

CCCED 2022 Testimony (Draft)

Mental Health Budget Hearing

Feb. 14, 2022

Thank you Chairs Krueger and Weinstein, as well as Chairs Brouk and Gunther, for the opportunity to discuss the Comprehensive Care Centers for Eating Disorders (CCCED). My name is Mary Tantillo, and I am the Director of the Western NY CCCED. WNYCCCED, along with Metro CCCED (based in New York City at New York-Presbyterian/NY Psychiatric Institute), and the Northeast CCCED (based in Albany at Albany Medical Center) provide a cost-effective, coordinated, and integrated model of care and infrastructure across the state.

We are here to ask that you restore funding to the CCCEDs, as our funding was again slashed by 90% in the Executive Budget. Without your support, this critical piece of health care access and infrastructure will close.

Eating disorders, including anorexia nervosa, bulimia nervosa, binge eating disorder (BED) and avoidant-restrictive food intake disorder (ARFID) are serious psychiatric illnesses associated with significant medical and psychiatric morbidity

(or illness) and high rates of mortality. Anorexia Nervosa has the highest mortality rate of all psychiatric illnesses, surpassed only by the death rate of opioid dependence. It is estimated that there are currently more than 18,000 New Yorkers living with anorexia nervosa or bulimia nervosa and a higher number living with BED.

New York State established the Comprehensive Care Centers for Eating Disorders in 2004 in an effort to keep residents in the state for treatment where possible and to avoid the creation of redundant services in order to maintain a high level of quality. Eating disorders are difficult to treat and require specialized clinicians and programs. Serious medical complications, including death, can result from inadequate treatment. A significant number of patients require intensive treatment that can best be provided by specialized inpatient, residential, partial hospitalization or outpatient programs. For example, there is one specialized inpatient psychiatric unit for eating disorders in the state at NYP as well as two adolescent centers, one at Northwell Health in Long Island and one at Golisano Children's Hospital in Rochester.

Early intervention is critical to successful outcomes for persons afflicted by eating disorders. Proper diagnosis is often missed because many health professionals still receive little to no education on this. Some clinicians don't see patients with EDs during their training and patients are reticent to discuss these symptoms with clinicians because they are in denial, ashamed or afraid of seeking treatment.

Once eating disorders are identified, treatment is often hard to navigate as treatment commonly requires both medical and behavioral health components of care. Some health systems and health insurance companies view these elements separately, making it difficult to arrange truly comprehensive, integrated and continuous care. Also, there are significant regional differences for treatment options for eating disorders. Additionally, some health insurance plans often limit treatment by cutting short some interventions or including coverage for some types of treatment settings and not others. For example, NY residents with Medicaid still have no coverage for residential ED treatment.

Through our comprehensive approach, the CCCEDs are able to offer a number of services that are not covered by health insurance but which are critical to timely recognition and treatment of eating disorders, for example:

- Care management/care coordination and transitional services including life coaching, patient-peer mentoring and parent-peer mentoring, especially for outlying areas with limited or no specialty care resources
- education of lay persons and professionals including *Project ECHO* videoconference training for providers and K-12 school personnel as well as other forms of on-line and in person statewide education
- research to identify trends, outcomes, and best practices for NY residents struggling with eating disorders

Without early identification and intervention, as well as comprehensive, coordinated and continuous care, eating disorders can become chronic and lead to increased physical and behavioral health complications, disability, and premature death. Providing these services is expected to significantly reduce downstream costs to New York State by decreasing acute care services and readmission rates for individuals with eating disorders, a population known to be high service utilizers in the absence of well-coordinated care. The CCCED model epitomizes a coordinated effective approach to high need/high cost individuals promoted by the NYS Department of Health and DSRIP. CCCED collaboration improves the quality of care and outcomes across the system and keeps

treatment services and costs within New York State. CCCED services support NY State's Triple Aim of improving care, improving health, and reducing costs.

Our centers have also been able to fill gaps and develop new services, using program funds to launch new initiatives including the only downstate partial hospital (day treatment) program at NYPres for individuals with eating disorders that have health insurance coverage through a public program (Medicaid and Medicare). Additionally, we are currently working on launching an upstate adolescent residential eating disorder program in Rochester. The Centers also support care coordination components that are not reimbursable by health insurance such as care management geared at keeping people in their homes and not using emergency or high intensity treatments. These programs are also the only ones that cover the full continuum of services specifically for Eating Disorder treatment for New Yorkers covered by Medicaid or Medicare.

We are thankful for support received from the Legislature and New York State.

However, as it has in recent years, the 2022-23 Executive Budget Proposal only provides \$118,000 in total funding for the Centers. We are grateful for the

\$1,060,000 in additional funding that the State Legislature has regularly provided

in the enacted budgets; without this funding, we would close. With 90% of annual state funding for the Centers contingent on an additional legislative appropriation, the level of uncertainty about future funding each year poses a number of challenges. At the same time funding has been reduced and less secure, the Centers have cared for an increased number of patients. COVID has only served to increase the demand for services. It has also been very difficult to meet the changing needs of patients and families and expand or develop new long-term evidence-based programming for prevention, early identification or relapse prevention without funding closer to our original level. Additionally, there are challenges recruiting for CCCED positions because it is difficult to hire and retain seasoned staff when CCCED leadership do not know if there will be funding in the coming year.

We know that the Legislature appreciates the unique services we provide. It is no exaggeration to say that lives depend upon them. We hope that you can once again fund our Centers at an appropriate level. Thank you again for the opportunity to testify. I'd be happy to answer any questions that you have.

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