November 15, 2021

The Honorable Ron Wyden
United States Senate
Chairman, Finance Committee
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Mike Crapo
United States Senate
Ranking Member, Finance Committee
219 Dirksen Senate Office Building
Washington, DC 20510

Dear Senators Wyden and Crapo,

The Eating Disorders Coalition for Research, Policy & Action (EDC) writes in response to your Request for Information solicited on September 21st. We appreciate your commitment to addressing the United States' growing mental health crisis and particularly changing these systems, which currently miss important opportunities for care coordination, workforce strengthening, and the inclusion of eating disorders screening, intervention, and treatment in federal mental health care programs. **Any future mental health legislative package must assertively include eating disorders care provisions, via trainings for health professionals and requirements for federally funded clinics and programs.**

Eating disorders are often overlooked as a standalone serious mental health condition and in their complex interactions with depression, anxiety, substance use disorder, and other co-morbidities. Nearly 30 million Americans of all ages, races, and genders will experience an eating disorder in their lifetime, and over 10,000 of them will die every year.[1] 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 in the emergency room than someone without an eating disorder.[2] Barriers to comprehensive treatment ultimately cost the U.S. economy $64.7 billion each year, with a $17.7 billion cost to the government.[3]

Eating disorder diagnoses and treatment center admissions have skyrocketed during the COVID-19 pandemic. 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 reported an increase in episodes. Moreover, increased social isolation, disruptions in routine, toxic social media algorithms, and other factors have resulted in disproportionate harm for children and adolescents. Nationally, we have seen a 25% increase in pediatric emergency room admissions for mental health conditions and a 30% increase in adolescent eating disorder diagnosis since the onset of the pandemic[4,5] causing national leaders to declare a national emergency in pediatric mental health.[6] The National Alliance for Eating Disorders saw a 108% increase in referrals and an 82% increase in support group attendance in 2020 and is on pace to surpass those figures in 2021.[7]

PO Box 96503-98807 ■ Washington D.C. 20090
202-543-9570
www.eatingdisorderscoalition.org

EDC EATING DISORDERS COALITION FOR RESEARCH, POLICY & ACTION

Disordered eating behaviors can appear in adolescents as early as age 5,[8] yet school-based mental health and eating disorders care is underfunded and lacks coordination. Adult care faces similar barriers, with marginalized and vulnerable populations particularly under-resourced despite higher prevalence rates.[9] These barriers are magnified by pandemic rises in food insecurity,[10] which is demonstrated to increase risk for eating disorders.[11]

We therefore urge you to make several changes to systems of care for mental health and substance use and ensure remedies for ongoing exclusions of eating disorders care:

Strengthening the Workforce

Authorize and Expand the National Center of Excellence for Eating Disorders

Problem: Only 20% of medical residency programs include even an elective rotation in eating disorders, making primary care professionals' trainings on the topic very limited. 21st Century Cures Act authorized HHS to train health professionals to screen, briefly intervene, and treat individuals affected by eating disorders. This authorization led to the creation of SAMHSA's National Center of Excellence for Eating Disorders (NCEED), housed at the University of North Carolina, and the granting of initial seed money to develop a primary-care specific protocol for eating disorders. This protocol has been successful, however, authorization for the Center will expire next year. Additionally, funds are needed to ensure a robust rollout and ongoing technical assistance, as well as the development of adaptive versions for specific populations (e.g., children/adolescents, the military, etc.).

- *Solution:* Building off the success of 21st Century Cures Act, we recommend authorizing NCEED to expand its SBIRT trainings to all medical specialties and expanding its trainings to school personnel, military and Indian Health Service providers, and others to help address the current eating disorders epidemic amongst specific populations. While NCEED does not live directly within the Senate Finance Committee's jurisdiction, building out this workforce development will help Americans receiving care under Senate Finance's jurisdiction.

Increasing Integration, Coordination, and Access to Care

Certified Community Behavioral Health Clinic (CCBHC) Reform

Problem: 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 and recent relief packages (including receiving $936 million from the Biden administration in July)[12,13] CCBHCs typically do not provide eating disorders care. Additionally, SAMHSA continues to classify eating disorders care as "specialized services" and therefore does not require CCBHCs to screen, assess, diagnose, or treat in-house.[14] However, marginalized and vulnerable populations are particularly under-

resourced in eating disorders identification and treatment despite higher prevalence rates.[15] These barriers are magnified by pandemic rises in food insecurity,[16] which is demonstrated to increase risk for eating disorders.[17]

- *Solution*: To reduce the significant care need amongst marginalized and lower income individuals, require CCBHCs to provide eating disorders screening, assessment, diagnosis, treatment planning, and outpatient treatment services in-house, just like other behavioral health conditions. At minimum, Screening, Brief Intervention, and Referral to Treatment (SBIRT) trainings in eating disorders should be furnished for all CCBHC staff providing direct care to fill existing gaps.

Community Mental Health Services Block Grant Reform

Problem: Traditionally, states have used Community Mental Health Services Block Grant (MHBG) funding primarily for interventions on substance use disorder, schizophrenia, bipolar disorder, anxiety, and depression – neglecting the high need among individuals with eating disorders. This misallocation is driven by the misconception that eating disorders only affect middle and high-income white women, and not the low-income communities of color that are the focus of MHBG funding.

- *Solution*: Introduce performance requirements for MHBG grantees that are inclusive of eating disorder outcomes in grantee communities.

Mental Health Care Coordination System

Problem: Individuals with recent mental health diagnoses often struggle to identify and access appropriate mental health care, leading their conditions to go untreated. Trends in prevalence of depression and other conditions translate into a growing number of people – in particular, adolescents and young adults – who go without treatment.[18]

- *Solution*: Build a state-based care coordination program modeled after Head Start[19] for mental health care to which Primary Care providers can refer patients for support with insurance eligibility and provider waitlists, and the creation of a structured care coordination plan to demonstrate improvement in their recovery process.
- *Solution*: Furnish trainings for judicial professionals and other criminal justice stakeholders to identify the signs and briefly intervene for individuals struggling with mental illness, particularly eating disorders.

Ensuring Parity Between Behavioral and Physical Health Care

Medicare Parity for Medical Nutrition Therapy

Problem: Although not often discussed, prevalence rates for eating disorders among Medicare beneficiaries are just as high as those of the general population: 3 to 6 percent.[20,21] However, older Americans with eating disorders are particularly vulnerable as existing chronic disorders or co-occurring conditions may already compromise their health.[22, 23] Among deaths due to anorexia nervosa, 78% occur among seniors – demonstrating that older Americans bear an outsized burden of eating disorder fatalities.[24] Comprehensive and successful eating disorders treatment is comprised of four critical components including psychiatric, psychological, medical, and Medical Nutrition Therapy (MNT). MNT is an evidence-based medical approach to treating chronic conditions, particularly eating disorders, through an individualized nutrition plan.[25] Unfortunately, Medicare Part B does not cover MNT for patients with eating disorders – even though it covers the same benefit for patients with diabetes or end-stage renal disease. Without coverage for this key care component, Medicare Part B beneficiaries are left without the comprehensive treatment they need to successfully recover.

- *Solution*: Pass H.R.1551/S.584 the Nutrition CARE Act to close the parity gap and provide Medicare coverage of MNT for patients with eating disorders at the same level as for patients with diabetes or end-stage renal disease.

Indian Health Service Action on Eating Disorders

Problem: There is limited research on the prevalence of eating disorders among American Indian and Alaska Native populations, and even less targeted eating disorders screening and treatment. One 1997 study found that nearly half of surveyed Native American girls were trying to lose weight – a rate higher than any other racial demographic.[26] Rates of dieting among Native American boys also reached almost one-third.[27]

- *Solution*: Fund Indian Health Service to ensure eating disorders care, including Medical Nutrition Therapy, is covered and provided within IHS care contexts.

Furthering the Use of Telehealth

Funding Mechanism for School Tele-Mental Health Care Facilitation

Problem: Nearly 120 million Americans currently live in a Mental Health Care Health Professional Shortage Area (HPSA).[28] 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.[29] Especially during the COVID-19 pandemic, telehealth has proved to be an important tool for connecting with providers, particularly mental health providers. 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.

EDC EATING DISORDERS COALITION FOR RESEARCH, POLICY & ACTION

- *Solution*: Create a funding mechanism for schools to facilitate tele-mental health appointments for students, particularly in Health Professional Shortage Areas.

Payment System Coverage for Digital Therapeutics

Problem: Recent research shows that telehealth and digital therapeutics may improve help-seeking behavior in adolescents.[30] As of 2018, 95% of teens had access to a smartphone[31] – 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.

- *Solution*: Build-in coverage through Medicaid or another payment system for text counseling and other digital therapeutics.

Improving Access to Behavioral Health Care for Children and Young People

Integrating Mental Health into Existing CMS LGBTQ-Targeted Programming

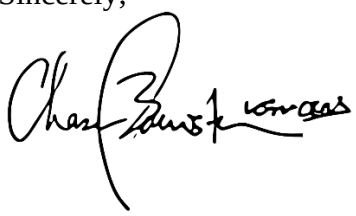
Problem: 40% of LGBTQ youth ages 13-24 and 52% of transgender/nonbinary youth seriously considered attempting suicide in the past year.[32] 68% of LGBTQ youth and more than 75% of transgender/nonbinary youth suffered from generalized anxiety disorder symptoms in the past two weeks.[33] Approximately 54% of LGBT adolescents have been diagnosed with a full-syndrome eating disorder in their lifetime, and another 21% suspect they have suffered from an undiagnosed eating disorder.[34] HHS currently operates multiple LGBTQ-targeted health promotion programs to encourage smoking cessation[35] and sexual health.[36] Anxiety, depression, and eating disorders often co-occur and can lead to tobacco use[37,38] and risky sexual behaviors.[39,40]

- *Solution*: Given the overrepresentation of LGBTQ youth and young adults in the Medicaid population, build a mental health promotion program within CMS focused on LGBTQ suicidal ideation as well as anxiety, depression, and disordered eating behaviors and integrate mental health promotion components into existing HHS LGBTQ-targeted smoking cessation and sexual health programs.

Thank you for your important work to advance mental well-being in America. The Eating Disorders Coalition stands ready to assist you in any way possible to expand provider training and treatment services for eating disorders and other mental health conditions. Building an inclusive and expansive mental and behavioral health system is critical to strengthening our communities and empowering a brighter future for every generation.

PO Box 96503-98807 ■ Washington D.C. 20090
202-543-9570
www.eatingdisorderscoalition.org

Sincerely,



Chase Bannister, MDIV, MSW, LCSW, CEDS
President of the Eating Disorders Coalition for Research, Policy & Action

---

[1] Report: Economic Costs of Eating Disorders | STRIPED | Harvard T.H. Chan School of Public Health

[2] Tackling Relapse Among Anorexia Nervosa Patients. (2013). *Eating Disorders Review*, 24, 9-11.; Yafu Zhao, M., & Encinosa, W., Ph.D. (2011, September). An Update on Hospitalizations for Eating Disorders, 1999 to 2009. Retrieved from http://www.hcup-us.ahrq.gov/reports/statbriefs/sb120.jsp

[3] Ibid.

[4] Leeb RT, Bitsko RH, Radhakrishnan L, Martinez P, Njai R, Holland KM. Mental Health–Related Emergency Department Visits Among Children Aged <18 Years During the COVID-19 Pandemic—United States, January 1-October 17, 2020. *MMWR Morb Mortal Weekly Rep 2020;*69:1675-1680. Retrieved from https://www.cdc.gov/mmwr/volumes/69/wr/mm6945a3.htm

[5] Tanner, Lindsay. (May 23, 2021). Pandemic has fueled eating disorder surge in teens, adults. Associated Press. Retrieved from Pandemic has fueled eating disorder surge in teens, adults (apnews.com).

[6] AAP, AACAP, CHA declare national emergency in children's mental health | AAP News | American Academy of Pediatrics

[7] Johanna Kandel, personal communication, May 2021.

[8] Ibid.

[9] Ibid.

[10] 54 million people in America face food insecurity during the pandemic. It could have dire consequences for their health | AAMC

[11] University Relations News Service, "Research Brief: Food Insecurity Raised Risk for Disordered Eating in Low-Income Adolescents," University of Minnesota Twin Cities (University of Minnesota, Twin Cities, August 13, 2020).

[12] SAMHSA Awards $250 Million to 100 Certified Community Behavioral Health Centers to Improve Community Substance Use Disorder and Mental Health Treatment Services | HHS.gov

[13] 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

[14] CCBHC-Criteria-Updated-May-2016 (samhsa.gov)

[15] Ibid.

[16] 54 million people in America face food insecurity during the pandemic. It could have dire consequences for their health | AAMC

[17] University Relations News Service, "Research Brief: Food Insecurity Raised Risk for Disordered Eating in Low-Income Adolescents," University of Minnesota Twin Cities (University of Minnesota, Twin Cities, August 13, 2020).

[18] National Trends in the Prevalence and Treatment of Depression in Adolescents and Young Adults | American Academy of Pediatrics (aappublications.org)

[19] Head Start Programs | The Administration for Children and Families (hhs.gov)

[20] Peat, Christine; Peyerl, Naomi; and Muehlenkamp, Jennifer. (2010). Body Image and Eating Disorders in Older Adults: A Review. The Journal of General Psychology, 135:4, 343-358.

[21] Mangweth-Matzek B, Hoek HW. Epidemiology and treatment of eating disorders in men and women of middle and older age. Curr Opin Psychiatry. 2017;30(6):446–451. doi: 10.1097/YCO.0000000000000356.

[22] Peat, Christine; Peyerl, Naomi; and Muehlenkamp, Jennifer. (2010). Body Image and Eating Disorders in Older Adults: A Review. The Journal of General Psychology, 135:4, 343-358.

PO Box 96503-98807 ■ Washington D.C. 20090
202-543-9570
www.eatingdisorderscoalition.org

[23] Ibid.
[24] Blog, R. L., & by Age, N. Older Clients and Eating Disorders By Stanley J. Dudrick, MD, FACS Today's Dietitian Vol. 15 No. 11 P. 44.
[25] National Cancer Institute. (n.d.) NCI Dictionary of Cancer Terms. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/medical-nutrition-therapy
[26] e8.full.pdf (aappublications.org)
[27] Ibid.
[28] Mental Health Care Health Professional Shortage Areas (HPSAs) | KFF
[29] Telehealth and Mobile Technology in Child, Youth, and Young Adult Behavioral Health (umaryland.edu)
[30] Kauer, S.D., Mangan C., and Sanci, L. (2014). Do Online Mental Health Services Improve Help-Seeking for Young People? A Systematic Review. Journal of Medical Internet Research 16(3). Retrieved May 30, 2018, from http://www.jmir.org/2014/3/e66/.
[31] Teens, Social Media & Technology 2018 | Pew Research Center
[32] The Trevor Project National Survey
[33] Ibid.
[34] Eating disorders and disordered eating behaviors in the LGBT population: a review of the literature | Journal of Eating Disorders | Full Text (biomedcentral.com)
[35] LGBT & Smoking | Smokefree
[36] Ready, Set, PrEP (hiv.gov)
[37] Smoking in eating disorders - PubMed (nih.gov)
[38] The Association of Cigarette Smoking With Depression and Anxiety: A Systematic Review (nih.gov)
[39] Eating disorders and disordered eating behaviors among women: Associations with sexual risk - PubMed (nih.gov)
[40] Psychiatric Disorders and Symptoms Associated With Sexual Risk Behavior (psychiatrictimes.com)