has led the Children’s Hospital Association, American Academy of Pediatrics, and the American Academy of Child and Adolescent Psychiatrists to launch “Sound the Alarm for Kids,”\(^{19}\)\(^{20}\) The pediatric mental health crisis will have lasting impacts on children for years to come.

During this time, it has been challenging for eating disorders providers to keep up with the demand for care. Eating disorder treatment providers have seen a 30-100% increase in demand for care, with call volumes and inquiries for care doubling, significantly increased acuity in nature of illness presented and wait times expanding from 1 week to 6-8 months in some areas of the country.\(^{19}\) Among our partner organizations, the National Eating Disorders Association saw a 40% increase in helpline call volume during the first year of the pandemic, and the National Alliance for Eating Disorders, staffed by licensed, specialized therapists who can assess for safety of callers, saw an 80% increase in helpline call volume in 2021. Additionally, the Alliance saw a 108% increase in referrals and an 82% increase in support group attendance in 2020 and has surpassed those figures this year.\(^{20}\)

### Eating Disorder Research and Data Collection

The eating disorders community and Congress have both recognized the limitations in federal funding for eating disorders research, which is estimated to total $57 million across HHS’ National Institutes of Health (NIH) and Department of Defense (DoD) Congressionally Directed Peer Reviewed Medical Research

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14 Otto, A; Jary, J; Sturza, J; Miller, C; Prohaska, N; Bravender, T & Jessica Van Huyssee. Medical admissions among adolescents with eating disorders during the covid-19 pandemic. *Pediatrics* 2021; 148; DOI: 10.1542/peds.2021-052201


17 Ibid.


Program (PRMRP) for FY 2021. While this is a significant increase from previous fiscal years, which average around $30 million annually for eating disorders (and solely within NIH), it does not adequately cover the need given the levels of severity and disability associated with eating disorders.

This dearth of federal funding for research in the field was recently highlighted by the United States Preventive Services Taskforce (USPSTF) release of an “I” grade, representing the USPSTF conclusion that current peer-reviewed, evidence-based research is insufficient to assess the balance of benefits and harms of screening for eating disorders for persons without symptoms. This grade letter does not mean that USPSTF discourages the use of screening for eating disorders, which would be associated with a grade “D”, but instead highlights the opportunity and responsibility for both the NIH and the Centers for Disease Control and Prevention (CDC) to conduct research over the next five years that can be utilized when USPSTF reconvenes to update their recommendations.

National Institutes of Health (NIH)

Historically, 15 NIH Institutes and Centers (ICOs) outside of the National Institute of Mental Health (NIMH) have funded approximately 45% of eating disorders research over the last five years. A greater investment is needed in both NIMH and other ICOs to address the significant gaps in research, prevention, and treatment across multiple co-morbid conditions. To address this need, Congress included report language within the Consolidated Appropriations Act, 2021 (P.L. 116-260) that can be found in Committee Report 116-450 encouraging further eating disorders research and coordination between the ICOs for research. Additionally, the language requested NIH to report on the increase in eating disorders research within the agency’s FY 2022 Congressional Justification. This victory was paved in part by leaders within the eating disorders community who wrote to Senate appropriators outlining the research gaps in eating disorders including:

Prevention and Early Identification

Risk Factor Identification and Prevention: Research provides the basics of eating disorders risk factors; however, more research is needed on the different types of risk factors, such as poor body image or body dissatisfaction and how to prevent the development of eating disorders when these factors arise. For example, there is only one prospective study to identify risk factors comparing Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge-Eating Disorder (BED), and purging disorder, limiting the predictability of eating disorder development to 60% accuracy. When these risk factors are well understood, health

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23 Eating Disorder Research.—The Committee commends NIH for supporting multi-Institute research on the chronic, fatal, and serious mental illnesses encompassing eating disorders that affect 30 million Americans during their lifetimes, and its association with other conditions such as diabetes, infertility, heart disease, PTSD, substance use, co-morbid mental illnesses, and tooth decay. The Committee recognizes that eating disorders are a deadly bio-psycho-social illness and that multiple research topics must be explored to understand, prevent, and treat eating disorders, including psychosocial issues; health disparities and food insecurity; environmental factors such as weight stigma; the complex interplay of metabolic processes; and maternal health. The Committee encourages NIH to increase support for eating disorders research and explore these and other research questions through multiple Institutes and Centers, including NIMH, NIDDK, NIMHD, and NIDA. The Committee directs NIH to inform the Committee on the steps taken to increase support for eating disorders and measures taken to improve prevention, diagnosis, and treatment of eating disorders in the fiscal year 2022 Congressional Justification.

professionals can confidently identify someone at risk for an eating disorder and work with them to stop the eating disorder from advancing.

**Early Identification and Intervention from Medical Professionals:** While research and information are available for medical professionals to early identify and intervene for eating disorders, medical professionals lack education, training, and practice due to limited dissemination. A survey of 637 medical schools showed that only 20% of medical residency programs offer an elective course on eating disorders. More research and activities are needed on how to best disseminate this information to medical professionals across the industry. Eating disorder curricula within medical schools must be expanded to develop further evidence-based training curricula and best practices.

**Weight Stigma and Health Outcomes:** NIH research has focused on weight loss and prevention of weight gain; however, limited research exists on the closely related social determinant weight stigma, its effects on a person’s health, and how this factor contributes to eating disorders. In turn, further research is needed to better understand body dissatisfaction and weight stigma, how health outcomes are impacted by weight stigma as distinct from purported effects of adiposity, and how weight stigma might contribute to the development of an eating disorder.

**Co-Morbidities Predicting Onset:** Eating disorders are associated with a host of co-morbid medical conditions such as Type I and II diabetes, polycystic ovary syndrome (PCOS), heart failure, and osteoporosis. However, the research is limited on how these comorbidities predict the onset of an eating disorder and intervention strategies for medical professionals. For example, there is a research gap in how it can be predicted if adolescents with anxiety disorder and other comorbidities will develop an eating disorder and what steps needed as intervention strategies.

**Nutrition Studies:** Nutrition studies often lack hard outcome measures to determine evidence-based nutrition recommendations. Without evidence-based findings, diet plans lacking a scientific basis will continue to be developed, causing disordered eating and other adverse health outcomes.

**Treatment**

**Clinical Details of Treatment:** More research is needed to better understand the clinical issues related to eating disorders treatment such as weight gain/loss, best time to transition between various levels of care, possible technological and digital therapeutic interventions, interventions that can be delivered more broadly, the effect of insurance coverage on treatment outcomes, and the management of comorbidities associated with eating disorders.

**Treatment Methods:** Research to understand the effectiveness of a combination of exposure treatment and other treatments during weight restoration, exposure treatments for all eating disorders, personalized treatment, and symptoms-based treatment.

**Longitudinal Studies:** Longitudinal studies are needed to track an eating disorder cohort over many years, and clarify course, outcomes, and predictors of outcomes. More long-term research is needed on how best to treat BED, Avoidant Restrictive Food Intake Disorder (ARFID), Atypical Anorexia Nervosa.

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26 Exposure treatment is a treatment method involving the exposure of a patient to their anxiety source is a safe environment to overcome the anxiety.
Recovery

Eating Disorder Relapse: Further research is needed around the eating disorder relapse period to better understand the predictive factors of relapse, relapse prevention strategies, and differences between population segments.

Relapse Prevention: While relapse prevention programs do exist, many are not built upon evidence-based practices and are not individualized for the patient. Multi-institute studies must be conducted to build robust evidence-based relapse prevention programs that employ evidence-based definitions of recovery, as well as individualized assessments, treatments, and predictors of recovery.

Recovery Transition Period: Little research has been performed on the transition period between the treatment center and the home. This is often the most perilous period for someone recovering from an eating disorder, where high rates of relapse are observed. Research is needed to identify best practices on how to support the transition from treatment centers back to home life, especially regarding nutrition.

Intersectionality

Underserved Populations: Research is needed to better understand the relationship between racism and weight stigma, the impact of marginalization on eating disorder risk and treatment, and the impact of food insecurity in different racial and ethnic and other economically marginalized groups. Further studies are also essential to examine the clinical presentation, risk factors, and testing of existing theoretical models with underserved populations, such as food insecure populations, racial/ethnic minorities, men, LGBTQ individuals, low-income persons, athletes, and military service members and veterans.

Culturally Competent Treatment: More research is needed to develop culturally competent treatments for diverse populations, such as transgender and gender non-conforming individuals, for whom gender- and transition-affirming treatment may be paramount to recovery.

Psychotropic Medication

NIMH should expand research focused on re-purposing already approved medications for use in eating disorders. There are many potential medications that have the potential to treat Anorexia Nervosa or ARFID if they could be appropriately evaluated.

NIH Recommendations

1. Triple the amount of eating disorders research studies across the various ICOs, focusing on the gaps in eating disorders research.
2. Provide Congress the FY21 report on the status of eating disorders research, as was directed within the Consolidated Appropriations Act, 2021 (P.L. 116-260).
3. Create an Interagency Eating Disorders Coordinating Committee, like the Interagency Autism Coordinating Committee\textsuperscript{27}, to further facilitate activities, programs, policies, and research related to eating disorders.
4. Build a mental health promotion program within HHS focused on LGBTQ suicidal ideation as well as anxiety, depression, and disordered eating behaviors and integrate mental health promotion components into existing LGBTQ-targeted smoking cessation and sexual health programs.

\textsuperscript{27} https://iacc.hhs.gov/about-iacc/overview/
Centers for Disease Control and Prevention (CDC)

The CDC has conducted almost no research around eating disorders, yet eating disorders are highly related to other priority areas for the CDC, including nutrition, physical activity, and obesity. Without recognition and attention to the role of eating disorders in these and other domains, the CDC’s prevention and health promotion interventions are not only less effective than they could be but also can lead to unintended consequences of worsening weight stigma and disordered eating and eating disorders in young people. For example, research has shown that youth facing food insecurity have higher levels of concerning dietary restraint and 2 times higher likelihood of uncontrolled eating compared to youth without food insecurity.28 Further, these youth also had higher BMI’s than youth without food insecurity.29 We also know that food insecurity impacts communities of color at higher rates than white communities, with Hispanic and Black households facing food insecurity rates that are 1.5 or 2 times higher than the national average.30 Without conducting research and analyzing prevention and intervention strategies that take into account these important comorbid conditions, the CDC’s work is incomplete.

CDC Recommendations

1. Under the Prevention Research Centers, study the following activities:
   a. The effects of youth obesity prevention programs on youth at-risk of disordered eating or an eating disorder.
   b. How school physical activity and nutrition promotion programs can be tailored to prevent eating disorders, disordered eating, weight stigma, and body dissatisfaction.
   c. Best mechanisms for prevention and early identification for historically underserved populations, including, but not limited to, persons of color and LBGTQ+.

2. Create a Translational Research Program, in coordination with NIH, to bring the science to practice.

Agency for Healthcare Research and Quality (ARHQ)

The utilization of Body Mass Index (BMI) in medical and non-medical settings and in federal agencies as a valid measure of health needs to be reexamined. The BMI model does not account for individual differences in body composition (i.e., muscle, bone density, shape, etc.) and is extremely harmful to individuals, especially youth. Pediatricians reported that BMI screenings may worsen stigmatization and body image already experienced by higher weight children, increasing the possibility of inappropriate weight-loss practices that could lead to eating disorders.31 A high BMI may lead parents to promote dieting or restriction of certain foods or for the child to adopt these techniques. Limiting the caloric intake of children can be harmful to a child’s growth and may lead children to sneak food, hide food, or overeat when they are presented with an unlimited amount of food. BMI reporting can also lead to peer weight talk and teasing in schools, or worse bullying.

29 Ibid.
30 Ibid.
Stigmatization of becoming fat in today’s society starts at a young age and children have an early awareness that having a fat body is socially unacceptable.32 Studies have found that children as young as 5 years old have already learned society’s cultural bias against fat people and that stigmatization of fat children by other children has increased by 41% in the last 40 years.33 Some of this suffering could be prevented if BMI screening were removed from medical and non-medical institutions (i.e., schools). BMI screenings also cause increased body dissatisfaction and put pressure on children (and adults alike) to achieve a certain body type which only increases the likelihood of developing an eating disorder. Children in higher weight bodies are at a higher risk for low self-esteem, depression, and social isolation. Self-esteem plays a key role in a child’s motivation and achievements. We need to do better to protect today’s children and adolescents through self-esteem and confidence building.

ARHQ Recommendations

1. Reevaluate screening for obesity via BMI measurements in medical and non-medical settings.

HHS Office of the Assistant Secretary of Health (OASH)

Interagency Task Force

Under the authorization of the 21st Century Cures Act, an informal interdepartmental working group on eating disorders under the leadership of the HHS’ Office on Women’s Health was established to enhance collaboration between agencies. This collaboration included a 2019 convening entitled, “How to Talk About Healthy Weight and Healthy Eating: A Cross-Disciplinary Dialogue on Messaging to Promote Healthy Behaviors and Positive Body Image” to foster collaboration between subject matter experts in obesity and eating disorders. However, a dedicated commitment to address the severity of eating disorders as a serious mental illness is warranted. Establishing a formalized task force on eating disorders to create federal leadership and detail short- and long-term recommendations to strengthen eating disorder research, awareness, prevention, intervention, and treatment including solutions to address health disparities in both public and private sectors.

Advising FTC on Social Media

Social media use increased 61% during the first COVID-19 wave34 while eating disorder hospitalizations more than doubled since March 2020.35 The rise in social media use among youth coupled with The Wall Street Journal’s Facebook Files series revealed Facebook’s own research teams knew the company platforms inflict damage on the physical and mental well-being of our nation’s youth.36 Facebook’s internal research found that 32% of teenage girls reported that when they feel bad about their bodies, Instagram makes them feel worse.37 Further, 65% of teenage users saw content that reinforced feelings of not being attractive and 60% saw content that reinforced feelings of not being good enough.38 Another report

32 Ibid.
33 Ibid.
37 Ibid. (33)
38 Ibid. (33)
conducted an analysis of 240 Instagram posts using 4 popular hashtags finding 52.9% directly supported an eating disorder; 88.3% promoted appetite suppressants; and over 38% emphasized the “thigh gap.”

The Federal Trade Commission (FTC) has the authority to penalize companies that engage in deceptive and unfair practices. Given this existing authority, the FTC should collaborate with a range of experts through OASH in mental health and social media addiction to better understand the ways in which these platforms are designing their algorithms or other internal processes that produce harmful outcomes for young users.

**OASH Recommendations**

1. Create and fund an Advisory Committee to inform the FTC of deceptive and unfair practices of social media companies.
2. Formalize an Interagency Task Force on Eating Disorders to increase interagency leadership and coordination.

**Centers for Disease Control and Prevention**

Section 13005 of the 21st Century Cures Act authorized HHS to update, expand, and publicize information and resources on eating disorders and advance public awareness on the types, seriousness, signs, and symptoms of eating disorders; methods to identify and refer; and the effects of media, discrimination, and bullying on body image and self-esteem. Under this authority, more action can be taken for promotion and prevention under the CDC. Given the recent impact of the COVID-19 pandemic and isolation on eating disorder diagnoses and hospitalizations, particularly among adolescents, it is incumbent upon the CDC to improve public understanding via a national awareness campaign. There continue to be several misunderstandings about the presentation of eating disorders that contribute to low identification and treatment rates, particularly for underserved communities. An assertive national awareness campaign is critical to improving public understanding of eating disorders, as authorized by 21st Century Cures, especially in the wake of pandemic-related increases.

**National Awareness and Eating Disorders Home**

An awareness campaign through the Centers for Disease Control and Prevention would align with previous activities the CDC has conducted. However, a barrier to establishing a campaign is that the CDC does not have a home to address eating disorders, which in turn creates no division leadership for programming, resources, and related activities. Based on our conversations with various Divisions and Centers within the agency, the placement we would recommend is the Division of Nutrition, Physical Activity, and Obesity (DNPAO). Currently, eating disorders information is dispersed among various divisions, centers, and branches, effectively making it a topic nowhere. This dispersant nature results in little coordination or communication between different CDC entities. Eating disorders placement within DNPAO would be a strong first step in prioritizing this illness as we cannot talk about obesity without talking about disordered eating behaviors and eating disorders. A sole focus on obesity prevention has shown to have unintended consequences for some individuals resulting in body dissatisfaction, weight stigma, and unhealthy weight control behaviors.

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39 SumOfUs. (2021). Eating disorders, plastic surgery, and skin whitening on Instagram: How young people are exposed to toxic content. Retrieved from [https://cdn.sanity.io/files/k97a60yb/production/579f4d97875580eb08d4c286c1d123f79d224226.pdf](https://cdn.sanity.io/files/k97a60yb/production/579f4d97875580eb08d4c286c1d123f79d224226.pdf)

Providing information, resources and supports on disordered eating and eating disorders within the same division affords the opportunity to provide education on the signs and symptoms of eating disorders, regardless of an individuals’ body size. Individuals in larger bodies often go undiagnosed for eating disorders. Discrimination against individuals in larger bodies can be problematic as it increases dissatisfaction with ones’ body weight/or shape, which is a risk factor for the development of an eating disorder. In order to improve the healthcare provided to both the obesity and eating disorder communities, there must be a greater exchange of specialized knowledge and care between health care providers working in the obesity field with those working in the eating disorders field and vice versa.

An alternative consideration would be to house eating disorders within the Division of Population Health, National Center for Chronic Disease Prevention and Promotion, School Health Branch. Given the age of onset of eating disorders can occur early in life, an awareness campaign or education efforts within schools can provide a foundation for prevention of this serious mental illness. Over the years, various organizations have created evidence-based, or evidence informed school curriculum on eating disorders, disordered eating and creating body confident school environments. Similar curricula have been developed for parents to ensure that what students are taught within the school setting carries into their home environment.

**CDC Recommendations**

1. Create a home for eating disorders, either within the Division of Nutrition, Physical Activity and Obesity or the Division of Population Health, School Health Branch.
2. Create a national awareness campaign.
3. Fund prevention programs for schools, like Be Real USA and Planet Health, to increase eating disorders prevention and body positivity amongst youth and resources for school personnel, parents, and guardians.
4. Re-instate items measuring “Unhealthy Weight Control Practices” within the standard and/or national Youth Risk Behavior Surveillance Survey (YRBSS).

**Substance Abuse and Mental Health Service Administration (SAMHSA)**

**National Center of Excellence for Eating Disorders**

Section 13006 of the 21st Century Cures Act authorized HHS to train health professionals to early identify, refer, and treat eating disorders. With this authorization, SAMHSA created the National Center of Excellence for Eating Disorders (NCEED), which provides training and technical assistance for health professionals on the management of eating disorders. In fact, NCEED recently created a program to train primary care health professionals on screening, brief intervention, and referral for treatment (SBIRT) for adults at risk of eating disorders (ED). This NCEED SBIRT-ED module is the first training program of its kind and represents a huge step forward in primary care recognition of and training for the prevalence of eating disorders. We applaud these efforts and encourage SAMHSA to re-fund NCEED to create an SBIRT model for children and adolescents and underserved populations. Congress supports these efforts and has included report language in FY22 directing these trainings to be implemented within the HRSA Primary Care & Training Enhancement grants.

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42 Ibid.(40)
**National Suicide Lifeline**

In a recent evaluation of the National Suicide Lifeline, “chatters whose main concern related to eating disorders and physical health had significantly and substantially higher odds of being more suicidal at the end of the chat than those who were mainly concerned about their depression.” The study revealed that there were some deficiencies in the crisis chat counselors’ interventions, with them being well-equipped to intervene with chatters whom depression was the main concern, but less favorable for eating disorders, with a recommendation to enhance crisis counselor training in these areas. Knowing the severity of eating disorders, this is a concerning finding that must be addressed, especially given there is currently not a National Hotline for Eating Disorders. With that, we’d urge further training on eating disorders by experts in the field as well as considering a federal National Eating Disorders hotline that callers can be referred to for help with emotional support and referral to care.

**SAMHSA Recommendations**

1. Increase NCEED funding to train more health professionals and expand their adult SBIRT program.
2. Create and fund a youth SBIRT program.
3. Formulate SBIRT for underserved populations including American Indians, LGBTQ, persons of color, and people with disabilities.
4. Require the suicide lifeline to be trained on eating disorders and provide referrals.
5. Create a nationally funded eating disorders 24/7 hotline to provide emotional support and referral for care to individuals affected by eating disorders.

**Indian Health Service (IHS)**

There is limited research on the prevalence of eating disorders among American Indian and Alaska Native populations. One 1997 study found that nearly half of surveyed Native American girls were trying to lose weight – a rate higher than any other racial group. Rates of dieting among Native American boys also reached almost one-third. In a 2000 National Eating Disorders Screening Program, more African American, American Indian, Asian/Pacific Islander, and Latino boys reported symptoms of eating disorders than did white boys. Symptomatic boys may be overlooked by clinicians, school personnel, parents, and others because the prevalence of eating disorders in boys is commonly underestimated. But as can be seen from in the 2000 study, the American Indian population is affected, and further research must be done.

**IHS Recommendations**

2. Fund Indian Health Service to conduct:
   a. Research and data collection on the prevalence of eating disorders among Native American & Alaska Native adolescents and adults through the Division of Planning, Evaluation, and Research; and

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45 Ibid.

b. Trainings in eating disorders screening, intervention, and referral for all Indian Health Service professionals who provide direct patient care in coordination with NCEED.

Health Resources and Services Administration (HRSA)
The FY22 Labor, Health and Human Services, Education and Related Agencies committee report passed the House earlier this year and includes language to further support and enable the agency to facilitate evidence-based trainings for health professional to identify patients with eating disorders and refer them to appropriate treatment. Given the lack of medical residency programs offering eating disorders training electives, large gaps in identification remain in the primary care setting and for specific demographics, which are discussed below.

Maternal Health and Eating Disorders
Although society is making progress to break down the stigma associated with mental illness, there is still much more work to be done to address the mental health needs of new and expectant mothers. Surprising to most, maternal mental health (MMH) disorders are the most common complication of pregnancy in the U.S., surpassing gestational diabetes and preeclampsia combined. Further, deaths by suicide, in combination with accidental drug-related deaths, accounted for almost 20% of postpartum deaths during 2010-2012. For the estimated 7.5% of pregnant women with an eating disorder, they are at increased risk of depressive symptoms during pregnancy compared to women without an eating disorder. Additionally, the pregnancy and postpartum period is a particularly high-risk period for the reemergence or worsening of disordered eating and body image concerns regardless whether the woman has a history of an eating disorder. Given the health risks of having an active eating disorder during pregnancy including antepartum hemorrhage, hyperemesis gravidarum, higher risk of miscarriage, cesarean sections, and postpartum depression, coverage and access to mental health treatment is paramount.

School-Based Health Centers and Telehealth
Access to mental health supports for children and adolescents, including eating disorders also presents significant gaps in care. Despite nearly 2,000 School-Based Health Centers (SBHCs) operating nationwide, SBHCs are required in statute only to provide “primary health services to children.” Simultaneously, the

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47 Primary Care Training and Enhancement – COVID-19 worsened eating disorders across the nation with one study reporting up to 76% of respondents engaging in eating disorder behaviors. Despite the medical and psychiatric acuity associated with eating disorders, many patients remain undetected and untreated as only 20% of surveyed medical residency programs offer elective training in eating disorders and 6% require such training. Within this total, the Committee provides up to $1,000,000 for the program, in coordination with SAMHSA’s National Center of Excellence for Eating Disorders, to provide trainings for primary care health professionals to screen, briefly intervene, and refer patients to treatment for the severe mental illness of eating disorders, as authorized under section 13006 of the 21st Century Cures Act (Public Law 114–255).


52 Ibid.


54 Social Security Act §2110 (ssa.gov)
prevalence of anxiety among children has increased 21% since 2017-2018 and teen suicide has increased by 26% since 2014-2016.\textsuperscript{55} Furthermore, nearly 120 million Americans currently live in a Mental Health Care Health Professional Shortage Area (HPSA).\textsuperscript{56} These shortages are particularly acute for children and youth enrolled in Medicaid and the State Children’s Health Insurance Program (CHIP) because many providers do not accept public insurance.\textsuperscript{57} Especially during the COVID-19 pandemic, telehealth has proved to be a vital tool for connecting with providers, particularly mental health providers. However, weaknesses in internet broadband coverage in underserved areas of the county limited access to tele-mental health for people in these areas. Moving forward, public school campuses can be a critical location for hosting tele-mental health appointments for students who live and/or go to school in HPSAs, especially for those living in homes without internet access or in areas of the country without strong internet coverage.

\textit{Care Coordination Modeled After Head Start}

Individuals affected by eating disorders and their loved ones spend up to six weeks of unpaid time off to help their loved ones identify and coordinate care. One successful federal program is the national Head Start programs for children, which assists families by referring them to specialized care, providing a care coordinator to schedule care, creating goals for care, and working through care. Creating a similar model for mental health for youth and adults will be a huge assistance to ensure individuals affected are able to receive care.

\textbf{HRSA Recommendations}

1. Integrate an eating disorders early identification program into Primary Care Training and Enhancement grants, considering NCEED as a resource.
2. Integrate eating disorders early identification training into maternity care programs.
3. Require HRSA School Based Health Center funds to be contingent on the school incorporating mental health prevention, early intervention, and referral into existing procedures.
4. Create a funding mechanism for schools to facilitate tele-mental health appointments for students, particularly in Health Professional Shortage Areas.
5. Build a state-based care coordination program modeled after Head Start for mental health care that can be referred to on behalf of a primary care provider and help connect patients with care based on their insurance eligibility, coordinate provider waitlists, and create a structured care coordination plan to demonstrate improvement in their recovery process.

\textbf{Access to Care and Recovery}

\textbf{SAMHSA}

\textbf{CCBHCs}

While we applaud Congress for its investments in Certified Community Behavioral Health Clinics (CCBHCs) and the significant investment they have received since the passage of the Excellence in Mental Health Act, we need to ensure that these investments are used to their full potential. Full Implementation of the CCBHCs model requires a significant investment in infrastructure and training to support the provision of high-quality mental health services.

\begin{itemize}
\item \textsuperscript{56} Kaiser Family Foundation (September 30, 2021). Mental Health Care Health Professional Shortage Areas (HPSAs) Retrieved from https://www.kff.org/other/state-indicator/mental-health-care-health-professional-shortage-areas-hpsas/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22%2C%22sort%22:%22%2C%22asc%22:7D.
\end{itemize}
Health Act and recent relief packages including receiving $936 million from the Biden administration in July.\(^{58,59}\) CCBHCs typically do not provide eating disorders care. Additionally, SAMHSA continues to classify eating disorders care as “specialized services” and therefore do not require CCBHCs to screen, assess, diagnose, or treat in-house.\(^{60}\) However, underserved and vulnerable populations are particularly under-resourced in eating disorders identification and treatment despite higher prevalence.\(^{61}\) These barriers are magnified by pandemic rises in food insecurity,\(^{62}\) which is demonstrated to increase risk for eating disorders.\(^{63}\)

**Serious Mental Illness Listing**

Serious mental illnesses (SMI) are defined as “someone over the age of 18 who has a diagnosable mental, behavioral, or emotional disorder that interferes with or limits one or more major life activities.”\(^{64}\) Given these complexities and limitations, illnesses that meet this definition are rightly afforded many benefits. For example, individuals with SMIs also have housing benefits offered to them under Section 811 of the Supportive Housing for Persons with Disabilities programs. The program allows persons with disabilities to live as independently as possible in the community by subsidizing rental housing opportunities.\(^{65}\) To the best of our knowledge, since eating disorders are not yet categorized by SAMHSA as an SMI, they do not qualify for this program. Individuals with eating disorders routinely must go to extraordinary lengths to access treatment and often are required to pay for these services out-of-pocket; therefore, access to subsidized housing programs should be ensured.

Eating disorders are often misunderstood and thought of as lifestyle choices, when in fact they are “bio-psycho-social diseases, which means that genetic, biological, environmental, and social elements all play a role.”\(^{66}\) We strongly recommend SAMHSA designate eating disorders as a SMI to allow individuals to access benefits that will help support them as they work to receive treatment and recover from their eating disorder.

**SAMHSA Recommendations**

1. Update requirements for CCBHCs to provide eating disorders screening, assessment, diagnosis, treatment planning, and outpatient services in-house, just like other behavioral health conditions.
   a. At minimum, SAMHSA should furnish Screening, Brief Intervention, and Referral to Treatment (SBIRT) trainings in eating disorders for all CCBHC staff providing direct care to fill existing gaps.

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58 SAMHSA Awards $250 Million to 100 Certified Community Behavioral Health Centers to Improve Community Substance Use Disorder and Mental Health Treatment Services | HHS.gov
59 With Pandemic Worsening the Mental Illness and Addiction Crisis, Biden Administration to Provide Nearly $2.5 Billion to States, Territories for Treatment, Prevention Aid | SAMHSA
61 Ibid.
62 54 million people in America face food insecurity during the pandemic. It could have dire consequences for their health | AAMC
64 SMI Advisor. “What is Serious Mental Illness?” Retrieved from smiadviser.org/about/serious-mental-illness.
b. Require eating disorders screening be included in Medicaid mandated EPSDT program and if the PHQ-9 used, require clinical follow up for evaluation of child if item #5 on dysregulation of eating behavior endorsed.

2. List eating disorders as a serious mental illness to allow state and local government to be able to support things like disability.

Centers for Medicare and Medicaid Services (CMS)

Telehealth

The COVID-19 pandemic has drastically changed health care delivery and we commend CMS efforts and Congressional efforts in providing numerous flexibilities in service delivery to ensure individuals can still receive the health care they need during this difficult period. The mental health impacts across the nation continue to persist with 47 percent of Americans reporting negative mental health effects related to worry and stress from the pandemic. According to FAIR Health, mental health conditions accounted for over 60 percent of the top five diagnoses delivered via telehealth in July 2021 versus 45 percent in July 2020.

To protect staff and patients and adhere to social distancing guidelines, eating disorders treatment centers pivoted quickly to telehealth for our PHP and IOP programs. This allowed for patients in residential or inpatient care or who required PHP in-person treatment to safely continue receiving care. We estimate that 75 percent of treatment centers are delivering care via telehealth in addition to providing in-person services. It is important to note that telehealth will never replace in-person care, but it will serve as an additional tool in providing specialized, multidisciplinary treatment to those in need. For example, one treatment center paired Medicaid patients in-person vital sign check-up with food pantry pick up for those experiencing food insecurity.

The pandemic has given providers the opportunity to study the efficacy of providing eating disorders treatment via telehealth with positive results. A recent study compared eating disorder care in a telehealth (virtual) IOP setting vs. IOP in-person setting and found no differences in patient outcomes. The findings included a significant decrease in eating disorders symptoms, depression, and perfectionism and a significant increase in body mass index/weight restoration. Another study examined outcomes of providing telehealth (virtual) IOP services and reported significant and clinically meaningful improvements in all outcomes measured including self-reported eating disorders symptoms, depression and self-esteem, and overall quality of life. Recent research also shows that telehealth and digital therapeutics may improve help-seeking behavior particularly in adolescents. As of 2018, 95% of teens had access to a smartphone.

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71 Ibid.


– opening up access points for mental health care. Particularly during the pandemic, telehealth services have become a critical mainstay of adolescent health and indicate the positive outcomes of service expansion.

These findings underscore what we have seen in treatment centers every day since the onset of the pandemic. Expanding access to eating disorders care through telehealth continues to fill a great need for individuals without transportation, individuals in communities where there are no local treatment options for specialized care, individuals residing in areas with inclement weather, increased participation in family-based therapy (FBT), and for individuals with co-occurring conditions that make it feasible to participate in treatment from home whereas their condition would normally result in a no-show appointment.

We urge permanently extending telehealth as a covered treatment modality under Medicaid and Medicare. Further, we recommend also providing regulations or guidance requiring telehealth as a covered treatment modality for mental health and substance use disorder within future Affordable Care Act (ACA) plan designs for the delivery of mental and behavioral health care services. Additionally, establishing payment parity with in-person services would allow providers to continue utilizing telehealth as a delivery option. For eating disorders providers, telehealth delivery is not a cost-savings for centers. We are still seeing patients in-person at higher levels of care. Further, some treatment centers have seen their liability insurance premiums increase as much as 30 percent as they transitioned to telehealth delivery. Without establishing payment parity, the continued use of telehealth as a delivery option for our patients will decline.

Care Coverage under Medicare

Prevention and early intervention are the best tools to prevent disease progression for those with mental illness or substance use disorders. Given the complexity of eating disorders, the multidisciplinary treatment team comprised of a medical provider, psychiatrist, psychologist, and registered dietitian is considered to be the key provider component for comprehensive eating disorders treatment. The exponential rise in eating disorders because of the pandemic further underscores the importance of early intervention.

Medicare does not cover residential, partial hospitalization (outside of a hospital), and intensive outpatient treatment for eating disorders. Further, it does not cover registered dietitian services or even an assessment from an eating disorder specialist or the provision of mental health crisis services. As Medicare historically sets the tone for what services other public health insurance and commercial insurance covers and reimburses for, Medicare inadequacies have been replicated within TRICARE and the commercial market which continues to be a disservice for individuals and families with MH/SUD.

Medical nutrition therapy is only covered for individuals with diabetes or end stage renal disease. This lack of coverage leaves individuals susceptible to disease progression and in need of a higher, costlier level of treatment. According to the American Dietetic Association, nutritional therapy conducted by a registered professional is an “essential component” for the treatment of patients with anorexia nervosa, bulimia nervosa, and other eating disorders. Research shows mental health interventions for eating disorders may not be successful if the underlying nutritional issues haven’t been addressed first, since nutritional deficiency causes cognitive issues (e.g., depression) that can impede recovery. Nutrition counseling

75 B. Farrington, personal communication, February 2021.
guides patients in identifying problematic behaviors and setting realistic and achievable nutrition related goals to support clients in making behavior changes. Nutrition education includes conversations about discrepancies between knowledge, beliefs, and behaviors, ultimately empowering the patient to normalize eating and make healthier decisions.\textsuperscript{78}

**CMS Recommendation**

1. Expand the PHE coverage to permanently cover telehealth under Medicare and Medicaid.
2. Expand telehealth under the ACA and institute parity in reimbursement to that of in-person services.
3. Create a pilot program to fund nutrition care services under Medicare under Centers for Medicare & Medicaid Innovation (CMMI).
4. Build-in coverage through Medicaid or another payment system for text counseling and other digital therapeutics.

Sincerely,

The Eating Disorders Coalition for Research, Policy, and Action