Legislative Study on Eating Disorders

Session Law 2017-57, Section 11E.11.(b)

Report to

The Joint Legislative Oversight Committee on Health and Human Services

By

North Carolina Department of Health and Human Services

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Background

Session Law 2017-57, Section 11E.11 requires a study on eating disorders in the State of North Carolina by the Department of Health and Human Services' (DHHS) Division of Public Health (DPH). Session Law 2017-57 further requires DHHS to report to the Joint Legislative Oversight Committee on Health and Human Services on its findings and recommendations on or before November 1, 2017.

This report reflects input requested from the University of North Carolina Center for Excellence for Eating Disorders (UNC CEED), the North Carolina Pediatric Society, and the North Carolina Academy of Family Physicians, as well as information from national organizations specializing in eating disorders. The report is arranged consistent with the required reporting elements outlined in Session Law 2017-57.

Eating Disorders Defined

UNC CEED identifies the following diagnoses as eating disorders:

- Anorexia nervosa: The disorder is marked by a very low body weight and malnutrition (less than 85% of expected), a fear of gaining weight, and an inability to restore weight.
- Bulimia nervosa: The disorder is marked by eating binges with a loss of control over eating and compensatory behavior (such as vomiting or excessive exercise).
- Binge eating disorder: The disorder is marked by eating binges with a loss of control and does not include compensatory behaviors in response to the eating binge.
- Avoidant Restrictive Food Intake Disorder: Consumption of certain foods is limited based on a food's appearance, smell, taste, texture, brand, presentation, or a past negative experience and leads to impairment and/or malnutrition.
- Other Specified Feeding and Eating Disorder: These include eating disorders such as atypical anorexia, bulimia nervosa (of low frequency and/or limited duration), binge eating disorder (of low frequency and/or limited duration), and purging disorder (vomiting following meals without binge eating behavior).

The National Institute of Mental Health (NIMH) indicates the following about eating disorders:

- Anorexia nervosa has the highest death rate of any mental disorder.
- People with bulimia nervosa usually maintain what is considered a healthy or relatively normal weight.
- Binge-eating disorder is the most common eating disorder in the United States. People with binge-eating disorder often are overweight or obese.
- Eating disorders affect both genders, although women have rates 2.5 times greater than men.
- Eating disorders often begin during adolescence and young adulthood, but children and older adults may also develop eating disorders.
- Eating disorders are not a lifestyle choice, but a disease caused by a complex interaction of genetic, biological, behavioral, psychological, and social factors. (https://www.nimh.nih.gov/health/topics/eating-disorders/index.shtml)

UNC CEED reports that North Carolina clinics as well as those in other states are seeing an increase in very young patients (8-9 years old) with eating disorders, as well as older patients

(40 years old or older). Middle-aged and senior patients are comprised of those with new onsets of eating disorders, those struggling with a chronic eating disorder, and those who have a relapse. Patients with eating disorders come from diverse socioeconomic, racial, and ethnic backgrounds.

Number of diagnosed incidences of eating disorders in North Carolina

No data source exists that has statewide data on the diagnosis of eating disorders in North Carolina. For 2014-2016 death certificate data, 17 North Carolina residents died that had an eating disorder noted as a contributing cause of death.

Data collected by our public schools and hospitals is summarized below:

- In the 2015-16 school year, North Carolina school nurses reported 64 elementary age students, 114 middle school students, and 210 high school students had an eating disorder (including anorexia and bulimia) that required some degree of action at school (such as keeping medication available, having an emergency and/or individual health care plan, or providing health related accommodations). For this group, 100 had an individual health plan (IHP) and 52 had a related 504 plan (educational accommodation plan for students who have access barriers, but are not eligible for special education).

- In 2016, 92 North Carolina residents were hospitalized with a primary diagnosis of an eating disorder. Emergency departments saw 156 North Carolina residents in 2016 with a primary diagnosis of an eating disorder.

Nationally, the National Institute for Mental Health (NIMH) reports that 2.7% of adolescents 13 to 18 years old have anorexia nervosa, bulimia nervosa, and/or binge eating disorder. For younger children (age 8 to 15 years), the eating disorder prevalence is 0.1%. (https://www.nimh.nih.gov/health/statistics/prevalence/eating-disorders-among-children.shtml)

Among the United States adult population, the report *"The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication"* provided lifetime prevalence estimates of anorexia nervosa, bulimia nervosa, and binge eating disorder as 0.6%, 1.0% and 2.8% respectively. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1892232/). This publication is a nationally representative face-to-face household survey and is not designed to provide state-level estimates.

Estimate of the number of individuals in North Carolina who are suffering from an eating disorder but who have not been formally diagnosed

No data exist on the number of North Carolina residents who have an eating disorder and have not been formally diagnosed. A literature review reveals there are no national estimates for this as well.

Nationally among adults, the NIMH reports that 33.8% of those with anorexia nervosa receive treatment during their lifetime (https://www.nimh.nih.gov/health/statistics/prevalence/eating-disorders-among-adults-anorexia-nervosa.shtml). For those with bulimia nervosa, 43.2% receive

treatment during their lifetime (https://www.nimh.nih.gov/health/statistics/prevalence/eating-disorders-among-adults-bulimia-nervosa.shtml). NIHM also reports that 43.6% of those with binge eating disorder receive treatment during their lifetime (https://www.nimh.nih.gov/health/statistics/prevalence/eating-disorders-among-adults-binge-eating-disorder.shtml).

Number of individuals in North Carolina who are being treated for an eating disorder

No data source exists that has comprehensive statewide data on the treatment of eating disorders in North Carolina, as no single data source exists for eating disorders residential treatment, outpatient treatment, and clinic based health services in North Carolina.

Strategies by which the State can increase awareness of, and disseminate information about, eating disorders, including their symptoms, effects, and preventative interventions

Recommendations from the organizations consulted for this report include:

- Raise awareness of the National Eating Disorder Association (NEDA) Toolkits, which are free resources designed to educate on eating disorders. Toolkits are available for parents, educators, coaches and athletic trainers, and medical professionals.
- Raise awareness of *"The Body Project"*, an evidence-based prevention program designed to reduce eating disorder cognitions and behaviors in teen girls and young adults.
- Raise awareness of the standardized screening measure, the SCOFF, for high school students.
- Share information on very common myths (for example, eating disorders only impact young, white women or are caused by parenting behaviors) so that professionals, including teachers, coaches, and health care providers do not overlook evidence of eating disorders.
- Promote tools such as *"Eating Disorders Myths Busted"* (a video series by National Institute for Mental Health, or NIMH; Cynthia Bulik, Ph.D., a NIMH grantee at the University of North Carolina). The video debunks nine myths about eating disorders and is available publicly at the NIMH web site.
- In the development of curriculum, focus on healthy eating, rather than focusing on blanket statements such as "fat is bad" that can lead to unhealthy behaviors. A focus on physical fitness and healthy eating, rather than on thinness or obesity, can help prevent disordered eating in children.
- Raise awareness of the UNC CEED educational resources, including their Twitter and Facebook accounts, along with their blog Exchanges (https://uncexchanges.org/).
- Encourage family meals, as adolescents who eat a social family dinner most days are less likely to initiate purging, binge eating, and frequent dieting.
- Shift education about the dangers of restrictive dieting earlier to the elementary school years and adapt lessons on body confidence and appreciation for this age.

These activities can be accomplished in partnership with several state and local agencies, including the North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services, through wellness awareness communications.

Adequacy of training provided to public school officials in identifying the symptoms of eating disorders and in providing support to the individuals and families affected by eating disorders

The Healthful Living Essential Standard Course of Study, which became effective in all North Carolina schools in the 2012-13 school year, includes objectives related to eating disorders at the middle and high school levels. The supporting materials for the standards include information on resources that teachers can share with students.

In addition, North Carolina Healthy Schools program focuses on improving the health of students and staff by providing coordination and resources within the context of the Whole School, Whole Community, Whole Child (WSCC) model, adopted in November 2016 by the North Carolina Board of Education.

Finally, the NC State Board of Education adopted a School-Based Mental Health Initiative in April 2017, that requires each Local Education Agency to develop and implement a plan for assessing and improving upon the effectiveness of existing supports for the mental health and substance use needs of its student population.

DHHS surveyed the organizations regarding the adequacy of training provided to public school officials, but has not yet received any responses.

Recommendations for improving education, prevention, early detection, and treatment of eating disorders

Recommendations from the organizations consulted for this report include:

- Increase education about eating disorders in medical school and residency curriculums and practice.
- Encourage providers to utilize the SCOFF screening at well child visits for children age 10 years and older.
- Recommend pediatricians and other providers who care for children who observe a significant decrease in weight-for-length percentile or body mass index over time to refer the patient for an eating disorder evaluation.
- Keep school counselors aware of community events and free education as well as online education offered by several eating disorder treatment centers in the state.
- Encourage insurance companies to pay for telemedicine options for treating eating disorders to address lack of providers in rural areas of the state.
- Recommend pediatricians follow the recommendations of the American Academy of Pediatricians on prevention of obesity and eating disorders in adolescents found at http://pediatrics.aappublications.org/content/early/2016/08/18/peds.2016-1649.

Availability of treatment consistent with the best practices described by the American Psychiatric Association and other published materials to individuals and families affected by eating disorders

The American Psychiatric Association (APA) indicates:

> "The most effective current treatments are behavioral interventions. In anorexia nervosa, family-based therapy is the treatment of choice in adolescents. For severely ill patients at very low weight who are unable to gain weight in outpatient treatment, admission to a specialized residential or hospital-based treatment program can be lifesaving. The most consistent indicator of relapse after intensive treatment is incomplete weight restoration, so reaching a healthy weight is necessary for recovery. Evidence now suggests that weight gain rates of three to four pounds a week are safe for patients with close medical monitoring and 24-hour nursing care. Some programs utilize feeding tubes. However, behavioral specialty programs are able to achieve weight gain of four pounds a week with oral feeding alone in most cases. Close outpatient follow up care following hospitalization is important as relapse risk is elevated for six months following inpatient treatment.
>
> For bulimia, cognitive behavioral therapy is the most successful outpatient treatment approach. Binge eating also responds to cognitive behavioral interventions. Interpersonal therapy is effective in both bulimia and in binge eating disorder. Some medications may be useful along with these therapies."
> (https://www.psychiatry.org/patients-families/eating-disorders/expert-q-and-a)

North Carolina has a variety of treatment facilities, including inpatient, residential, and partial hospitalization. In addition to the UNC CEED and the Duke Center for Eating Disorders, private, for-profit treatment centers include Veritas Collaborative, Renfrew, Tapestry, and Carolina House.

One barrier to treatment is that very few eating disorder treatment centers accept Medicaid, Medicare, or Tricare (the health insurance program covering most members of the military and their families). Medicare does not cover medical nutrition therapy for adults with eating disorders. In addition, respondents reported insurance companies negotiate contracts to reimburse at rates lower than Medicaid and Medicare, and providers opt not to enter into those contracts, reducing the availability of treatment providers.

The availability of inpatient psychiatric beds dedicated to inpatient treatment of eating disorders at UNC Hospitals has been reduced from 10 beds to 6 beds due to the increase in patients presenting at the emergency department in acute psychiatric crisis. This results in longer wait times for patients with eating disorders to receive inpatient care.

Other issues the Division identifies that are related to the objectives of this study

The Task Force on All Payer Claims Database convened by the North Carolina Institute of Medicine (NCIOM) for the North Carolina General Assembly recommended establishing an

All-Payer Claims Database. Such a database would create a data source for understanding the diagnosis and treatment patterns of eating disorders in North Carolina. For more information on this report, see http://www.nciom.org/publications/?claims-data-to-improve-health-in-north-carolina-a-report-from-the-nciom-task-force-on-all-payer-claims-database-2.

To address some of the significant treatment gaps for eating disorders, the development of the UNC Center of Excellence for Eating Disorders (CEED) Ambassador Program has been proposed, and UNC CEED is pursuing private and public funding for this initiative. The program has three broad aims: (1) Educate pediatricians on the detection of eating disorders in their patients and help pediatricians guide parents to family-based therapy resources; (2) Identify and train 7 therapists across the state in family-based therapy, ensure coverage across the state by focusing on the major metros in North Carolina (Wilmington, Greenville, Hickory, Asheville, Charlotte, Fayetteville, Greensboro) and provide weekly supervision via video-conferencing; and (3) Measure the fidelity of family-based therapy practice in sessions and evaluate potential expansion in services in each of these regions.

The North Carolina Pediatric Society reports that mandating specific training in eating disorders has just been incorporated into medical training requirements in many post medical school specialty areas. However, most pediatric, family medicine, internal medicine, psychiatry, and obstetrics and gynecology programs do not have specific exposure/training with skilled providers in eating disorders. Licensed Dietetic Nutritionists (LDN) have specialized training, and some LDN are certified in eating disorder treatment (CEDRD) but the term “nutritionist”, “life coach”, or “trainer” does not guarantee any knowledge of nutrition, or eating disorders.