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Ex Officio, Executive Director  
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January 14, 2020

NIMH Strategic Planning Team  
6001 Executive Boulevard, Room 6200, MSC 9663  
Bethesda, MD 20892-9663

Dear NIMH Strategic Planning Team,

The members of the Academy for Eating Disorders, the leading international organization representing physicians, psychiatrists, psychologists, academic researchers, and others concerned with addressing the serious mental disorders classified as Eating Disorders, applaud the work that the National Institute of Mental Health (NIMH) is doing to support research that could help find new and improved ways to diagnose and treat eating disorders. Your support of research on the etiology, diagnosis, and treatment of Eating Disorders is critical to improving our ability to advance this field with evidence and method.

As you know, eating disorders will affect 30 million Americans sometime in their lives. Furthermore:

- Eating disorders do not discriminate – men and women, young and old, in all economic classes and racial and ethnic groups are affected.
- Prevalence estimates of eating disorders are elevated among active duty military personnel.
- Eating disorders have the second highest mortality rate of any psychiatric disorder, (second only to opioid use disorder) and an adolescent with anorexia nervosa has nearly 10 times the risk of dying than a same-age healthy peer.
- Eating Disorders can be successfully treated, but sadly only about a third of people that need it will get treatment – and among those with a severe and enduring eating disorder access to treatment is tragically diminished even further.

Although these conditions are serious and can be fatal, research funding for Eating Disorders is significantly less than that allotted to other serious illnesses, especially when considering the numbers affected and the disability-adjusted life years lost.

We applaud the strategic approach you take to address mental health in general and congratulate you on the outstanding draft of your new 5-year plan.

We wanted to share feedback collected from some of our constituent members that might help strengthen your strategy.

1. Anorexia nervosa is a chronic illness with high morbidity and mortality. Because individuals with anorexia nervosa often become severely malnourished and emaciated, and because they tend to be resistant to treatment, they often require higher levels of care. The key focus of treatment has been to increase caloric intake and weight gain. While this can be lifesaving in the short-run, weight loss and relapse after discharge are common. There is a spectrum of treatment approaches across providers for anorexia nervosa care due to a lack of standard care models. There is limited knowledge regarding which treatment, or what combinations of interventions are most successful for the treatment of I'm anorexia nervosa. In recent years accumulating data suggest there are powerful genetic and neurobiological contributions to this illness. However, there has been little in the way of transforming those insights into more effective treatments or developing policies to standardize eating disorder care. We would welcome the opportunity to work with NIMH to work through research and massive outcomes data collection, a better understanding of what evidence-based treatment methods can be successfully and sustainably applied to reduce relapse.
2. On Page 9, Mental Health Equity: Does NIMH collaborate with CMS and/or are they open to it? One additional source of mental health inequity that could be added here is lack of insurance coverage for the recommended level of care/service provider needed to treat mental illnesses effectively. This of course applies to Eating Disorders but possibly many other mental health conditions that require specialty treatment (e.g., OCD, substance use disorders, etc.).
3. On Page 14, Harnessing the Power of Data: Are there any considerations here for ensuring that increased use of "big data" approaches still ensure anonymity of research participants and security of large swaths of identifiable information? As "big data" becomes more frequently integrated into mental health services research and delivery, there is also an opportunity to educate patients about their rights with data and data sharing. We believe that could also be an avenue for important scientific inquiry.
4. Page 29, Objective 3: Interventions for effectiveness in community practice settings: Community-based participatory research (CBPR) is not mentioned here but could be an important addition to strengthen progress toward this objective. CBPR typically involves more clear and continuous integration of stakeholder perspectives into all aspects of the research process, from design to execution to sustainable implementation. The result is that there is a clearer path for dissemination and increased likelihood of community uptake of the developed interventions.
5. While great strides in mental health identification and treatment are occurring in the United States under your stewardship, great research and work in prevention and treatment is occurring in other countries around the world. We know you have taken steps in recent years to improve your cooperation with medical professionals and agencies around the world but think perhaps this could be more prominently positioned in your strategic plan. Because AED

is an international organization with members in 43 countries, we have developed a strong network of professional allies around the world and would welcome the opportunity to support the NIMH international outreach.

In addition, AED would like to endorse the recommendations made by the Coalition of Associations to Advance Psychological Science, of which AED is a member.

Thank you for your outstanding work to address and improve mental health and thank you for the opportunity to provide thoughts on your very well crafted 2020 Strategic Plan.

Respectfully,



Elissa M. Myers, CAE, IOM, MA  
Executive Director  
Academy for Eating Disorders