

Kentucky Eating Disorder Council

Melissa Cahill, Chair

Dr. Alexandria Pruitt, Psy.D., HSPP, Vice Chair

Kate Overberg Wagoner, LCSW, LCADC, CPS, Staff

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KENTUCKY
EATING DISORDER
COUNCIL

Table of contents

Introduction	3
Activities	4
Findings	6
Recommendations and Goals	6

Introduction

The Louisville Eating Anxiety Treatment Laboratory and Clinic's eating disorder fact sheet reports an estimated between six (6) to twenty (20) % of individuals in the United States will suffer from an eating disorder at some point in their life (Louisville EAT Lab <http://www.louisvilleeatlab.com/blog--in-the-press/eating-disorder-fact-sheet>). Based on this information, it is estimated that as many as 900,000 Kentucky citizens may experience symptoms of eating disorder.

Recognizing the importance of proper intervention and treatment for eating disorders, Kentucky passed legislation that was signed into law on July 1, 2020, by Governor Andy Beshear. This legislation created a new chapter of Kentucky Revised Statutes and the Kentucky Eating Disorder Council (KEDC). Enactment of this legislation made Kentucky only the second state in the nation to create a legislatively created body to address the increasing behavioral health concerns related to eating disorders. KEDC's purpose is to increase prevention and awareness of eating disorders, increase access and availability of evidence-based treatment, and improve supportive recovery efforts for individuals and families. A long-term goal of the KEDC is to improve health education by encouraging physical activity, healthy food intake, and decreasing outdated, but omnipresent, education that equates lower body mass index (BMI) as the sole indicator of positive physical health.

Eating disorder is an umbrella term used to describe symptoms related to disturbed or abnormal eating habits. The phrase 'eating disorder' implies only visible symptoms are a part of the disease and does not describe the physical, psychological, and emotional damage that those dealing with eating disorders may experience. There are at least five different types of eating disorders, all with different symptoms and requiring different prevention and treatment modalities. Eating disorders frequently co-occur with substance use and misuse, anxiety and depression, and suicidal ideation. Without proper intervention and treatment, eating disorders can result in heart failure, kidney failure, osteoporosis, and other physical illnesses.

Often, by the time an eating disorder is properly diagnosed, the individual requires a high level of care such as inpatient treatment, which can cost up to \$68,000 per month and does not account for lost time at school or work. Outpatient treatment can cost up to \$200 per session; insurance coverage for eating disorder care is minimal. Currently, there are no residential or inpatient treatment facilities in Kentucky. Individuals and families must seek treatment out of state. There is only one specialized outpatient clinic in the state for eating disorder care.

The KEDC was proposed to identify gaps in treatment for those in need of eating disorder services. Along the process, the need for improved health education and prevention, screening, and recovery support services were also identified as needed in Kentucky.

The council is comprised of nineteen (19) individuals representing government entities, fields of knowledge, and intersects with those at risk of disordered eating, as well as fulfilling the statutorily mandated categories for representation.

In addition to the mandated membership, many individuals from similar fields, and different fields of work, have reached out to council members in order to be a part of the work the council is engaging in.

Each committee includes council members, as well as representation from additional state agencies such as the Department for Community Based Services (DCBS), Family Resource and Youth Service Centers (FRYSC), universities such as the University of Louisville and the University of Kentucky, private agencies, and individuals with lived experience.

According to KRS 210.051, the KEDC shall:

- Oversee the development and implementation of eating disorder awareness, education, and prevention programs;
- Identify strategies for improving access to adequate diagnosis and treatment services;
- Assist the cabinet in identifying eating disorder research projects;
- Work with the Cabinet for Health and Family Services and other appropriate entities to routinely examine existing surveillance systems, data collection systems, and administrative databases to determine the best strategies for implementing evidence-based eating disorder measures that provide data for program and policy planning purposes;
- As reasonably as possible, collaborate and coordinate on data research projects with the Cabinet for Health and Family Services and other appropriate entities;
- Make recommendations regarding legislative and regulatory changes as appropriate;
- Apply for grants from the federal government, private foundations, or other sources that may be available for programs related to eating disorders; and
- Report annually on its activities, findings, and recommendations to the Governor and the Legislative Research Commission.

Activities

During the first meeting of KEDC, members reviewed KRS 210.051 and were asked to share, in their own words, their vision for what the council is tasked with. The council decided to categorize statutorily mandated goals and form subcommittees to guide council activities. The council formed subcommittees on education and prevention, research, and advocacy and legislation.

The Education and Prevention subcommittee developed a speaker's bureau that identified subject matter experts on the specific forms of eating disorders, and populations served,

including individuals comfortable with providing training, and individuals knowledgeable in the development of training topics.

Professional development opportunities were identified, proposals for continuing education were submitted, and education on eating disorders was provided to about 500 individuals.

Members created infographics to raise awareness of signs/symptoms and educate on the prevalence of eating disorders in adults and youth and shared statewide. Additional infographics were developed to help family members and friends support loved ones in recovery from an eating disorder during the holidays and raise awareness for how individuals in recovery may set boundaries for themselves.

Presentations were made to the State Interagency Council (SIAC), Chief Executive Officers (CEOs) of community mental health centers (CMHCs) and the directors of substance use treatment and children's services, substance use treatment of community mental health centers (CMHCs) and regional prevention centers by Dr. Alexandria Pruitt, PsyD, HSPP, Vice-Chair KEDC, on the development and activities of the council.

The Research subcommittee developed and disseminated a survey to behavioral health providers at CMHCs, behavioral health service organizations (BHSOS), and multi-service groups (MSGs) to assess screening and treatment practices of behavioral health providers. Over seventy (70) responses from across Kentucky expressing interest in receiving education and resource on evidence-based screening and treatment for eating disorders. The committee plans to release the survey to medical providers for additional assessment of knowledge and expertise of diagnosis and treatment of eating disorders. The Louisville Center on Eating Disorders is serving as the data analyst for the survey and plans to publish findings. While treatment providers report screening for eating disorders and conscientious efforts to treat or refer for appropriate treatment, each respondent of the survey has requested education on evidence-based screening and treatment modalities and a provider directory for appropriate referrals.

The subcommittee also developed and proposed a set of five questions proposed to be added to the Kentucky Behavior Risk Factor Surveillance System (KY BRFSS), the Kentucky specific version of the national Behavior Risk Factor Surveillance System conducted by the Centers for Disease Control and Prevention (CDC). The subcommittee's proposal was accepted, and members were invited to present to the KY BRFSS steering committee members on the research, explaining the need for more information and the research behind the proposed questions. Kentucky specific data on eating disorders is only collected through one statewide survey, the Youth Risk Behavior Survey (YRBS), and is specific to school-aged youth; data on eating disorders has not been collected from the YRBS since 2015. Asking questions on the KY BRFSS will expand knowledge of prevalence rates of symptoms of disordered eating in adults statewide and will be used to promote improved education, awareness, and intervention of eating disorders. The council received notification of approval of the proposed questions on December 21, 2021.

The Advocacy and Legislation subcommittee wrote a letter of support for H.R. 3711/S.2907, the Nutrition CARES Act, which supports access to medical nutrition therapy for individuals with an eating disorder, covered under Medicare Part B.

Committee members Melissa Cahill KEDC Chair, Ruby Jo Lubarsky, Justin Wallen, and Dr. Andrea Krause presented on the state of eating disorders and insurance reimbursement to the Joint Interim Committee on Banking and Insurance regarding the lack of sustainable insurance reimbursement rates to providers. Low reimbursement rates from insurance companies to providers result in the cost of care falling to the individual, families paying out of pocket for services, thus preventing knowledgeable service providers from providing care, resulting in individuals leaving Kentucky to receive care.

After the presentation, the Kentucky Department of Insurance (DOI) reached out to Melissa Cahill and requested KEDC's input on the implications of the passing of HB 50, which sought to amend KRS 304.17A-661 to improve mental health care coverage and eating disorders. The committee met with DOI staff to share concerns that insurance reimbursement rates eating disorder treatment providers earn for services rendered are not high enough to sustain the treatment individuals need and therefore prohibits providers from maintaining their program. An additional meeting was held on December 21, 2021 with KY DOI, commercial health providers and was attended by Representative Ken Fleming. KY DOI staff are welcoming of KEDC to help determine guidelines for insurance companies to reimburse for services rendered for the care of eating disorders.

Plans have been developed to attend Advocacy Day at the Capitol is scheduled for Wednesday, March 2, 2022.

Findings

The council made the following findings:

- Formal education around eating disorders is not a core concept taught in the fields of knowledge represented on the council and is only rarely offered as an elective.
- Continuing education on eating disorders is infrequently offered to those same represented fields and is not required for any field of knowledge.
- Informal feedback received from presentations to CMHC CEOs and directors revealed that staff are aware that eating disorders are ongoing and problematic in their populations. Still, knowledge and resources are limited, and therefore, clients are not screened or treated for eating disorders at the rate needed.

Recommendations and Goals



Based upon the activities and accomplishments outlined above, the council and its subcommittees developed a strategic plan and identified the following recommendations and goals 2022:

- Identify training opportunities in order to provide training on evidence-based screening for eating disorders, brief intervention, and referral to the appropriate level of care. The committee's preferred method for training is in person though virtual opportunities will also be identified.
- Identify and implement an evidence-based prevention program targeted to students. For example, The Body Project is a group-based intervention that provides a forum for high school girls and college aged women to confront unrealistic appearance ideals and develop healthy body image and self-esteem. It has repeatedly been shown to effectively reduce body dissatisfaction, negative mood, unhealthy dieting, and disordered eating. This program may be difficult to implement without funds and may face difficulty due to COVID restrictions that may still be in place.
- Establish access to a provider directory for any provider specializing in evidence-based eating disorder treatment referral for services, including level of service provided [e.g., outpatient care, intensive outpatient (IOP), partial hospitalization program (PHP), etc.]. Determine which providers utilize evidence-based practices to treat eating disorders before adding them to the resource directory in order to prevent a referral to a provider falsely advertising their ability to treat.
- Advocate for increased reimbursement rates for eating disorder treatment providers so they may continue to provide needed treatment. The current reimbursement rate for eating disorder treatment is akin to the reimbursement rate for substance use treatment; eating disorder treatment is far more complex though and requires a treatment team including a therapist, a dietician, and a physician.
- Participate in an advocacy day at the Capitol to coincide with National Eating Disorder Awareness week. Coordinating advocacy days may help elevate the needs of promoting and legislating information about appropriate nutrition.
- Administer a survey to collect data from medical providers to determine similar gaps in care as behavioral health providers; a continuous monitoring for data gaps will continue, even with addition of screening questions to KY BRFSS.
- Develop and submit a budget request to DBHDID, or submit grant applications to potential funders, to support the addition of Kentucky specific questions to the KY BRFSS (\$5,000 per question per DPH).

- Secure funds for a full-time staff person to support research activities, coordinate and support training opportunities and coordinate and support outreach efforts for improved health education for citizens of Kentucky and for future health providers.
- Secure and maintain a website to serve as a data dashboard, a clearinghouse for research and data, and a means by which to request education and training.