



July 1, 2020

Champions Circle
Residential Eating Disorders Consortium

Executive Circle

Clementine
Eating Recovery Center
The Emily Program
Monte Nido
Oliver-Pyatt Centers
Veritas Collaborative
WithAll

The Honorable Diana DeGette
House Committee on Energy and Commerce
United States House of Representatives
2111 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Fred Upton
House Committee on Energy and Commerce
United States House of Representatives
2183 Rayburn Office Building
Washington, D.C. 20515

Policy Circle

Academy for Eating Disorders
National Eating Disorders
Association (NEDA)
The Renfrew Center

Dear Congresswoman DeGette and Former Chairman Upton,

On behalf of the Eating Disorders Coalition for Research, Policy & Action (EDC), we thank you for the development of the 21st Century Cures 2.0 concept paper addressing several policy solutions to assist in our pandemic response, and the promotion of new solutions to improve access and delivery of care to Americans.

Leadership Circle

Alliance for Eating Disorders
Awareness
Bannister Consultancy
Gail R. Schoenbach FREED
Foundation
International Association of
Eating Disorders Professionals
(iaedp)
Focus Treatment Center
Reasons Eating
Disorder Center
The Donahue
Foundation

The Eating Disorders Coalition for Research, Policy & Action (EDC) is a nonprofit organization comprised of patient and caregiver advocates, treatment providers, advocacy organizations, and academics, aimed to advance the recognition of eating disorders as a public health priority throughout the U.S. By promoting federal support for improved access to care, the EDC seeks to increase the resources available for education, prevention, and improved training, as well as for scientific research on the etiology, prevention, and treatment of eating disorders.¹

Advocacy Circle

Center for Change
Laureate Eating Disorders
Program
Walden Behavioral Care

Although society is making progress to break down the stigma associated with mental illness, there is still more work to be done to address the mental health needs of older Americans. Surprising to most, the prevalence rate for seniors with eating disorders is similar to that of the general population at 3 - 4% with anorexia nervosa being the most common.^{2, 3} Although the symptomology of eating disorders in seniors is the same for younger populations, weight loss may be associated with a known medical illness or side effect of a pharmacologic treatment making diagnosis or misdiagnosis common and appropriate treatment delayed.⁴

Support Circle

Academy of Nutrition and
Dietetics
Alsana: Eating Disorders
Treatment and Recovery
Centers
Cambridge Eating Disorder
Center
Center for Discovery
Eating Disorder Hope
Mirasol Eating Disorder Recovery
Centers
Multi-Service Eating Disorders
Association
Park Nicollet Melrose Center
Rosewood Centers for Eating
Disorders
The Center for Eating Disorders at
Sheppard Pratt
Strategic Training Initiative for the
Prevention of Eating Disorders
(STRIPED)

Prevention, early intervention, and comprehensive treatment are key to staving off eating disorders progression regardless of where an individual resides in the life course. With an estimated death every 52 minutes as a direct result of an eating disorder and an annual cost of \$64.7 billion to the U.S. economy, further attention is warranted to support individuals, families, and loved ones affected by this mental illness.⁵ The COVID-19 pandemic has only exacerbated mental health conditions. The toll of extreme social isolation and loneliness has led to an increase in eating disorder

Hope Circle

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Eating Disorder Therapy LA
F.E.A.S.T.
International Federation of
Eating Disorders Dietitians
(IFEDD)
Moonshadow's Spirit
Project HEAL
Stay Strong Virginia
Rogers Behavioral Health
The National Association of
Anorexia
Nervosa and Associated Eating
Disorders
Wrobel & Smith, PLLP

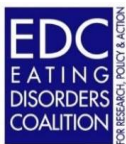
¹ Eating Disorders Coalition. "Mission & Goals." https://www.eatingdisorderscoalition.org/inner_template/about_us/mission-and-goals.html

² 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.

³ Aziz, Victor; Rafferty, Danika; and Jurewicz, Isabella. (2017). Disordered eating in older people: some causes and treatments. *BJPsych Advances*, 23:5, 331-337.

⁴ *Ibid.*

⁵ Deloitte Access Economics. (June 2020). *The Social and Economic Cost of Eating Disorders in the United States of America: A Report for the Strategic Training Initiative for the Prevention of Eating Disorders and the Academy for Eating Disorders*. Retrieved from <https://www.hsph.harvard.edu/striped/report-economic-costs-of-eating-disorders/>



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behaviors, including an increase in restrictive eating in those with anorexia nervosa and more frequent binge eating episodes for those with bulimia nervosa and binge eating disorder.⁶

As we work together to address the mental health needs of Americans across the country, the EDC would like to address two areas within the 21st Century Cures 2.0 concept paper: (1) Caregiver Integration and (2) CMS Modernization and the relationship to eating disorders.

- **Title II, Caregiver Integration:** Caregivers for individuals with eating disorders provide six weeks of informal, unpaid care each year.⁷ Without the proper resources available for carers to address this complex mental illness, recovery can be prolonged. Later life transitions including loss of family, widowhood, increased dependence on others, and chronic condition management are just some of the factors that can serve as contributors to disordered eating behaviors and eating disorders in older adulthood. Adding to the complexity, carers have their own personal reactions to the mental illness that can impede recovery if there is division within the family unit, collusion with some aspects of the illness, and other emotions.⁸ Given these complicated dynamics, the availability of resources that allows for the individual in recovery to decide the level of engagement with the carer is critical.

Emotion-Focused Family Therapy⁹ is one resource for parents and caregivers of individuals regardless of age. Through education, video demonstration, and skills practice, carers are able to gain tools to address meal support and symptom interruption, emotion coaching, relationship repair, and identify and overcome fears that may surface through the carer journey. Individual and family-based therapy (FBT) are also key components to teach the carer how to best support the individual with an eating disorder and acknowledge their own potential disordered eating behaviors and beliefs. Further resource development is needed to ensure that individuals with eating disorders and the individuals and families that care for them are equipped with the most up-to-date information to inform their recovery.

Title VI, CMS Modernization Regarding General Coverage: The fastest-growing segment of the Medicare population are disabled beneficiaries—individuals under the age of 65 who receive Social Security Disability Insurance (SSDI).¹⁰ Importantly, Medicare does not provide coverage for any mental illness at the intensive outpatient (IOP) level of care. This poses a huge barrier for Medicare/SSDI beneficiaries with a mental illness as the individual will have to wait until their condition deteriorates enough to be admitted to a higher level of care (e.g. Inpatient). Unfortunately, if the individual's primary mental illness is an eating disorder, Medicare does not cover residential treatment for eating disorders. These structural program restrictions create unnecessary barriers for comprehensive treatment and need to be adjusted to better serve this population.

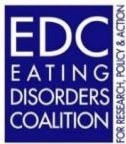
⁶ Termorshuizen, J.; Watson, H.; Thornton, L.; Borg, S.; Flatt, R. ... & Cynthia Bulik. (April 2020). Early Impact of COVID-19 on Individuals with Eating Disorders: A Survey of ~1000 Individuals in the United States and the Netherlands. *medRxiv*. Retrieved from <https://www.medrxiv.org/content/10.1101/2020.05.28.20116301v2>

⁷ Deloitte Access Economics. (June 2020). *The Social and Economic Cost of Eating Disorders in the United States of America: A Report for the Strategic Training Initiative for the Prevention of Eating Disorders and the Academy for Eating Disorders*. Retrieved from <https://www.hsph.harvard.edu/striped/report-economic-costs-of-eating-disorders/>

⁸ Treasure, Janet & Nazar, Bruno. (2016). Interventions for the Carers of Patients With Eating Disorders. *Current psychiatry reports*, 18(2), 16. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4718944/>

⁹ <https://www.emotionfocusedfamilytherapy.org/>

¹⁰ O'Leary, J.; Sloss, E.; & Melnick, G. Disabled Medicare Beneficiaries by Dual Eligible Status: California, 1996-2001. *Health Care Finance Review*, 2007; 28(4): 57-67. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4194998/>



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An additional barrier to receiving comprehensive care is the lack of Medicare coverage for outpatient medical nutrition therapy (MNT) for eating disorders. This treatment involves nutritional diagnostic, therapy, and counseling services for disease management, which typically involves specially designed meal plans developed by a registered dietitian or nutrition professional. The significant morbidity and mortality associated with eating disorders in older adults, and the range of secondary health issues that arise because of the eating disorder including cardiac, metabolic, gastric, and bone conditions,¹¹ makes early diagnosis and proper treatment paramount.

According to the American Dietetic Association, nutritional therapy provided by a registered professional is an “essential component” for the treatment of patients with anorexia nervosa, bulimia nervosa, and other eating disorders.¹² 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.¹³ Without minimizing the risk of a cascade of pathophysiological events for this older population, the morality rate can be as high as 30-40%.¹⁴

Thank you again for your leadership and hard work on the developing the next iteration of innovative health care policy reforms. We look forward to continuing to work with you to support the mental health of all Americans.

Sincerely,

Eating Disorders Coalition for Research, Policy & Action

¹¹ Rome, E.S. and Ammerman, S. (2003). Medical complications of eating disorders: an update. *Journal of Adolescent Health*, 33, 418-426.

¹² Ozier, AD & Henry, BW. “Position of the American Dietetic Association: nutrition intervention in the treatment of eating disorders.” *NCBI/NLM/NIH*. <https://www.ncbi.nlm.nih.gov/pubmed/21802573>

¹³ Rosen, David. (2010). Clinical Report—Identification and Management of Eating Disorders in Children and Adolescents. *American Academy of Pediatrics*, 126:6.

¹⁴ Dudrick, Stanley. (2013). Older Clients and Eating Disorders. *Today's Dietitian*, 15:11, 44.