

LEGACY OF HOPE SUMMIT

MANY VOICES. ONE GOAL. HEALING.

A Consensus-Based Report
on Eating Disorders in the U.S.
and Recommendations for the Path Forward[®]

Table of Contents

The Summit	iv
The Participants	v
Endorsements	vi
Overview	
Eating Disorders in the U.S. – A History of Disparate Treatment.....	1
Why is That? – Myths and Misunderstandings	2
The Truth About Eating Disorders.....	2
A Public Health Crisis.....	3
Eating Disorders: A Statistical Breakdown By Type	3
Section I: Early Detection, Intervention, And Prevention	
The Status Quo	8
Point of Consensus.....	9
Early Detection and Intervention	9
Short and Long Term Goals	9
Goal No. 1	9
Recommended Strategies for Achieving Goals	9
Obstacles Preventing the Achievement of Goals.....	9
Strategy for Navigating and Overcoming Obstacles.....	9
Goal No. 2	10
Recommended Strategies for Achieving Goals	10
Obstacles Preventing the Achievement of Goals.....	10
Strategy for Navigating and Overcoming Obstacles.....	10
Prevention	10
Short and Long Term Goals	10
Goal No. 3	10
Recommended Strategy for Achieving Goal.....	10
Obstacles Preventing the Achievement of Goal	11
Strategies for Navigating and Overcoming Obstacles.....	11
Goal No. 4	11
Recommended Strategy for Achieving Goal.....	11
Obstacles Preventing the Achievement of Goal	11
Strategies for Navigating and Overcoming Obstacles.....	11

Section II: Accessibility, Affordability, And Accountability

The Status Quo..... 13
 Point of Consensus..... 13
 Short and Long Term Goals.....14
 Recommended Strategies for Achieving Goals14
 Obstacles Preventing the Achievement of Goals14
 Strategy for Navigating and Overcoming Obstacles 15

Section III: Standards Of Care

The Status Quo.....17
 Point of Consensus.....18
 Short and Long Term Goals..... 19
 Recommended Strategies for Achieving Goals..... 19

Section IV: Research And Research Funding

The Status Quo..... 21
 Points of Consensus 22
 Short Term Goals..... 24
 Long Term Goals..... 26
 Recommended Strategies for Achieving Goals..... 27
 Obstacles Preventing the Achievement of Goals 27
 Strategies for Navigating and Overcoming Obstacles 28

Section V: Advocacy, Education, And Legislation

The Status Quo..... 30
 Point of Consensus.....31
 Short and Long Term Goals.....31
 Recommended Strategies for Achieving Goals..... 32

Section VI: Eating Disorder Issues In A COVID-19 World

Introduction..... 37
 Eating Disorders and Social Justice 37
 COVID-19: Health and Mental Health..... 38
 COVID-19 and Eating Disorders..... 39
 Eating Disorders and Mental Health..... 40
 COVID-19 Advocacy Issues 41

Appendix A (Diagnostic Criteria for AN, BN, BED, and ARFID)..... 43

Appendix B (Health and Medical Consequences of AN, BN, BED, and ARFID) 45

Appendix C (Recent Resources re: COVID-19 and ED/Mental Health) 47

Appendix D (Link to: Social and Economic Cost of Eating Disorders in the U.S.) 48

Endnotes..... 49

The Summit

In January 2020, more than two dozen nationally-respected experts and thought leaders in the field of eating disorders convened for the Legacy of Hope Summit. The goals of the Summit were ambitious: (1) to articulate and reach a consensus regarding a series of recommendations that would have a significant beneficial impact on those afflicted with eating disorders, their loved ones, and the eating disorders community as a whole; (2) to develop short and long term strategies for implementing those recommendations; (3) to identify likely obstacles to their implementation; and (4) to chart a course for successfully navigating and overcoming those challenges.

To facilitate their efforts, Summit participants were assigned to five work groups - one for each of the Consensus Points outlined in this Report according to their stated preferences and areas of expertise. However, in order to build a true consensus and derive the full benefit of their broad-based experience, each participant also was afforded an opportunity to provide input on any or all of the other work groups in advance of the Summit and many did so. The resulting work-product of each of the groups, in turn, was collected, vetted, and approved by each of the group members, before being circulated to the group as a whole for their review, comment, and approval.

The Report then went through a series of revisions within the individual work groups, before being circulated a second time to the Summit participants for their final review and approval. Once a unanimous consensus was reached, each of the Summit participants was encouraged to reach out to colleagues and other principal stakeholders across the broad spectrum of disciplines in the eating disorders field, as well as those with lived experience, for their review and support. This Report is the culmination of those efforts and represents the collective wisdom and consensus recommendations of all Summit participants and endorsers.

All acknowledge that there is much work still to be done and that there is room to quibble over a word here or a phrase or sentence there. However, given the gravity of the situation and the preciousness of the lives hanging in the balance, the consensus is that: (1) the status quo is unacceptable; (2) the need for a thoughtful and unified plan of action is immediate; and (3) the time for meaningful progress is long overdue. Thus, the Summit participants' and the supporting signatories' hope is that this Report will be a living document that will serve as a catalyst for further consensus-building and a blueprint for hope and healing for years to come.¹

The Participants

Any undertaking of this magnitude simply would not be possible without the contributions and selfless dedication of scores of people and organizations. This Report and the work required to generate it certainly is no exception, especially in light of the myriad challenges the COVID-19 virus presented in 2020. At the top of that list are the eating disorders professionals and thought leaders who attended the Legacy of Hope Summit with hearts and minds open to the need for change, a desire for consensus, a willingness to think outside the box, and a commitment to leaving an indelible legacy of hope and healing. They include:

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Overview

Eating Disorders In The U.S. – A History Of Disparate Treatment

On February 4, 1983, Karen Carpenter, one of this country's and the 20th century's most recognizable and beloved music icons died at the age of 32. Her reported cause of death? "Emitine Cardiotoxicity" – a condition often associated with ipecac abuse/poisoning. Her actual cause of death? Complications from anorexia and bulimia nervosa². Historically, a high-profile celebrity death like Ms. Carpenter's would exponentially heighten public awareness relating to the culprit illness and act as a catalyst for fundraising efforts in support of medical and scientific research aimed at better understanding, seeking the early detection of, improving treatment protocols for, and, ultimately, eradicating and/or preventing the disease. Indeed, the historical landscape is replete with examples of that phenomenon, particularly in the United States.

But, news about Ms. Carpenter's death was different. Despite her substantial notoriety and the fact that hers is widely-believed to be the first high-profile celebrity death caused by an eating disorder in the United States, Ms. Carpenter's struggles only marginally increased public awareness of these insidious, life-threatening illnesses. They also did not prompt an outpouring of research funding aimed at identifying their root causes, educating front line health care providers as to what could be done to identify them earlier, treat them more effectively, and/or prevent or temper their deadly proliferation. Instead, her death resulted in the advancement of what would turn out to be one of many misguided and stigmatizing myths concerning these illnesses, namely that they are traceable "to the failings of mom and dad".³

Troublingly, in the nearly 4 decades that have passed since Ms. Carpenter's tragic death shined a very public, but brief spotlight on eating disorders in the U.S., meaningful progress has been painstakingly slow in several areas that fundamentally affect the majority of those suffering from, tasked with treating, and charged with better understanding these illnesses, despite the tireless and selfless efforts of many. Those areas include: (1) education, advocacy, and legislative initiatives; (2) the availability, accessibility, and affordability of quality care; (3) the development of nationally agreed upon, evidenced-based standards of care; (4) the scientific, sociologic, medical, and epidemiologic research necessary to better define and support those standards; and (5) strategies aimed at early identification, intervention, and prevention.

Thus, it should come as no surprise that, during this same period, the number of people battling eating disorders in the United States and worldwide has increased in every decade and continues to do so at an alarming rate.⁴ Even more alarming is the fact that, with increasing frequency, children as young as 9 and 10 years old are being diagnosed with these illnesses.⁵ Left unchecked, the prevalence of eating disorders in the U.S. may well reach epidemic proportions and, if they are not already, compete for a spot as one of this country's leading public health crises. And yet, there still remains no concerted public outcry that something be done (immediately), no outpouring of state, federal, and private research funding, and no insistence that life-saving care be afforded and affordable to the millions who continue to suffer.

Why Is That? Myths And Misunderstandings

Why is that? Why are eating disorders, which indiscriminately afflict millions of American men, women, adolescents, and children and are a causative factor in claiming thousands of American lives every year, viewed so differently than other statistically less virulent and less prolific life-threatening and even non-life-threatening illnesses in this country?

There are a number of factors that have tamped down the sense of societal and legislative outrage that should accompany the shocking statistics surrounding eating disorders. Most are grounded in decades-old myths and misunderstandings. In no particular order they include:

Eating disorders are a choice – not a disease (i.e., they are self-inflicted).

Eating disorders are little more than a diet gone bad (i.e., a lack of self-discipline).

Eating disorders only afflict adolescent white girls of privilege (i.e., they are a rich kid's problem).

Eating disorders are a phase (i.e., "Just give them time, they'll grow out of it").

Eating disorders are all about food (i.e., who needs treatment, when all that's needed is to eat more or eat less).

To have an eating disorder, you have to be seriously underweight (i.e., "You don't look like you have an eating disorder").

Eating disorders really aren't that dangerous (i.e., "I've never known or heard of anyone who died as the result of an eating disorder").

You can't "see" an eating disorder, so it must not be real (or as real) (a common, but no less substantial obstacle that many mental illnesses face in garnering public support).

The Truth About Eating Disorders

That being the case, the best, most logical starting point to change the dialogue, to begin redefining the eating disorders landscape, and to chart a course forward is with knowledge that dispels myths and articulates the TRUTH. Thankfully, the eating disorders community took a giant step forward in doing just that when a committee of the Academy for Eating Disorders in collaboration with Dr. Cynthia Bulik, a distinguished

Professor of Eating Disorders in the School of Medicine at the University of North Carolina at Chapel Hill, established what's come to be known as the Nine Truths. Those Truths have since been adopted and widely disseminated by a plethora of U.S. and international eating disorders organizations.⁶ They include the following:

- Truth #1:** Many people with eating disorders look healthy yet may be extremely ill.
- Truth #2:** Families are not to blame for eating disorders, and can be the patients' and providers' best allies in treatment.
- Truth #3:** An eating disorder diagnosis is a health crisis that disrupts personal and family functioning.
- Truth #4:** Eating disorders are not choices, but serious biologically-influenced illnesses.⁷
- Truth #5:** Eating disorders affect people of all genders, ages, races, ethnicities, body shapes and weights, sexual orientations, and socio-economic statuses.
- Truth #6:** Eating disorders carry an increased risk for both suicide and medical complications.
- Truth #7:** Genes and environment play important roles in the development of eating disorders.
- Truth #8:** Genes alone do not predict who will develop eating disorders.
- Truth #9:** Full recovery from an eating disorder is possible. Early detection and intervention is important.

A Public Health Crisis⁸

There is more TRUTH to be found in the statistics:

An estimated 9% of the U.S. population or 28.8 million Americans will have an eating disorder in their lifetime.

An estimated 10,200 deaths per year or 1 death every 52 minutes in the U.S. are directly or indirectly attributable to an eating disorder.

Eating disorders **affect people of all ages** (from 5 to 80), **races, ethnicities, genders, and sexual orientations.**

For myriad reasons, **only a small percentage of people afflicted with eating disorders (i.e., 10 - 20 percent) seek help.**

An even smaller percentage of eating disorder sufferers receive care from a provider who specializes in the treatment of eating disorders.

Of those fortunate to gain access to quality care, few receive the intensity and length of care they require.

People of color who suffer from eating disorders are **half as likely** to be properly diagnosed and to receive treatment.

The estimated **annual cost** of eating disorders in the U.S. is **\$64.7 billion.**

Included in that figure is an estimated loss of **\$16.3 billion in revenue to U.S. employers.**

Eating disorders in the U.S. also account for an estimated **\$239 million in costs to hospital systems.**

Eating Disorders: A Statistical Breakdown By Type

While Anorexia Nervosa (AN), Bulimia Nervosa (BN), and Binge Eating Disorder (BED) are the most often discussed of the family of eating disorders, there are a number of other types of disordered eating conditions

that fall on the illness spectrum, two of which, Avoidant Restrictive Food Intake Disorder (ARFID) and Other Specified Feeding or Eating Disorder (OSFED), also are recognized in the DSM-V. However, the statistical data relating to the latter diagnosis and other disordered eating conditions is in its relative infancy. Accordingly, the following synopsis provides brief descriptions of and pertinent statistics relating to only the four most prevalent forms, together with associated reference sources.⁹

Anorexia Nervosa

What is it?

Anorexia is a form of eating disorder characterized by a highly regimented restriction of the intake of calories needed to sustain normal body function. Typically, but not always, it is accompanied by a significant loss of body mass and an intense fear of gaining weight.

Statistics:

1. **Prevalence:** The one year estimated prevalence of AN is 0.16% for females and .09% for males.¹⁰ The lifetime prevalence of AN is 0.71% for females and 0.53% for males.¹¹
2. There has been a significant rise in the incidence of AN in young women ages 15-19 in each decade since the 1930's.¹²
3. **Mortality Rate:** The standardized mortality ratio (SMR) for AN (i.e., the percentage of observed deaths in the study population divided by the percentage of expected deaths in the entire population of origin) is 5.86.¹³
4. 60% of AN-related deaths are attributed to sudden cardiac arrest, organ failure, or suicide.¹⁴
5. **Treatment Rate:** Only one third of AN sufferers in the United States obtain treatment.¹⁵
6. The probability of relapse after treatment of those suffering from AN is 25%.¹⁶
7. **Average Age of Onset:** The average age of onset of AN is 16-17 years, but younger children are becoming afflicted with increasing frequency.¹⁷
8. 60% of those suffering from AN who survive can be expected to make a full recovery.¹⁸
9. 25% of those diagnosed with AN may experience a diagnostic cross-over to BN.¹⁹

Bulimia Nervosa

What is it?

Bulimia nervosa is an eating disorder characterized by recurrent episodes of binge eating in combination with inappropriate compensatory behaviors (e.g., self-induced vomiting, laxative misuse, etc.).

Statistics:

1. **Prevalence:** The one year estimated prevalence of BN for females is 0.32% and for males is 0.05%.²⁰ The lifetime estimated prevalence of BN for females is 1.36% and for males is 0.24%.²¹
2. **Mortality Rate:** The standardized mortality ratio (SMR) for BN is 1.93.²² Moreover, it is estimated that

- 3.9% of BN sufferers will die as a result of this illness.²³
3. **Treatment Rate:** Only 6% of BN sufferers in the United States obtain treatment.²⁴
 4. 8% of BN sufferers may experience a cross-over diagnosis of AN and 9% may cross-over to a diagnosis of BED.²⁵
 5. The probability of relapse after treatment of those suffering from BN is 17%.²⁶
 6. **Average Age of Onset:** The average age of onset of BN is 18 years, but more recent studies suggest the age of onset may be declining.²⁷
 7. An estimated 35% of people with BN engage in self-harm behaviors.²⁸

Binge-Eating Disorder

What is it?

Binge-eating disorder is characterized by recurrent episodes of binge eating during which individuals sense a lack of control and consume larger amounts of food than most people would under comparable conditions.

Statistics:

1. **Prevalence:** The one year prevalence of BED for females is 0.96% and for males is 0.26%.²⁹ The lifetime estimated prevalence of BED for females is 2.7% and for males is 1.70%.³⁰
2. **Mortality Rate:** The standardized mortality ratio (SMR) for BED is 1.92.³¹ Moreover, it is estimated that 5.2% of individuals suffering from eating disorders not otherwise specified (the former diagnosis that BED, among other forms of disordered eating, was included in under the DSM-IV) die from health complications associated with those illnesses.³²
3. An estimated 15% of BED sufferers attempt suicide.³³
4. **Treatment Rate:** Approximately 43% of BED sufferers in the United States obtain treatment.³⁴
5. Approximately 8% of BED sufferers may experience a cross-over of BN.³⁵
6. **Average Age of Onset:** The average age of onset for BED is 25 years or older.³⁶
7. The probably of relapse after treatment of those suffering from BED is approximately 11%.³⁷

Avoidant / Restrictive Food Intake Disorder (ARFID)³⁸

What is it?

ARFID is characterized by an “avoidance or restriction of food intake” to the extent that it becomes “clinically significant [in the] failure to meet requirements for nutrition or insufficient energy intake through oral food intake.”³⁹ ARFID bears many similarities to AN and other eating disorders in that it involves behaviors aimed at limiting the amount and/or types of foods consumed. However, there are important differences between ARFID and AN.⁴⁰ ARFID features can present in early childhood, persist through childhood, and lead to low grade or quite severe height and weight growth deficiencies. However, ARFID also: (1) can be diagnosed across the lifespan

in all genders, races, and ethnicities; and (2) can occur across the weight spectrum (i.e., patients need not be underweight or have abnormal growth patterns to be eligible for the diagnosis) due to the fact that the diagnostic criteria specify that marked interference with psychosocial function is sufficient to diagnose the condition, when restrictive or avoidant features are present.

Statistics:⁴¹

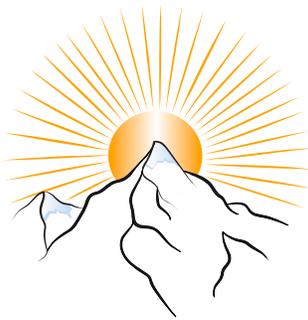
1. **Prevalence:** Because the diagnostic criteria for ARFID is fairly new, the research regarding its prevalence is still in its relative infancy, when compared with AN, BN, and BED.⁴² However, some research data does exist:

Children and Adolescents: A 2015 retrospective analysis of 2,231 consecutive new referrals (ages 8–18 years) to 19 Boston-area pediatric gastroenterology clinics, revealed 33 (1.5%) ARFID cases, 22 of whom (67%) were male.⁴³ An additional 54 cases (2.4%) met one or more ARFID criteria but there was insufficient information in the medical record to confer or exclude the diagnosis.⁴⁴ Additionally, one study estimates the prevalence of ARFID in school children aged 8–13 years at 3.2%.⁴⁵

Adults: In a 2019 study, based on a retrospective review of charts from 410 consecutive referrals (ages 18-90 yrs. of whom 73% were female) to a tertiary care center for neurogastroenterology examination, from January through December 2016, researchers found 26 patients (6.3%) who met the full diagnostic criteria for ARFID and 71 cases (17.3%) who had clinically significant avoidant or restrictive eating behaviors, but who lacked sufficient information for a definitive diagnosis of ARFID.⁴⁶

2. **Gender Dispersion:** Unlike other ED diagnoses (e.g., AN and BN), individuals with ARFID are more likely to be male (29% (ARFID) vs. 15% (AN) vs. 6% (BN)).⁴⁷
3. **Age of Onset:** Patients with ARFID have generally been found to be younger than those with AN or BN (12.9 yrs. (ARFID) vs. 15.6 yrs. (AN) vs. 16.5 yrs. (BN)),⁴⁸ though the disorder can be diagnosed across the lifespan.
4. **Duration of Illness:** Early research suggests that the duration of illness for those with ARFID is longer than AN and BN in many cases (33.3 mos. (ARFID) vs. 14.5 mos. (AN) vs. 23.5 mos. (BN)).⁴⁹
5. **Comparative Prevalence of Comorbid Conditions:** As compared with AN and BN, patients with ARFID are more likely to have a comorbid medical condition (55% (ARFID) vs. 10% (AN) vs. 11% (BN)) or anxiety disorder (58% (ARFID) vs. 35% (AN) vs. 33% (BN)), but are less likely to have a mood disorder (19% (ARFID) vs. 31% (AN) vs. 58% (BN)).^{50, 51}

It was against this backdrop that the Summit convened...



SECTION I:
Early Detection, Intervention, and Prevention

The Status Quo⁵²

Various presentations of eating disorders occur in people from all walks of life across the lifespan, yet they remain under-detected and under-treated. Despite the fact that there is increasing evidence that school-based eating disorder screening at elementary, middle, and high school levels is as effective as other health-based screenings in reducing the dollars spent and years lost in later treating and battling those diseases (not to mention the impact they have on quality of life), such screenings and referrals for early intervention are not routinely done in U.S. schools at any level. In fact, there has never been an organized national screening program in place in school or primary healthcare settings for pre-adolescents. Further, in 2013, the Centers for Disease Control (CDC) removed several questions from the National Youth Risk Behavior Survey (YRBS) that had provided surveillance for those engaging in disordered eating behaviors.

K-12th grade comprehensive health education (including a focus on health literacy, adopting healthy behaviors, and valuing wellbeing) with a parent component provides the opportunity for increasing knowledge and skills to act in healthy ways and builds personal value for healthy behaviors at home and in schools. Although K-12th grade comprehensive health education is mandated in most states, there are no formal assessments as there are with other subjects like math and language arts. As a result, health education is fit into curriculums as an afterthought and not a priority. In addition, there is no uniform K-12th health education teacher training to enable teachers to confidentially address sensitive health topics and build a healthy norm within the classroom. In addition, prevention efforts in adults are almost non-existent with the exception of programs that focus on college students. The lack of education of healthcare providers exacerbates this problem among children, adolescents, and adults.

The same conundrum exists in the areas of early detection and treatment intervention. More specifically, there is an evolving body of medical and scientific literature indicating that both can have a meaningful impact on eating disorder sufferers' symptom severity, quality of life, and mortality rate and yet disturbingly few individuals with eating disorders across the diagnostic spectrum receive treatment. Even more troublingly, symptoms that could lead to early detection and intervention are often missed in atypical presentations, males, communities of color, and people with body types and weights not commonly perceived to be associated with eating disorders. Additionally, there exists an under recognition of the complex psychiatric (e.g., mood disorders, non-suicidal self-injury, and suicide risk) and medical comorbidities (e.g., cardiac, metabolic, endocrine, etc.) associated with eating disorders.

Although universal prevention is ideal, there is some debate as to whether it is achievable. Evidence from targeted prevention efforts, however, is convincing many that universal prevention is possible. To date, however, little has been done to implement and disseminate prevention initiatives and there is a considerable amount of work still to be done in estimating the willingness and the cost associated with their implementation.

Point of Consensus

Eating disorder outcomes and prevention efforts can be improved by implementing creative health education initiatives that focus on societal perceptions, early detection, and timely, effective intervention. Such initiatives should be geared toward parents/guardians, families, other caretakers, and frontline healthcare providers in order to maximize impact.

A. Early Detection and Intervention

Short And Long Term Goals

Goal #1: Acquire the knowledge necessary to:

- recognize risk behaviors, at-risk statuses, early development of the illnesses in typical and atypical clinical presentations; and
- appropriately intervene and/or refer.

Recommended Strategies for Achieving Goals

Broadly disseminate evidence-informed content, strategies, and tools via a nationally-recognized, not-for-profit organization with the ability to reach a diverse group of stakeholders. The National Center of Excellence for Eating Disorders (NCEED)—the nation’s first and only federally-funded center of excellence focused on eating disorders—is well-positioned to disseminate this education and training, particularly given its ties to federal partners.

Obstacles Preventing the Achievement of Goals

There will likely be difficulty in adequately reaching all stakeholders who might play a role in detection and early intervention. This is particularly true for primary care and frontline providers as they already are heavily burdened with screening a variety of mental and physical health conditions.

Strategy for Navigating and Overcoming Obstacles

Key partnerships with organizations will help promote strategy (e.g., the Accreditation Counsel for Continuing Medical Education (ACCME); Boards of primary care specialties; the CDC; teachers’ unions; state education departments; National Association of State Mental Health Program Directors (NASMHPD); Campus Health Services; National Alliance of Mental Illness; National Association of School Psychologists; The National Medical Association; The National Association of Black Psychologists; the Association of Hispanic Mental Health Professionals; American Dental Association; Chairs of pediatrics departments; school nurses associations; American Psychological Association (APA); National Association of Anorexia Nervosa and Associated Disorders (ANAD), etc.).⁵³

Goal #2: Implement developmentally/age/gender/race/culturally-appropriate screening practices in primary care and ambulatory care settings.

Recommended Strategies for Achieving Goal

K-12 and public colleges/universities: Engage with legislative bodies to enact legislation that compels providers (and other stakeholders) at publicly-funded institutions to receive education and training on eating disorder detection and early intervention.

Adults: Develop standards of practice for screening and early intervention and/or leverage the power of electronic medical records (e.g., Epic) to help providers engage in this process. For example, an electronic medical record/clinic workflow might include a brief screening for eating disorders which then triggers specific steps and/or referrals for patients at high risk.⁵⁴

Obstacles Preventing the Achievement of Goal

Lack of awareness or buy-in from primary care providers and other frontline clinicians who may see screening for yet another condition as an additional burden; viewing eating disorders as a low priority concern; prioritization of addressing “obesity problem” overeating disorders; and general lack of understanding about the screening process.

Strategy for Navigating and Overcoming Obstacles

Using influencers and/or consensus building organizations⁵⁵

B. Prevention

Short And Long Term Goals

Goal #3: K-12: Implement comprehensive health education programs that meet the National Health Education Standards (from the CDC) and include culturally-appropriate information that focuses on social-emotional development, enhancement of protective factors, and establishment of healthy peer norms.

Recommended Strategy for Achieving Goal

Use legislative efforts to enforce mandates and measurements for state education departments.

Obstacles Preventing the Achievement of Goal

Not every state can or will enforce/adopt the mandates due to:

- Limited resources
- Lack of recognition and prioritization of eating disorders
- Lack of collaborative effort focused on early detection and prevention between the public and mental health disciplines

Strategies for Navigating and Overcoming Obstacles

- Nominate/identify a group that lobbies for these initiatives
- Build grassroots support and understanding for the importance of implementing K-12th grade comprehensive health education with built in assessments
- Use other health indicators such as dietary patterns, diabetes, and mental illness rates as a way to build support for eating disorder screenings and implementation of K-12th grade comprehensive health education
- Develop a mechanism for cross discipline dialogue between public and mental health professionals using easy-to-implement, low cost programs (e.g., existing technology programs).⁵⁶

Goal #4: Adults: Include eating disorder-informed content into existing higher education and workplace wellness initiatives (e.g., employee-based programs that promote improving dietary and physical activity patterns, stress reduction, mindfulness practices, etc.).

Recommended Strategy for Achieving Goal

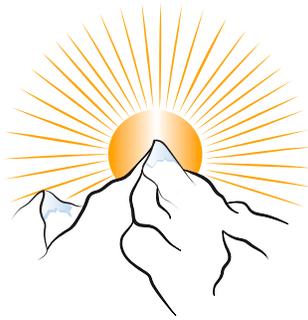
Promote the cost-saving value of the wellness initiatives

Obstacles Preventing the Achievement of Goal

Lack of awareness or buy-in from employers/companies, schools, and organizations

Strategies for Navigating and Overcoming Obstacles

- Use influencers to encourage change from within corporate governance.
- Sell as a quality improvement in the workplace (lower cost associated with health insurance; increased importance in value-based care, etc.).
- Highlight the the cost to employers from absenteeism, turnover, etc. of undiagnosed or untreated eating disorders.



SECTION II:
Accessibility, Affordability, and Accountability

The Status Quo

Eating disorders are treatable illnesses, and full recovery is possible given access to quality care for the requisite period of time. However, too few patients have access to timely evaluation and/or the appropriate level and duration of care required to achieve and sustain full recovery. A number of factors contribute to this state of affairs, including: (1) the prohibitive cost of treatment at every level of care; (2) health insurers' refusal to reimburse or adequately reimburse for the required care; (3) the disparity between what is covered by private and government funded insurance; (4) biases related to a narrow perception of the type of person who is most likely to struggle with an eating disorder; and (5) the relative scarcity of eating disorder providers and support resources, especially in underserved populations and areas.

Lack of access to expert evaluation and treatment for eating disorders is especially prevalent in populations that do not conform to existing stereotypes. Thus, it is vital that we develop models of education, early identification, and support that effectively engage and support all at-risk populations.

Lastly, accountability by providers at all levels of care is essential. Relapse rates appear exceedingly high but are difficult to quantify because those in a position to do so (e.g., residential treatment providers) rarely report short and long-term outcomes for the treatments they provide and there is no empirically-derived, consensus-driven definition of recovery with which to evaluate outcomes.

To address the gaps in access to and availability of expert care, as well as demonstrate treatment effectiveness, the eating disorders field must strive to ensure that all impacted populations are: (1) properly screened and identified; (2) educated on evaluating treatment options grounded in evidence-based practices; and (3) afforded access to appropriate levels and quality of care. We believe these are the essential components to obtain full recovery – and that they are achievable.

Point of Consensus

Those afflicted with eating disorders,
their loved ones, and the eating disorders community as a whole
would benefit from greater accessibility to affordable quality care,
as well as greater transparency and accountability on the part of
in-hospital, residential, and outpatient health care providers
with respect to their qualifications, methodologies, and standardized outcomes.

Short and Long Term Goals

1. Establish true partnerships between clients and their families that address individualized treatment needs while working within the framework of uniform treatment standards.
2. Establish empirically derived consensus definitions of recovery that are inclusive for all patients and practical for both research and treatment settings.
3. Establish field consensus on treatment standards, including core components of treatment at every level of care with consideration of cultural differences (i.e., to the extent practicable, treatment standards and venues should account/allow for the full spectrum of eating disorder patients, including different dietary needs, family structures, gender expressions, religious faiths, body weights, etc.).
4. Establish field consistency and transparency on the collection and dissemination of data and outcomes, including over time.
5. Establish comprehensive, multidisciplinary education materials on eating disorders for relevant training programs (MDs, PhDs, MSWs, RDs, etc.) and broadly disseminate via NCEED.
6. Emphasize care provided within the community.
7. Develop and utilize nationally accepted, empirically-supported standards designed to accurately quantify patient progress.
8. Develop a consensus approach on methods for assessing readiness for change (independent adult populations).
9. Remove gender specific criteria for admission at all levels of care.

Recommended Strategies for Achieving Goals

1. REDC, AED, and other prominent advocacy/professional organizations to mandate and support data collection and publication using common metrics.
2. Conduct research into barriers to treatment access for individuals with eating disorders in the U.S.⁵⁷

Obstacles Preventing the Achievement of Goals

1. Lack of Training for:
 - a. Non-professional caregivers
 - b. Medical providers
 - c. Graduate level clinicians⁵⁸
2. Failure to provide clients/families with descriptions of the full nature of eating disorders treatment and recovery.
3. Cultural Incompetence: Issues related to working with underserved populations.
4. Lack of Medicaid/Medicare coverage.
5. The failure of third party payors to reimburse in a timely manner and at an appropriate rate relative to the provider's and/or facility's level of expertise/level of care.

6. Lack of consensus about even the basics of eating disorders care at higher levels of care (e.g., establishing weight ranges, defining weighing protocols, etc.).

Strategy for Navigating and Overcoming Obstacles

1. In situations where medical and psychiatric stability are present, use low-intensity interventions related to screening, early identification, use of online resources, and guided self-help.
2. Training of non-professionals to provide peer support/coaching.
3. Nutrition psychoeducation via apps and other online support mechanisms.
4. Use of algorithms to inform treatment and level of care decisions.
5. Virtual treatment/teletherapy at all levels of care.
6. True informed consent: A statement read by all providers/centers outlining all options.
7. Increase funding for research focused on marginalized communities with eating disorders.
8. Hire more people who reflect the full spectrum of eating disorder sufferers.



SECTION III:
Standards of Care

The Status Quo

There are four categories of stakeholders in the field of eating disorders in the U.S.:

1. Advocacy Organizations:

Alliance – Alliance for Eating Disorders Awareness
ANAD – Anorexia Nervosa and Associated Disorders
EDC – Eating Disorders Coalition for Research, Policy & Action
EDLS – Eating Disorders Leadership Summit
F.E.A.S.T – Families Empowered and Supporting Treatment for Eating Disorders
NEDA – National Eating Disorders Association
Project HEAL

2. Professional Organizations:

AED - Academy for Eating Disorders
iaedp – International Association of Eating Disorder Professionals

3. Trade Group:

REDC – A consortium of over 30 eating disorder treatment programs in the U.S.

4. Educational and Training Group:

NCEED – The nation’s first and only federally-funded center of excellence dedicated to eating disorders, which was founded in 2018 by SAMHSA and whose mission is to advance education and training of healthcare providers and to promote public awareness of eating disorders and eating disorder treatment.

Each of these stakeholders has a significant interest in the standards used in regulating the diagnosis and treatment of eating disorders in the United States, three areas of which are discussed herein. Those areas include: (1) National regulatory standards for the accreditation of eating disorders treatment facilities; (2) National accreditation of professionals specializing in the treatment of eating disorders; and (3) Standards/guidelines for determining the type and level of care eating disorders patients receive.

1. NATIONAL REGULATORY STANDARDS FOR EATING DISORDERS TREATMENT PROGRAM ACCREDITATION

The two prominent regulatory organizations in the U.S. are the Joint Commission of Accreditation of Hospitals (JC) and the Commission on Accreditation of Rehabilitation Facilities (CARF). As a result of a multi-organizational task force comprised of representatives from AED, iaedp, and NEDA and led by AED, both JC and CARF have adopted eating disorders specific criteria for inpatient, residential and partial hospital programs

to be accredited as disease specific programs. These criteria are in need of continuous revision. Presently, however, there is not a dedicated resource within the field to monitor the criteria. One of the continuing gaps in criteria for being a specialized eating disorders program is how to assess the level of specialized competencies within all of the disciplines used in the treatment of eating disorders (e.g., medical, psychiatric, psychotherapy, nursing, nutritional, and others).

2. NATIONAL CREDENTIALING OF EATING DISORDERS PROFESSIONALS

The regulatory and insurance payors are progressively looking to the professional community for some credentialing mechanism that demonstrates that an individual has specialized training in the diagnosis and treatment of eating disorders. Currently, iaedp is the only professional organization in the U.S. that has created and offers an eating disorders specific certification process for various disciplines. Unfortunately, the iaedp credentialing process has not been thoroughly endorsed by other professional organizations in the U.S.

3. NATIONAL STANDARDS AND GUIDELINES FOR DETERMINING THE TYPES AND LEVELS OF CARE FOR EATING DISORDERS

There are multiple organizations, consortiums and industry groups that have issued guidelines relating to the treatment of eating disorders. Overall there is moderate to high consensus that several evidence based treatments exist for outpatient treatment of AN, BN and BED. Unfortunately, there is less consensus regarding the best treatment strategies for eating disorders patients who do not remit with outpatient treatment. Historically, the American Psychiatric Association (APA) guidelines have been the gold standard for determining levels of care (outpatient, intensive outpatient, partial hospital, residential, inpatient) in the U.S. Unfortunately, these guidelines were suspended over the last several years and are currently undergoing revision. Although the APA guidelines were generally regarded as the gold standard, they have never been formally endorsed by all of the eating disorders organizations in the U.S.

Point of Consensus

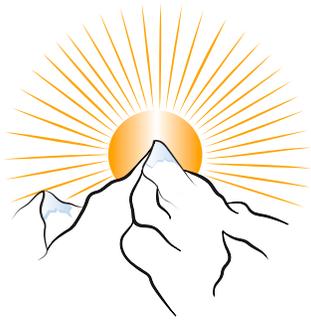
Those afflicted with eating disorders,
their loved ones, health care providers, and the eating disorders community as a whole,
would benefit from the establishment and maintenance of
treatment program accreditation, professional credentialing, and treatment type and
levels of care guidelines.

Short and Long Term Goals

1. Both the JC and CARF guidelines need to be continuously monitored and revised.
2. We need consensus regarding professional credentialing.
3. Ensure that the soon-to-be published APA guidelines reflect the input of all stakeholders in the eating disorders field.
4. Once the revisions are finalized, there needs to be a multi-organizational statement of support for the guidelines.

Recommended Strategies for Achieving Goals

1. We recommend that REDC establish a committee that maintains regular contact with these regulatory organizations. This committee should also explore how these organizations are assuring that staff in these programs have specialized training in the diagnosis and treatment of eating disorders.
2. We urge the two predominant professional organizations, iaedp and AED to collaborate on the process and content necessary for credentialing individuals. We recommend that iaedp include on its credentialing committee a member from the AED Board. It is important that the agreed upon process and content be endorsed by both organizations.
3. The new APA guidelines, a working draft of which is expected in the Spring, will have a substantial effect on how eating disorders care is delivered in the U.S. As the revision process unfolds, there will be some opportunity for interested parties to review and comment on the proposed changes. All stakeholders in the eating disorders field should embrace the opportunity to comment.
4. We propose that The Eating Disorder Leadership Summit spearhead the effort of drafting a multi-organizational statement of support for the APA guidelines resulting from the aforementioned process and build a consensus for the issuance of that statement.



SECTION IV:
Research and Research Funding

The Status Quo

Research funding for eating disorders is not commensurate with the severity of these illnesses. The federal funding allotted to eating disorders research in 2015 borders on the absurd - approximately \$0.73 per affected individual. By contrast, the federal government supported autism research at a per affected individual rate of \$58.65, schizophrenia research at a rate of \$86.97, and Alzheimer's Disease research at a rate of \$88. These figures are not offered to diminish in any way the severity of the latter diseases, but merely to highlight a gross disparity that has prevailed in the U.S. for decades where eating disorders are concerned. The figure associated with eating disorders research funding has decreased over time, given that, in 2011, it was \$0.93 per affected individual. Suffice it to say, there is only so much research progress one can expect with such limited resources.

Developing a career in eating disorders research is extremely challenging given the disparity between clinically relevant problems and research funding availability and priorities. As a result, the eating disorders field is hemorrhaging young eating disorder scholars. Moreover, researchers are striving to answer questions that have the greatest chance of being funded versus answering questions that are most important to the field. In other words, instead of science, clinical experience, and patients' needs driving science aimed at creating clinical impact, money is driving the science because researchers are scrambling to keep their jobs. Further, under conditions of scarce resources, it becomes harder for science to self-correct because a) people find contrary findings threatening and b) it is extremely hard to switch research programs if one's original research hypotheses were proven incorrect. In other words, because switching programs of research is exceedingly difficult, researchers are incentivized to design studies aimed at supporting their model or treatment as opposed to identifying when a treatment or model fails, even though we need failures to move science forward. Scarce resources also limit data sharing, open science, replication, and reproducibility.

There are bottlenecks that hamper the development of new eating disorder researchers. On the positive side, there are an increasing number of eating disorder experts available to train new eating disorder researchers in clinical psychology doctoral programs. On the negative side, we cannot expect this trend to be maintained because obtaining a faculty position at a major research university in clinical psychology has become increasingly difficult. Thus, many newly trained psychology scholars are taking positions with higher undergraduate teaching loads, which reduces research productivity. In addition, fewer academic medical centers offer training to physicians (including psychiatrists) and medical students in eating disorders care and research.

Moreover, the changes in academic medical centers have impacted opportunities for clinical psychologist training at the internship level, driving promising young scholars away from the field. One key driver of the changes occurring in academic medical centers is that eating disorder care is neither as profitable as other forms of medical care (e.g., bariatric surgery), nor as likely to result in research money given the limited NIH expenditures in this area. In addition, patients with insurance are increasingly seeking care at for-profit treatment centers, reducing the availability of patients to serve both as research participants and to help educate the next generation of clinicians

about eating disorders. From the research side, obtaining the sample sizes needed for definitive research is difficult. From the clinician side, there is a shortage of physicians, psychologists, and therapists adequately exposed to EDs.

With regard to nutrition research, there is an extreme shortage of quality research. Most research focuses on “concerns about obesity”, and almost none of this research investigates negative outcomes with regard to eating pathology. The bariatric surgery literature similarly fails to adequately address eating pathology.

Points of Consensus

- The establishment and implementation of effective, empirically/evidence-based standards of care requires research across a broad spectrum of domains (e.g., epidemiology, genetics, neurobiology, medicine, behavior, psychology, sociology, neuroscience), a diverse range of populations, adequate private and government funding, and the free exchange of ideas and information among all who share a commitment to understanding, treating, and, ultimately, markedly diminishing the negative impact of eating disorders.
- The “eating disorder stereotype” has limited the field’s definition of eating disorders and eating disorders research. It also limits the perceived public health impact of eating disorders, impacts perceptions of who gets diagnosed with an eating disorder, and contributes to the perception that “disordered eating” and eating disorders are fundamentally different (versus representing different points on a spectrum of eating behavior ranging from normal/healthy to extremely pathological). This has led to barriers and delays in providing care related to eating behaviors and cognitions. **One first step in improving the eating disorders field with respect to research and funding is to reclassify eating disorders as Eating Spectrum Disorders (ESD) to encompass the full spectrum of eating pathology.**
- The eating disorders research field has historically been criticized for being insular. The field would benefit from greater participation in wider mental health research at all levels (conferences, leadership in generalist mental health organizations, publication in generalist journals, participation in generalist editorial boards and NIH study sections; regular dialogue with CDC).
- Although NIH institutes that target “medical” conditions are increasingly funding research studying behavioral interventions, NIMH has moved in the opposite direction and is largely the institute of neuroscience. Foundational research that led to major treatment successes (DBT, FBT, CBT for a range of disorders) is significantly more difficult to obtain from

NIMH, given the increased focus on biological aspects of mental health. We need an institute (or other funding mechanism) that funds behavioral science in the area of mental health. This would also facilitate the study of combined behavioral and biological interventions. Such an endeavor should be taken on by more than just the ED field (e.g., partner with the Coalition for the Advancement and Application of Psychological Science). Importantly, the lack of funding is driving promising and sorely needed junior researchers out of the field into clinical jobs.

- Seven key limitations in the research literature must be addressed:
 1. Researchers and clinicians need greater respectful collaboration in identifying and addressing clinically relevant questions. This could potentially be self-funded by treatment centers, bypassing the NIMH problem.
 2. We have insufficient, understandable research addressing problems in the dissemination and implementation of our existing effective treatments. Although NIMH has a funding mechanism for dissemination and implementation research, this mechanism is designed to advance dissemination and implementation science, which is aimed at big-picture, cross-cutting dissemination and implementation questions. This poses two problems for the ED field. First, dissemination and implementation science is extremely jargon heavy and aimed at the large-scale questions, meaning that many of its findings are hard (if not impossible) to translate into easy to understand, practical solutions for specific problems. Second, the funding mechanism is not intended to answer any questions that are very specific to one type of setting, disorder, and/or treatment. For this reason, this research for EDs will need to be funded outside NIMH's dissemination and implementation funding stream to address eating disorder specific questions.
 3. We need significant expansion of research studying clinically relevant questions with diverse populations to understand to what degree treatments that were developed with predominantly white, female populations can be applied (or need to be modified) to meet the needs of all people who struggle with eating pathology.
 4. We need increased research investigating how to translate nomothetic treatments (i.e., treatments developed based on averages) into idiographic (i.e., treatments developed and personalized based on the individual) evidence-based treatment.
 5. We need to make it easier to present and publish negative findings.
 6. Eating disorders researchers should be encouraged to freely share pre or post prints so that clinicians and service users may have unrestricted access to the research.
 7. We need increased research on low-cost, scalable interventions and to study novel strategies aimed at creating broad public health impact.

Short Term Goals

1. Change Conceptualization of Eating Disorders

- a. Introduce and begin to validate the concept of Eating Spectrum Disorders (ESD); encourage researchers to consider what full dimensional classification of eating pathology would look like. This would include research on symptom-based classification and the interaction of symptoms with treatment.
- b. Challenge categorical distinctions (e.g., disordered eating vs. eating disordered; recovered, partially recovered, not recovered; anorexia nervosa binge/purge vs bulimia nervosa; binge-eating with dieting vs atypical anorexia nervosa; anorexia nervosa, restrictive with low insight vs avoidant restrictive food intake disorder) and work toward dimensional assessment of these outcomes.
- c. Advocate/lobby that eating disorder cognitions and behaviors be assessed in current studies examining other psychiatric patient populations such as mood, anxiety, and substance use disorders. Currently, we believe that because eating disorders are generally only evaluated and considered by researchers within this field, the impact of ESD on other mental illnesses is missed. This could look like a supplement for existing NIMH grants, and would be particularly helpful if targeted to existing large-scale studies in addictions and mood disorders.

2. Bridge the Clinical-Research Gap

- a. Develop a menu of standardized self-report measures that are routinely used pre/post and, optimally at follow-up across treatment centers and with other providers of ESD care. Suggested possible measures: Eating Disorder Examination-Questionnaire (EDE-Q), Patient Health Questionnaire-8 (PHQ-8), Generalized Anxiety Disorder-7 (GAD-7), demographics, weight, height. Recording if patient aware of weight or not for any clinical treatment setting or study. This development should include exploration of existing and past initiatives, including the NIH Assessments/Toolkit for Eating Disorders.
- b. Answer Fundamental Questions
 - i. Expected treatment course/symptom fluctuations.
 - ii. How does clinical course vary based on the specific ESD diagnoses vs. clinical symptoms?
 - iii. Tracking eating symptoms amongst the majority of people with eating disorders that never need intensive/inpatient care for an eating disorder.
 - iv. Determine when it is appropriate to transition between levels of care and how long is needed for an appropriate course of treatment.
- c. Improve dialogues between clinicians and researchers
 - i. Provide pre/post prints freely available to clinicians.
 - ii. Link the annual meeting of the Eating Disorder Research Society (EDRS) and the International Conference on Eating Disorders (ICED) to improve attendance at both and allow researchers to attend more generalist and/or related specialty conferences. Linking EDRS and ICED (e.g., have

EDRS precede ICED in the same location) will reduce both the costs and carbon footprint for those who attend both conferences, as well as free up time.

- d. Improve attention to issues of diversity in ESD research
 - i. Ask ESD journal editors to require that all studies report a full breakdown of race/ethnicity, gender identity, and socio-economic status
 - ii. Replicate existing findings in diverse populations.
 1. Create library of results needing replication or extension into other populations.
 2. Offer mentorship through AED or EDRS to help scholars frame replication studies that are adequately powered and designed to confirm or refute initial study findings.
- e. Encourage researchers to start studying low-cost, scalable interventions in conjunction with clinician networks.

3. Accept Comorbidity As Norm in ESD

- a. Move into more consistent dimensional assessment of eating pathology in conjunction with tracking anxiety, depression, and substance use disorders.
- b. Work with NIH to add funding mechanisms that support collection of eating pathology data for existing studies of depression, anxiety and substance use disorders.
 - Broaden our engagement with NIH study sections and staff (e.g., identify study sections that are more amenable to investigation of comorbidity and dimensional assessment so that such studies can be routed to these study sections).
- c. Educate NIH reviewers to accept real patients rather than perfect patients without comorbidities, as well as patients without a 'strict' diagnosis. Disseminate information to eating disorder researchers about NIH study sections that welcome and/or are open to dimensional approaches to eating disorders and those that model comorbidity. For example, some NIH study sections include Biobehavioral Regulation, Learning, and Ethology (BRLE), Behavioral Genetics and Epidemiology (BGES), Psychosocial Development, Risk, and Prevention (PDRP).

4. Retaining/Building New Researchers in ESD and Reducing Insularity

- a. Educating researchers at conferences on how to get papers published in generalist journals.
- b. Educating researchers on how to review for generalist journals.
- c. Approach editors of key journals about initiatives to publish both negative and replicated findings.
- d. Begin creating an action plan for a new NIH institute.

Long-Term Goals

- 1. Change DSM from Eating and Feeding Disorders to Eating Spectrum Disorders, or alternative conceptualization that can cover all types of eating disorder behaviors and related cognitions**
- 2. Create Centralized ESD Research Consortium**
 - a. Input Clinical Data - programs, outpatient clinicians, or patients themselves could send standardized data (5 or 6 recommended measures) at regular intervals creating access to standardized and large datasets (i.e., big-data) to answer relevant clinical questions.
 - b. Individual researchers can sign onto bigger projects.
 - c. Commitment to funding a larger range of eating disorder researchers so that we broaden the researcher base and bring more creativity to the table.
- 3. Establish Key Measures in Assessment of ESD**
 - a. Identify other alternatives for determining “health” instead of weight/BMI (e.g., Total T3; Leptin) and determine when focus should be on weight and BMI in addition to other metrics. Ensure (and develop) metrics for determining “health” that are appropriate for diverse and underrepresented persons.
 - b. Bridge and engage with obesity research to ensure assessment of eating disorder behaviors in their research. While we recognize there may be concerns about these collaborations, to strengthen the science of eating disorders, as well as decrease weight stigma and biases in the obesity field, the best approach will be collaborative, in which we draw from the ‘best’ of each field, such that both fields can benefit mutually from each other.
- 4. Expand Funding Base**
 - a. Challenge funding sources to move away from categorical diagnosis.
 - b. Create new sources of funding that will let science and clinical questions drive science (as opposed to NIMH funding priorities).
 - c. Create a new NIH institute or alternative funding mechanism at a similar level to address the consensus research points.
 - d. Find ways to use Centers for Medicare and Medicaid Services (CMS) database to promote evidence-based outpatient care.

5. Broaden Base of ESD Researchers

- a. Identify generalist journals that need or could benefit from ESD aware professionals on their editorial boards; develop a plan to get those representatives on the boards.
- b. Support movement of researchers in ESD into and back from other broader areas (e.g., anxiety, depression, behavioral genetics); encourage researchers in other areas (mood, trauma, addiction) to conduct studies in ESD and support those researchers to obtain publications/grants in ESD.

Recommended Strategies for Achieving Goals

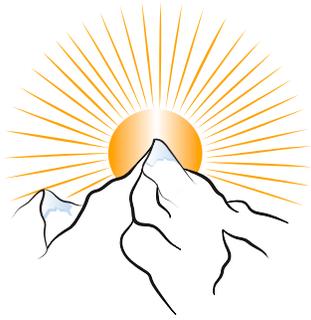
1. Build Support for Eating Spectrum Disorders by:
 - a. Conducting a literature review (and/or metanalysis) to set the stage for discussion.
 - b. Encourage researchers to collect data to create an empirically supported dimensional classification system for ESD.
 - c. Obtaining Support of Major Players: American Psychiatric Association (for DSM), AED/ICED, Center for Medicare and Medicaid Services, NIH, NEDA, iaedp, Residential Treatment Programs (both for and not-for profit), the Hierarchical Taxonomy of Psychopathology (HiTOP).
2. Work with EDRS and AED to build support for a combined meeting.
3. Work with REDC, AED, iaedp, NEDA, and treatment centers to begin standardization of measures and open publishing of outcome data to create a centralized ESD research consortium.
4. Build or enhance workshops in iaedp, EDRS, AED, etc. on team science and collaboration across treatment centers, medical providers, and scientists to achieve united goals.
5. Work with conferences and organizations to create education and training, possibly the newly established North Carolina Center for Eating Disorder Excellence and other funded education and advocacy centers, for researchers and trainees on how to obtain ESD funding, how to be on NIH study sections/identify study sections appropriate for one's work, how to identify program officers whose programs fund eating disorders work (e.g., Janani Prabhakar, Mark Chavez, Julia Zehr, Mary Rooney), publish in more general journals, how to do open science.

Obstacles Preventing the Achievement of Goals

1. Change is Hard. People like the status quo.
2. Retraining / Reeducating on ESD may be needed.
3. Some may be committed to the existing but narrow definitions of AN/BN/BED.
4. The lack of funding and financial prioritization available to create and build these initiatives.
5. If the field does not grow by inviting others in, then slices of the pie will be too small for those here now.
6. Tensions within the field between academic and for-profit residential treatment centers.

Strategies for Navigating and Overcoming Obstacles

1. Identify concerns and obstacles.
2. Lobby players to support conceptualization.
3. Develop new funding streams to support innovative/spectrum approaches (i.e., invite and pay researchers to join ESD consortium standardization for big clinical questions).
4. Collaborate with members of the ESD field who have tried to accomplish some of these goals in the past to learn from their experiences.



SECTION V:
Advocacy, Education, and Legislation

The Status Quo

There are a number of organizations in the eating disorders community whose Mission Statements include and whose leadership and membership groups have long been committed to: (1) promoting state and federal legislative initiatives relating to eating disorders research, training, treatment, and awareness; (2) advocating on behalf of eating disorders sufferers with respect to issues including early intervention, greater accessibility to affordable, evidence-based care, and enhanced insurer reimbursement for treatment; and (3) educating parents, students, teachers, coaches, and frontline health care providers on best practices relating to the early detection, treatment, and risks associated with these life-threatening illnesses.⁵⁹

There also are dozens of websites, webpages, and social media based private and public groups, whose participants serve as zealous advocates, offer peer-to-peer and/or professional support, and provide educational resources on behalf of those who are battling or in recovery from eating disorders and the loved ones committed to supporting them, as well as those seeking to learn more about these often overlooked and frequently misunderstood illnesses.⁶⁰ Finally, there are countless individuals with lived experience, tech savvy clinicians, bloggers, and others who consistently use their voices and platforms to raise awareness, promote education, and actively lobby on all matters eating disorder related.

Despite the selfless and tireless efforts of these individuals and organizations, however, federal and state governments have been slow to take a proactive role in addressing the myriad needs confronting the ED community. Indeed, notwithstanding the fact that eating disorders advocates have been aggressively pursuing federal legislative assistance since the introduction of the Federal Response to Eliminate Eating Disorders Act (FREED Act) in 2009⁶¹ and introduced similar legislation again in 2011,⁶² 2013,⁶³ and 2015,⁶⁴ it was not until December, 2016, when President Obama signed the 21st Century Care Act into law that the words “eating disorders” first appeared in a piece of enacted federal legislation in the United States.

Make no mistake, that legislation is significant in that it: (1) clarifies that insurance coverage of eating disorders treatment is subject to the parity provisions of the MHPAEA; and (2) articulates the need for and plans to better educate medical professionals and the general public about early identification of eating disorders. However, there is considerable work to be done in advancing and funding the ground-breaking research and other educational initiatives that were integral pieces to the FREED Act and addressing the plethora of other needs confronting those suffering from eating disorders and of those who have dedicated their professional lives to better understanding and treating these illnesses.

Point of Consensus

When it comes to core issues affecting all sufferers of eating disorders
(e.g., the benefit of early intervention,
reasonable accessibility to evidence-based care,
the quality and affordability of care,
the need for research,
increased public awareness and support,
and legislative initiatives)
those afflicted with eating disorders, their loved ones, and the eating disorders
community as a whole
would benefit from speaking with a unified voice.

Short And Long Term Goals

1. Prioritize Consensus Building

As the autism experience dramatically illustrates, the ability to unify (i.e., reach a consensus) and speak with a singular voice significantly enhances the likelihood of achieving the legislative, funding, and educational objectives of those who share a common enemy (e.g., autism) – and the same is true of eating disorders. Conversely, speaking with a splintered voice makes it difficult for those who are in a position to legislate, fund, and/or otherwise effect meaningful change to identify and respond to core issues and needs.

2. Develop Carefully Tailored Messaging

Word selection, message framing, and a clear understanding of and sensitivity to the intended audience are critically important to being heard and achieving desired results in the legislative, corporate, academic, and public arenas that are indispensable to the achievement of the ED community's goals. The same is true with respect to the individual decision-makers and decision-influencers who are the intended and/or likely recipients of that messaging.

3. Develop And Work From A Common Set Of Data

Advocacy, education, legislative, and funding initiatives are much more impactful if they are grounded in empirical data that is credible and readily defensible. For too long, the eating disorders community has been reliant on incomplete, anecdotal, and/or inconclusive data that only serves to: confuse, if not distort its intended messaging; convey a sense of disorganization; diminish the credibility of the community as a whole; and detract from the gravity of the situation.

4. Make More Effective And Concerted Use Of Technology

The proliferation of social media platforms provides the eating disorders community with a ready and cost-effective means of reaching tens, if not hundreds of thousands of individuals and organizations from a single laptop in a matter of minutes. Exploring creative ways of harnessing and maximizing the use of these currently underutilized resources to further educational, advocacy, and legislative initiatives is and, in the years to come, will be critical to their success.

5. Open Cross-Disciplinary Lines Of Communication

Two of the take-aways from the Summit were: (1) the well-spring of ideas that can come from providing a space in which diverse members of the ED community (e.g., researchers, clinicians, academicians, advocates, people with lived experience, and family members) can freely express their thoughts; and (2) a sense of regret that there are too few opportunities to do so. Meaningful progress depends on making such cross-disciplinary exchanges (real or virtual) the rule, rather than the exception.

6. Redouble Efforts Relating To Diversity And Inclusion

There is a growing awareness that issues related to racial, ethnic, size, and cultural diversity, as well as gender identity and sexual orientation, have a significant impact on all aspects of an individual's diagnosis, treatment, and recovery from an eating disorder. To the community's credit, progress has been made when it comes to embracing and attempting to rectify those disparities. However, there is much work left to be done to reshape and refocus the predominate lenses through which these illnesses historically have been viewed to ensure that diverse populations gain increased visibility.

7. Return To Our Collective Roots With Humility

It's easy, given the busyness and daily demands of life and the often soul-depleting nature of eating disorders, for those charged with advocating, educating, and/or promoting legislative initiatives on behalf of those who suffer from eating disorders to lose sight of the fact that we are fighting a common enemy (eating disorders) and are committed to a common goal (making quality care accessible and affordable to all eating disorders sufferers and working towards the eventual eradication of those illnesses). The same is true for those whose lives have been touched by eating disorders and who have made the study and/or treatment of eating disorders their life work. In that fight, humility should be our guiding principle.

Recommended Strategies for Achieving Goals

1. Consensus Building

Convene a virtual summit meeting of representatives of the leading eating disorder advocacy organizations and stakeholders or, alternatively, utilize the already existent EDLC for a twofold purpose:

- a. To commit to speak with a singular voice on core issues and emergent needs facing all eating disorder sufferers, including unique considerations of race, gender identity, sexual orientation, ethnicity, size, and/or age (e.g., the accessibility, availability and affordability of care; the need for evidenced-based standards of care; the need for more robust research and research funding; and the need for adequate and equitable treatment from insurers); and
- b. To reach a consensus on a specific platform of messaging that is fact based, data supported, narrowly tailored to the intended audience(s), apolitical, capable of ready adaptation to all forms of social, print, and video media, and highly compelling, together with a corresponding commitment that each stakeholder will push the messages out – consistently and enthusiastically – cognizant of the fact that doing so benefits all sufferers.

2. Tailored Messaging

It's impossible to control, nor should any effort be made to control, the messages individuals choose to post on their social media platforms relating to eating disorders. However, those organizations who serve as the faces and voices of the eating disorder community as a whole have a heightened responsibility to ensure that the messages they create and promote are evidence-based, carefully framed and reflect a clear understanding of and sensitivity to their intended audience(s) (i.e., those who are likely to “consume” them).

Those audiences include: state and federal legislators, corporate executives, insurance company representatives, frontline physicians and clinicians, private foundations, and wealthy individual benefactors – many of whom lack even a fundamental understanding of eating disorders and their life-threatening nature. They do, however, tend to be highly sophisticated and to have certain expectations with respect to advocacy and messaging when it comes to groups and individuals vying for their attention, their monetary and policy support and/or philanthropy – all of which are critical to the achievement of the eating disorder community's goals.

That being the case, that messaging cannot be relegated to those who lack the experience, discretion, sophistication, and communication skills required to maximize the likelihood that it will be heard and favorably acted upon. Instead, ideally, those charged with advocacy, education, and/or advancing legislative initiatives in the eating disorders community should retain and rely on professional publicists, media consultants, and marketing firms to assist them in formulating, tailoring, and properly disseminating the critical messaging referenced in the preceding point.

3. Help Facilitate the Timely and Efficient Dissemination of Critical Research Findings and Data

Eating disorder education and advocacy, as well as the promotion of legislative initiatives aimed at advancing the needs of eating disorder sufferers stand to benefit significantly from ground-breaking research, including the initiatives outlined in this Report, as well as the remarkable work that already has been and is being done in the United States and in a myriad of other countries around the world who are battling these insidious illnesses. The recent publication of the AED/STRIPED economic impact study (Appendix D) is a prime example, especially with respect to identifying the estimated societal, health care, and personal economic costs of eating disorders in the United States.

However, the impact of these and other initiatives is only as great as the mechanisms that exist to facilitate its prompt and efficient dissemination to organizations and individuals who are in a position to make effective use of it in furtherance of its intended purposes and to effect change (i.e., legislators, corporate executives, insurance company representatives, frontline physicians and clinicians, elementary and secondary educators and administrators, private foundations, and wealthy individual benefactors). With proper guidance from researchers, those in the advocacy, education, and legislative initiative(s) community and their established distribution networks could be uniquely situated to assist in those efforts.⁶⁵

4. More Effective Use Of Technology

As in the case of messaging (above), the importance of the effective, concerted, consistent, and proper use of technology to the achievement of eating disorder advocacy, education, and legislative goals cannot be overstated and, therefore, must be spearheaded by highly-qualified and highly-skilled professionals, especially as it relates to core (consensus based) messaging. That can and should be accomplished in one of several ways.

First, the leading eating disorder advocacy organizations and stakeholders or, alternatively, the members of the EDLC, working from a place of consensus, could contribute on a pro rata basis towards the retention of a full-time expert in the field to design and establish a game plan for implementing a comprehensive strategy for efficiently and cost-effectively disseminating critical messaging to the target audiences.⁶⁶ Alternatively, NCEED could designate such an expert, who, in turn, could be informed by the aforementioned stakeholders, since it already has ties to the target audiences and access to the requisite channels.

Second, if budgetary constraints make full-time employment impossible, secure the services of the aforementioned expert for purposes of designing the strategy and training hourly employees and interns in each of the member organizations to execute that plan with the understanding that the consultant will be available on an as needed basis.

Third, implement policies and procedures and, carefully, monitor compliance to ensure that those who have the access/authority required to post on the organization's social media and other internet platforms understand what is (and is not) permitted in the way of messaging as it relates to core issues impacting all eating disorder sufferers.

5. Cross-Disciplinary Lines Of Communication

In addition to annual or semi-annual conferences at which stakeholders or their designees deliver formal presentations to other stakeholders, eating disorders community organizers and sponsors should focus on arranging in-person or virtual conferences aimed at promoting the free exchange of ideas and information among professionals with an eye towards:

- a. fostering more open lines of communication among the various disciplines;
- b. identifying and prioritizing gaps and goals needed to advance the core objectives of the eating disorders community as a whole;
- c. relationship and consensus building;
- d. providing opportunities for the next generation of treatment providers to benefit from the knowledge and

- wisdom acquired by long time leaders and practitioners in the field; and
- e. affording those charged with advocating, educating, and advancing legislative initiatives with a broad based understanding of cutting edge developments and research in the field to further enhance their efforts.

Simply put, where communication is concerned, the eating disorder community needs to reach beyond those who already appreciate the seriousness of these illnesses. It is time to shift the focus and the messaging (in a more concerted way) to those outside the eating disorder community, who not only remain largely underinformed about the magnitude and gravity of the problem, but in many instances are uniquely situated to be instrumental in effecting meaningful change once provided with a clear understanding of what change is needed.⁶⁷

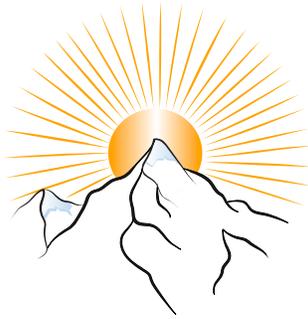
6. Greater Diversity And Inclusion

Eating disorders do not discriminate based on age, ethnicity, race, sexual orientation, gender identity, size, and/or economic status and yet, if the eating disorders community were to take an objective snapshot of the current landscape, it also would be forced to admit that those differences are not adequately represented in positions of influence in the eating disorder field (e.g., clinicians, researchers, executive and/or board of director positions in advocacy organizations, academicians, etc.). It is up to the eating disorders field to be intentional in reconstituting its own house to reverse that state of affairs.

As importantly, it is undeniable that being different (i.e., not fitting the stereotypic mold of an eating disorder sufferer – affluent (or at least reasonably well insured), well-educated, white female) makes a difference when it comes to: the likelihood of being properly and timely diagnosed; the availability, accessibility, affordability, and quality of care; the chance of being treated by a provider who is sensitive to racial, ethnic, gender identity, sexual orientation, and/or cultural dynamics and/or nuances that may influence the recovery journey; and post-treatment support communities comprised of like-experienced and/or like-minded peers. That too, needs to change and the advocacy stakeholders can take a powerful and lead role in educating and advocating for that change, beginning immediately.

7. Back to Basics and the Need for Humility

Few professional and advocacy communities are populated with individuals and organizations whose fundamental purpose is (or should be) to one day “put themselves out of business,” but the field of eating disorders is one of them. And, ideally, one day that will happen (i.e., because of our collective efforts, eating disorders will be eradicated or their threat so minimal as to only need a fraction of the resources currently dedicated to fighting them). In the interim, however, all who warrior against these illnesses, especially those charged with advocating, educating, and/or promoting legislative initiatives on behalf of all those who suffer from eating disorders must not lose sight of the fact that: (1) we are all in this (and stronger) together; and (2) humility is where each of our journeys began and it is the light that will illuminate the path forward to the journey’s end.



SECTION VI:

Eating Disorders Issues in a COVID-19 World

Introduction⁶⁸

Advocacy for eating disorders is an urgent, compelling, and rapidly changing issue, significantly intensified by the COVID-19 pandemic. During the first two months of the COVID-19 crisis, the National Eating Disorders Association (NEDA) experienced a 78 percent increase in calls to its help line compared to the same time period last year. Another organization reports a 75% increase in the number of conversations about eating disorders on its Crisis Text Line. Over 80% of requests were from women, with half under the age of 17.⁶⁹

The impact of COVID-19 on mental health issues generally has already been documented, with both “significant and sustained increases” in clinical depression and anxiety disorders, “above historical norms.” These increases occur more frequently in women, minorities, those with pre-existing health problems, and young people (under 34 years old). Social isolation as mandated by the stay-at-home orders may intensify these issues and delay addressing them.⁷⁰

The COVID crisis also demonstrates the ongoing significant consequences of economic and racial disparities and the social determinants of health. Black Americans are dying from COVID at a rate twice that of white Americans. Although they represent 13% of the U.S. population, African Americans account for 24 % of the COVID related deaths when race is known.⁷¹

These disparities must be acknowledged in our advocacy efforts, as African Americans and other minority groups have a comparable rate of eating disorders in the U.S. but are less likely to be identified and referred for services. The pervasive stigmatization of large bodies - particularly large black women’s bodies - is an example of systemic racism, often resulting in medical advice about weight loss, with no actual assessment of the health of the individual. Restrictive dieting is routinely recommended, potentially contributing to more health problems including clinical eating disorders. Research now suggests that it is the stigma related to large bodies and not the weight itself that creates the health problems associated with a high BMI.⁷² All advocacy, prevention and outreach must incorporate these concerns, so they do not cause further harm to this vulnerable group and contribute to the development or exacerbation of an eating disorder.⁷³

Eating Disorders And Social Justice

2020 was a critical time in race relations in the U.S. – catalyzed by the deaths of several unarmed black Americans at the hands of the police – and the U.S. is facing these racial and social issues head-on in a remarkably different way than ever before. The ED community too must address these issues as we move forward.

Eating disorders are often thought of as diseases that primarily impact young, wealthy, straight, white females – this is a myth. The truth is that, while groups that are vulnerable are likely at similar risk, they simply do not have equal access to care, due to stereotypes regarding who is at risk, increased stigma, the prohibitive cost of

treatment, or some combination of all three. The truth is that all vulnerable groups are equally at risk but simply do not have equal access to care, whether because of stereotypes regarding who is at risk, increased stigma, or the prohibitive cost of treatment. For this reason, minorities, low-income people, LGBTQI individuals, and people with disabilities suffer from eating disorders at high rates but are generally not as visible in our healthcare system.

Advocacy efforts must be transdiagnostic, reflecting the entire spectrum of eating disorders- anorexia nervosa, bulimia nervosa, otherwise specified and unspecified eating disorders, binge-eating disorder, rumination disorder, pica, and avoidant/restrictive food intake disorder. Often, the focus of advocacy, research and treatment has been on anorexia nervosa, but all eating disorders seriously threaten the health and wellbeing of those who suffer, independent of diagnosis or weight.

We must devote outreach, prevention, education, treatment and support services to all, regardless of race, ethnicity, sexual orientation, gender identity, size, socioeconomic class, age, and ability. All those affected by eating disorders must be included in all initiatives. Advocacy related to eating disorders must be informed by a perspective of social justice. Stated otherwise, an inclusive effort must be made to meet the needs of constituents of all races, ages, socio-economic status, sexual orientation, gender identity, size, and ethnicity, as said in the previous sentence, with awareness of how the needs of many of these groups have been systematically ignored to their detriment- and to the detriment of the field.

COVID-19: Health and Mental Health⁷⁴

According to the KFF Health Tracking Poll issued in May 2020, nearly half of the adults surveyed report that they or a member of their household have delayed or skipped health care visits due to the COVID pandemic. In addition, 39% report that their mental health has been negatively affected by the COVID outbreak, with 12% stating it has had a “major impact.”

Women are more likely than men to report a negative mental health impact (46% to 33%). In households that report income or job loss, 46% state that this has negatively affected their mental health.

Over 30% report falling behind paying bills and struggling to afford basic expenses such as food and insurance. For at least one fourth of American homes, people have struggled with food insecurity, skipping meals or relying on charity or government sources for food, with Latino and Black families reporting a higher incidence of these challenges.

Due to the surge in unemployment, 55% of respondents said that Medicaid is important to them or their families and 23% who are not currently on Medicaid predict that they will apply for it in the next year. The majority of respondents (56 %) support the concept of a national health plan like “Medicare for all” and 68% support a public option.

These economic issues will hit eating disordered individuals and their families hard as treatment is an additional and often unanticipated expense in the family budget. Skipping health care visits can be a death sentence for eating disorder patients.

COVID-19 and Eating Disorders

Eating Disorders are complex biopsychosocial disorders with the second highest mortality rate of all mental illnesses, only surpassed by opioid addiction.

The COVID pandemic has implications for the eating disorder population due to the medical risks caused by malnutrition, starvation, and other pathogenic weight loss behaviors. Untreated medical complications of severe eating disorders likely pose greater risk to patients than COVID-19 infection.⁷⁵

These risks include:⁷⁶

- Malnutrition affects all organ systems.
- Reduced body fat and slower digestive processes impair the body's response to infections.
- Reduced muscle strength compromises the ability to cough- lungs may not be cleared efficiently or fully.
- "Respiratory reserves" may already be impaired, requiring more medical care and possible use of ventilator.
- Low Carb intake and stores increase likelihood of hypoglycemia.
- Eating disorders often cause metabolic and electrolyte imbalances, increasing risk for cardiac events

Furthermore, the shared global trauma caused by the pandemic creates anxiety and fear due to the uncertainty about its course globally, nationally, and individually. Isolation and fear intensify the loneliness and disconnection that many suffering from eating disorders already have. Hopelessness may set in. Some may give up on recovery, convinced that they are going to die anyway from the virus.

This pandemic has resulted in a significant degree of food insecurity across the globe including in countries and groups that have not typically experienced this. Food insecurity is known to co-occur with and contribute to eating disorders.⁷⁷

Those with symptoms of anorexia may experience food insecurity as a justification to not eat, or to restrict more. With food supplies being more limited, it may be difficult for those at all stages of recovery, but especially for those early in this process, to find the foods they feel are safe to eat. Already struggling with intake and weight, they may decline even more. For those who have achieved some degree of recovery, COVID related stressors may trigger relapse.

Due to the atmosphere of scarcity, those with tendencies to engage in binge-type behaviors may have difficulty controlling their behavior around food, may panic and buy food impulsively, and may engage in symptoms more frequently. The constant promotion of having home deliveries of favorite foods due to the restrictions on eating in restaurants, has encouraged bingeing behaviors for many struggling with eating disorders.

For many, the shutting down of gyms and other opportunities to exercise, as well as the push to “shelter in place,” has stimulated fear of weight gain. The talk about the “COVID 19,” or the “Quarantine 15” is omnipresent, creating weight concerns and intensifying the shame and confusion about their relationship with food for people both with and without eating disorder histories. Greater use of social media and exposure to media images of beauty in general can intensify body image concerns, as can the increased reliance on video conferences for education, socialization, and even treatment. Seeing their image on screens may cause distress. As life as we have known it spins out of our control, controlling weight and appearance may become critical goals, contributing to eating disorder symptomatology.

Fear of contracting the virus may also result in obsessive pursuit of nutritional remedies, including restrictive diets and fasting, hoping to increase immunity.

Family tensions may develop secondary to these stressors. Eating disorders are always a challenge to relationships and conflicts can escalate. Anxiety and depression may become a shared family experience, even to the point of hopelessness and suicidal ideation.

Finally, rates of suicide in those with eating disorders are elevated compared to other mental health disorders (depression, bipolar, schizophrenia). The COVID crisis may add to this incidence, as social distancing and isolation are prominent ways to avoid infection.⁷⁸

Eating Disorders and Mental Health

In the COVID-19 era, access to mental health services is crucial, especially for those with eating disorders. Yet our mental health care system has never met the needs of this patient population. To say our mental health care system is broken suggests that it once was more effective, efficient and responsive to the needs of these patients and families. That has never been true. Some privileged and economically secure families do have access to a relatively full complement of the services needed but this is rare at best. Many communities have no specialty programs designed for the specific needs of eating disorders and no medical or mental health professionals with experience treating these conditions.

Even those with insurance often cannot access the correct level of care or type of program for their individual needs. For example, comorbidity is frequent, with many patients needing a program that can treat more than one condition (such as trauma and eating disorders, substance abuse and eating disorders). Furthermore, recovery takes place over a long period of time and insurance often does not provide for continuity and ongoing services.

COVID-19 Advocacy Issues

All services currently in use for eating disorders treatment must be re-examined in light of the COVID-19 crisis and the information shared above regarding significant racial disparities and other social determinants of health.

Telehealth must be seen as a viable and critical resource with innovations and research to support best practices. Virtual interventions are absolutely essential and must be supported by insurance, third party payors and regulatory agencies and validated with research and consumer input regarding what works for them.

Specifically, we need:

- Specialized training in telehealth practices
- Ongoing supervision and research of digital health services
- National licensing or credentialing of mental health professionals (NOTE: Although there already is some movement towards achieving this objective with PsyPact®, the current system is determined on a state by state basis)
- Methods for addressing emergency or crisis situations at a distance - such as suicidality, self-harm or medical emergencies
- Assurance of privacy and confidentiality when providing digital services
- Payment for digital services including valid guided self-help tools
- Outreach to all at risk groups for education, screening, diagnosis and referral to treatment resources.
- Developing detection and early intervention programs utilizing non-licensed community workers similar to programs for depression and substance abuse in underserved communities.
- Improved training of medical personnel and educators at all levels in the prevention and management of eating disorders.

For now, we are in desperate need of:

- Free and low-cost clinical services
- Group support, round the clock
- Hotlines with appropriate supervision by experts in eating disorders
- Culturally sensitive outreach to groups who have been marginalized by the field to date, including: Midlife and older women; Males; LGBTQI; Minority groups- Hispanic, African American, Asian, and others.
- Support and education for families and loved ones.
- Outreach and clinical interventions must also be adapted to the needs of those who are disabled, especially those with sensory limitations.
- An end to the systemic weight stigma and body shaming that contributes to negative self-esteem and overvaluation of thinness, as these cultural forces promote eating disorders across all diagnoses.

Finally, we need a detailed advocacy agenda, surpassing the ideas above, informed by the many organizations that have advocated for eating disorders over the years, including NEDA, EDC, AED, The Alliance, ANAD, FEAST, iaedp, REDC, Project Heal, and smaller organizations such as MEDA, as well as community based resources that best know the needs of the marginalized groups who have not been “at the table” to date. The Eating Disorder Leadership Council may be the optimal vehicle to harness such resources and develop an organic, constantly evolving advocacy agenda that can address the rapidly changing environment in which eating disorders develop. (See Appendix C – Recent Resources)

Appendix A

Diagnostic Criteria for Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, and ARFID from the Diagnostic and Statistical Manual of Mental Disorders (DSM-V)

Anorexia Nervosa

1. Restriction of energy intake relative to requirement, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health.
2. Intense fear of gaining weight or of becoming fat, or persistent behavior that interferes with weight gain, even though at a significantly low weight
3. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

Bulimia Nervosa

1. Recurrent episodes of binge eating
2. Recurrent inappropriate compensatory behaviors (such as self-induced vomiting, misuse of laxatives, fasting, or excessive exercise) in order to prevent weight gain
3. The binge eating and inappropriate compensatory behaviors both occur, on average, at least 1x/week for 3 months.
4. Self-evaluation is unduly influenced by body shape and weight.
5. The disturbance does not occur exclusively during episodes of anorexia nervosa

Binge Eating Disorder

1. Recurrent episodes of binge eating.
2. Binge eating episodes are associated with three or more of the following:
 - a. Eating much more rapidly than normal
 - b. Eating large amounts of food when not feeling physically hungry
 - c. Eating until feeling uncomfortably full
 - d. Eating alone because you are embarrassed by how much you're eating
 - e. Feeling disgusted with oneself, depressed, or very guilty after overeating
3. Marked distress regarding binge eating.
4. The binge eating occurs, on average, at least 1x/week for 3 months.
5. Binge eating is not associated with the regular use of inappropriate compensatory behavior and does not occur exclusively during the course of bulimia nervosa or anorexia nervosa

Avoidant/Restrictive Food Intake Disorder

1. An eating or feeding disturbance (e.g., apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following:
 - a. Significant weight loss (or failure to achieve expected weight gain or faltering growth in children).
 - b. Significant nutritional deficiency.
 - c. Dependence on enteral feeding or oral nutritional supplements.
 - d. Marked interference with psychosocial functioning.
2. The disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice.
3. The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way in which one's body weight or shape is experienced.
4. The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.

Appendix B

Health and Medical Consequences of Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder,⁷⁹
and ARFID⁸⁰

Anorexia Nervosa

The acute and long-term medical consequences associated with anorexia nervosa can include:

- Abnormally slow heart rate and low blood pressure
- Damage to the structure and function of the heart; increased risk of heart failure and death
- Reduction of bone density (osteopenia and osteoporosis) which results in dry, brittle bones
- Muscle loss and weakness
- Severe dehydration, which can result in kidney failure
- Edema (swelling)
- Fainting, fatigue, lethargy and overall weakness
- Dry skin and hair, brittle hair and nails, hair loss
- Anemia (can lead to fatigue, shortness of breath, increased infections, and heart palpitations)
- Severe constipation
- Prepubertal patients may have arrested sexual maturity and growth failure.
- Drop in internal body temperature, with subsequent growth of a downy layer of hair called “lanugo,” which is the body’s effort to keep itself warm
- Amenorrhea (loss of menstrual cycle)
- Infertility, increased rates of miscarriage and other fetal complications
- Increased risk for suicide

Bulimia Nervosa

The acute and long-term medical consequences associated with bulimia nervosa can include:

- Severe dehydration and electrolyte imbalances (dangerous levels of sodium, calcium, potassium and other minerals). This can lead to irregular heartbeats, possible heart failure and death.
- Chronically inflamed and sore throat
- Inflammation and possible rupture of the esophagus
- Potential for gastric rupture
- Decalcification of teeth, enamel loss, staining, severe tooth decay and gum disease as a result of repeated exposure to stomach acid
- Edema (swelling)
- Chronic irregular bowel movements, constipation and other gastrointestinal problems
- Peptic ulcers and pancreatitis
- Swollen, enlarged salivary glands in the neck and jaw area
- Acid reflux disorder
- Infertility, increased rates of miscarriage and other fetal complications

Binge-Eating Disorder

The acute and long-term medical consequences associated with binge eating disorder can include:

- High blood pressure
- High cholesterol levels
- Heart disease as a result of elevated triglyceride levels
- Type II diabetes mellitus
- Obstructive sleep apnea
- Edema (swelling)
- Kidney disease
- Gall bladder disease
- Arthritis (degenerative) - caused by hormonal imbalances and vitamin deficiencies as well as increased stress on the joints
- Infertility
- Various forms of cancer
- Increased rates of irritable bowel syndrome (IBS), fibromyalgia and insomnia have also been reported

Avoidant / Restrictive Food Intake Disorder

The acute and long-term medical consequences associated with ARFID can include:

- Constipation, abdominal pain, cold intolerance, and/or lethargy
- Stomach cramps, other non-specific gastrointestinal complaints (constipation, acid reflux, etc.)
- In females, menstrual irregularities—missing periods or only having a period while on hormonal contraceptives (this is not considered a “true” period)
- Difficulties concentrating
- Abnormal laboratory findings (anemia, low thyroid and hormone levels, low potassium, low blood cell counts, slow heart rate)
- Height stunting
- Dizziness
- Fainting/syncope
- Sleep problems
- Muscle weakness
- Poor wound healing
- Impaired immune function

Appendix C

Recent Resources re: COVID-19 and ED/Mental Health

Eating disorders in the time of COVID-19 <https://jeatdisord.biomedcentral.com/articles/10.1186/s40337-020-00295-3>

Preprint- Bulik C, *et al.* Early Impact of COVID-19 on Individuals with Eating Disorders: A survey of ~1000 Individuals in the United States and the Netherlands. medRxiv 2020. doi: <https://doi.org/10.1101/2020.05.28.20116301>

Phillipou, A., Meyer, D., Neill, E., Tan, E. J., Toh, W. L., Van Rheenen, T. E., & Rossell, S. L. (2020). Eating and exercise behaviors in eating disorders and the general population during the COVID -19 pandemic in Australia: Initial results from the COLLATE project. *International Journal of Eating Disorders*. Advance online publication. DOI: 10.1002/eat.23317 [Full text available at: <https://onlinelibrary.wiley.com/doi/10.1002/eat.23317>]

Rodgers, R. F., Lombardo, C., Cerolini, S., Franko, D. L., Omori, M., Fuller-Tyszkiewicz, M., Linardon, J., Guillaume, S. (2020). The impact of the COVID -19 pandemic on eating disorder risk and symptoms. *International Journal of Eating Disorders*. Advance online publication. DOI: 10.1002/eat.23318

Taylor, C. B., Fitzsimmons-Craft, E. E., & Graham, A. K. (2020). Digital technology can revolutionize mental health services delivery: The COVID -19 crisis as a catalyst for change. *International Journal of Eating Disorders*. Advance online publication. DOI: 10.1002/eat.23300

NCEED partnered with UNC CEED on a longitudinal study looking at the effects of COVID19 on eating disorders. The baseline results are published and NCEED created 2 summary documents of those baseline results: one for healthcare providers and one for families/caregivers.

Appendix D

Link to: Social and Economic Cost of Eating Disorders in the U.S.

<https://cdn1.sph.harvard.edu/wp-content/uploads/sites/1267/2020/07/Social-Economic-Cost-of-Eating-Disorders-in-US.pdf>

Endnotes

¹Notably, the Summit participants were asked to contribute a “Legacy List” of 10 of the most important lessons, pieces of advice, or practice tips relating to eating disorders that they’ve learned, been given, or used in the course of their work in the field. Those lists will be collated and published at a later date as a stand-alone resource.

²According to experts, Ms. Carpenter’s initial ED behaviors were those of a classic restrictor, but later included purge behavior incited by the use of ipecac. The latter, combined with her restrictor behavior, most likely led to hypokalemia, cardiac dysrhythmia, and death.

³Video: The Pulp Message of the Week, by Richard Zoglin (Time Magazine), Jan. 2, 1989 (A Review of “THE KAREN CARPENTER STORY” CBS; 1/1/20)
<http://content.time.com/time/subscriber/article/0,33009,956657,00.html>

⁴Wade, T. D., Keski-Rahkonen A., & Hudson J., (2011) Epidemiology of Eating Disorders. In M. Tsuang and M. Tohen (Eds.), Textbook in Psychiatric Epidemiology (3rd ed.) (pp. 343-360). New York: Wiley; Hudson J. I., Hiripi E., Pope H. G. Jr., & Kessler R. C. (2007), The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication. *Biological Psychiatry*, 61, 348-358; Streigel-Moore R. H., & Franko D. L. (2003), Epidemiology of binge eating disorder. *International Journal of Eating Disorders*, 34, S19-S29.

⁵Rozzell K, Moon DY, Klimek P, Brown T. Prevalence of Eating Disorders Among US Children Aged 9 to 10 Years: Data from the Adolescent Brain Cognitive Development (ABCD) Study [published online November 26, 2018]. *JAMA Pediatr*.doi:10.1001/jamapediatrics.2018.3678.

⁶Those organizations include: Families Empowered and Supporting Treatment of Eating Disorders, National Association of Anorexia Nervosa and Associated Disorders, National Eating Disorders Association, The International Association of Eating Disorders Professionals Foundation, Residential Eating Disorders Consortium, Eating Disorders Coalition for Research, Policy & Action, MultiService Eating Disorders Association, Binge Eating Disorder Association, Eating Disorder Parent Support Group, International Eating Disorder Action, Project HEAL, and Trans Folx Fighting Eating Disorders – to name a few.

⁷HJ Watson, CM Bulik, et. al, Genome-wide association study identifies eight risk loci and implicates metabolic-psychiatric origins for anorexia nervosa. *Nat Genet*. 2019 Aug;51(8):1207-1214. doi: 10.1038/s41588-019-0439-2. Epub 2019 Jul 15. PMID: 31308545; PMCID: PMC6779477.

⁸Social and Economic Cost of Eating Disorders in the United States of America Report for the Strategic Training Initiative for the Prevention of Eating Disorders and the Academy for Eating Disorders, Deloitte Access Economics (June 2020) <https://tinyurl.com/yc4yleeu> (“Deloitte/STRIPED Study”).

⁹The DSM-V diagnostic criteria for each of the referenced illnesses are found in Appendix A. However, more simplistic definitions are provided in the text for greater reader accessibility.

¹⁰Deloitte/STRIPED Study, Table 2.3, p. 19 (and studies cited therein).

¹¹Deloitte/STRIPED Study, Table 2.6 at p. 23 (and studies cited therein). *Cf.* Hudson, J., Hiripi, E, Pope, H., and Kessler, R, The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication: *Biological Psychiatry*, 61:348-58 (2007); Keski-Rahkonen A, Raevuori A, Hoek HW. *Epidemiology of Eating Disorders: An Update*. Annual Review of Eating Disorders: CRC Press 2018:66-76.

¹²Hoek, H. W., & van Hoeken, D. (2003). Review of the Prevalence and Incidence of Eating Disorders. *International Journal of Eating Disorders*, 34(4), 383-396.

¹³Deloitte/STRIPED Study, Table 2.10, p. 28 (and studies cited therein). *Cf.* Arcelus J, Mitchell AJ, Wales J, *et al.* Mortality Rates in Patients with Anorexia Nervosa and Other Eating Disorders: A Meta-analysis of 36 Studies. *Archives of General Psychiatry*. 2011;68(7):724-731.

¹⁴Fairburn CG, Harrison PJ. *Eating Disorders*. *The Lancet*. 2003;361:407-416.

¹⁵Hoek and van Hoeken (2003). Review of the Prevalence and Incidence of Eating Disorders. *International Journal of Eating Disorders*, 386-396.

¹⁶Fairburn CG, Harrison PJ. *Eating Disorders*. *The Lancet*. 2003;361:407-416.

¹⁷*Compare* Keski-Rahkonen A, Raevuori A, Hoek HW. *Epidemiology of Eating Disorders: An Update*. Annual Review of Eating Disorders: CRC Press 2018:66-76. Hudson, J., Hiripi, E, Pope, H., and Kessler, R, The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication: *Biological Psychiatry*, 61:348-58 (2007) (mean age of onset is 18.9).

¹⁸Garner DM, Bemis KM. A Cognitive-Behavioral Approach to Anorexia Nervosa. *Cognitive Therapy and Research*. 1982;6:123-150.

¹⁹Fairburn CG, Harrison PJ. *Eating Disorders*. *The Lancet*. 2003;361:407-416.

²⁰Deloitte/STRIPED Study, Table 2.3, p. 19 (and studies cited therein).

²¹Deloitte/STRIPED Study at Table 2.6, p. 23 (and studies cited therein). *Cf.* Hudson, J., Hiripi, E, Pope, H., and Kessler, R, The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication: Biological Psychiatry, 61:348-58 (2007); Keski-Rahkonen A, Raevuori A, Hoek HW. Epidemiology of Eating Disorders: An Update. Ann. Review of Eating Disorders: CRC Press 2018:66-76.

²²Deloitte/STRIPED Study, Table 2.10 (and studies cited therein).

²³Crow, S.J., Peterson, C.B., Swanson, S.A., Raymond, N.C., Specker, S., Eckert, E.D., Mitchell, J.E. (2009) Increased Mortality in Bulimia Nervosa and Other Eating Disorders. American Journal of Psychiatry 166, 1342-1346.

²⁴The National Institute of Mental Health: Eating Disorders: Facts About Eating Disorders and the Search for Solutions. Pub No. 01-4901. www.nimh.nih.gov/health/publications/eating-disorders-new-trifold/index.shtml.

²⁵Castellini G, Lo Sauro C, Mannucci E, *et al.*, Diagnostic Crossover and Outcome Predictors in Eating Disorders According to DSM-IV and DSM-V Proposed Criteria: A 6-year Follow-up Study. Psychosomatic Medicine. 2011;73:270-279.

²⁶Castellini G, Lo Sauro C, Mannucci E, *et al.*, Diagnostic Crossover and Outcome Predictors in Eating Disorders According to DSM-IV and DSM-V Proposed Criteria: A 6-year Follow-up Study. Psychosomatic Medicine. 2011;73:270-279.

²⁷Keski-Rahkonen A, Hoek H, Linna M, *et al.*, Incidence and Outcomes of Bulimia Nervosa: A Nationwide Population-Based Study. Psychological Medicine. 2009;39:823-831. *Cf.* Hudson, J., Hiripi, E, Pope, H., and Kessler, R, The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication: Biological Psychiatry, 61:348-58 (2007) (mean age of onset is 19.7).

²⁸Fairburn CG, Harrison PJ. Eating Disorders. The Lancet. 2003;361:407-416.

²⁹Deloitte/STRIPED Study, Table 2.3, p. 19 (and studies cited therein).

³⁰Deloitte/STRIPED Study at Table 2.6, p. 23 (and studies cited therein). *Cf.* Hudson, J., Hiripi, E, Pope, H., and Kessler, R, The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication: Biological Psychiatry, 61:348-58 (2007); Erskine HE, Whiteford HA. Epidemiology of Binge Eating Disorder. Current Opinion in Psychiatry. 2018.

³¹Deloitte/STRIPED Study, Table 2.10, p. 28 (and studies cited therein).

³²Anorexia Nervosa and Related Eating Disorders, Inc. website. <http://www.anad.org/get-information/about-eating-disorders/eating-disorders-statistics/>

³³Deloitte Access Economics. *Paying the Price: The Economic and Social Impact of Eating Disorders in Australia*. New South Wales: The Butterfly Foundation. 2012.

³⁴The National Institute of Mental Health: *Eating Disorders: Facts About Eating Disorders and the Search for Solutions*. Pub No. 01-4901. www.nimh.nih.gov/health/publications/eating-disorders-new-trifold/index.shtml.

³⁵Castellini G, Lo Sauro C, Mannucci E, *et al.*, Diagnostic Crossover and Outcome Predictors in Eating Disorders According to DSM-IV and DSM-V Proposed Criteria: A 6-year Follow-up Study. *Psychosomatic Medicine*. 2011;73:270-279.

³⁶Deloitte Access Economics. *Paying the Price: The Economic and Social Impact of Eating Disorders in Australia*. New South Wales: The Butterfly Foundation. 2012. *Cf.* Hudson, J., Hiripi, E, Pope, H., and Kessler, R, The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication: *Biological Psychiatry*, 61:348-58 (2007) (mean age of onset is 25.4).

³⁷Castellini G, Lo Sauro C, Mannucci E, *et al.*, Diagnostic Crossover and Outcome Predictors in Eating Disorders According to DSM-IV and DSM-V Proposed Criteria: A 6-year Follow-up Study. *Psychosomatic Medicine*. 2011;73:270-279.

³⁸<https://www.nationaleatingdisorders.org/learn/by-eating-disorder/arfid>

³⁹DSM-V Task Force. Feeding and Eating Disorders. In: American Psychiatric Association, eds. *American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders*. 5th edition. Washington, DC: American Psychiatric Press; 2013; 329-338.

⁴⁰Most notable is the fact that, unlike AN, the restriction of food intake or avoidance of certain foods associated with ARFID is due to a fear of medical consequences, or an aversion to certain food textures or types not a drive for thinness or weight loss attempts per se. In addition, while individuals with ARFID can be dissatisfied with their body weight or appearance, they tend to see their body size and shape as it really is (i.e., they do not experience the body image disturbances associated with AN).

⁴¹The most comprehensive and up to date survey of the literature relating to ARFID is: Bourne L, Bryant-Waugh R, Cook J, Mandy W. Avoidant/restrictive food intake disorder: A systematic scoping review of the current literature. *Psychiatry Res*. 2020 Jun;288:112961. doi: 10.1016/j.psychres.2020.112961. Epub 2020 Apr 4. PMID: 32283448.

⁴²See Table 2 in Bourne L, Bryant-Waugh R, Cook J, Mandy W. Avoidant/restrictive food intake disorder: A systematic scoping review of the current literature. *Psychiatry Res.* 2020 Jun;288:112961. doi: 10.1016/j.psychres.2020.112961. Epub 2020 Apr 4. PMID: 32283448 for a comprehensive collection of prevalence related research.

⁴³Eddy KT, Thomas JJ, Hastings E, *et al.* Prevalence of DSM-5 avoidant/restrictive food intake disorder in a pediatric gastroenterology healthcare network. *Int J Eat Disord.* 2015;48(5):464-470; *see also* Fisher MM, Rosen DS, Ornstein RM, *et al.* Characteristics of avoidant/restrictive food intake disorder in children and adolescents: A “new disorder” in DSM-5. *J Adolesc Health.* 2014;55(1):49-52 (where, in retrospective case-control study of 712 8–18-year-olds, the authors found 98 (13.8%) who met the ARFID diagnostic criteria).

⁴⁴Norris ML, Spettigue WJ, Katzman DK. Update on eating disorders: Current perspectives on avoidant/restrictive food intake disorder in child and youth. *Neuropsychiatr Dis Treat.* 2016 Jan 19;12: 213-218. <http://dx.doi.org/10.2147/NDT.S82538> (finding that the rate of ARFID ranged from 5% to 14% among pediatric inpatient ED programs and as high as 22.5% in a pediatric ED day treatment program)(studies referenced therein).

⁴⁵Kurz S, van Dyck Z, Dremmel D, Munsch S, Hilberg A. Early-onset restrictive eating disturbances in primary school boys and girls. *European Child Adolescent Psychiatry.* 2015;24:779–85.

⁴⁶Murray, Helen & Bailey, Abbey & Keshishian, Ani & Silvernale, Casey & Staller, Kyle & Eddy, Kamryn & Thomas, Jennifer & Kuo, Braden. (2019). Prevalence and Characteristics of Avoidant/Restrictive Food Intake Disorder in Adult Neurogastroenterology Patients. *Clinical Gastroenterology and Hepatology.* 18. 10.1016/j.cgh.2019.10.030.

⁴⁷Fisher MM, Rosen DS, Ornstein RM, *et al.* Characteristics of avoidant/restrictive food intake disorder in children and adolescents: A “new disorder” in DSM-V. *J Adolesc Health.* 2014;55(1):49-52; *see also* Norris ML, Robinson A, Obeid N, Harrison M, Spettigue W, Henderson K., Exploring avoidant/restrictive food intake disorder in eating disordered patients: A descriptive study. *Int J Eat Disord.* 2014;47(5): 495-499; Keery, H., LeMay-Russell, S., Barnes, T.L. *et al.* Attributes of children and adolescents with avoidant/restrictive food intake disorder. *J Eat Disord* 7, 31 (2019). <https://doi.org/10.1186/s40337-019-0261-3> (41% (ARFID) vs. 15% (AN)).

⁴⁸*Id.*

⁴⁹Fisher MM, Rosen DS, Ornstein RM, *et al.* Characteristics of avoidant/restrictive food intake disorder in children and adolescents: A “new disorder” in DSM-V. *J Adolesc Health.* 2014;55(1):49-52.

⁵⁰Fisher MM, Rosen DS, Ornstein RM, *et al.* Characteristics of avoidant/restrictive food intake disorder in children and adolescents: A “new disorder” in DSM-V. *J Adolesc Health.* 2014;55(1):49-52; *see also* Keery, H., LeMay-Russell, S., Barnes, T.L. *et al.* Attributes of children and adolescents with avoidant/restrictive food intake disorder. *J Eat Disord* 7, 31 (2019). <https://doi.org/10.1186/s40337-019-0261-3> (75% (ARFID) vs. 61% (AN)).

⁵¹Kambanis, P. Evelyn & Kuhnle, Megan & Wons, Olivia & Jo, Jenny & Keshishian, Ani & Hauser, Kristine & Becker, Kendra & Franko, Debra & Misra, Madhusmita & Micali, Nadia & Lawson, Elizabeth & Eddy, Kamryn & Thomas, Jennifer. (2019). Prevalence and correlates of psychiatric comorbidities in children and adolescents with full and subthreshold avoidant/restrictive food intake disorder. *International Journal of Eating Disorders.* 53. 10.1002/eat.23191 (finding that of 74 children and adolescents with full or sub threshold ARFID: (1) nearly half (45%) met the criteria for a current comorbid psychiatric diagnosis; (2) more than half (53%) met the criteria for a lifetime comorbid diagnosis; and (3) more troublingly, 8% endorsed current suicidality, while 14% endorsed lifetime suicidality).

⁵²Credit: Eating Disorders Prevention and Early Intervention: What Research Shows & What New Research Is Needed, STRIPED (Harvard T.H. Chan School of Public Health and Boston Children’s Hospital). <https://cdn1.sph.harvard.edu/wp-content/uploads/sites/1267/2012/08/STRIPED-Fact-Sheet-on-Eating-Disorders-Early-Detection.pdf>

⁵³Important Contacts: National Center of Excellence for Eating Disorders; National Eating Disorders Association; Academy for Eating Disorders; International Association of Eating Disorder Professionals; Eating Disorders Coalition; State Medical Boards.

⁵⁴To this end, NCEED was recently granted \$300,000 in supplemental funding by the Substance Abuse and Mental Health Services Administration (SAMHSA); that provided the initial funding to establish NCEED to develop a primary care-specific protocol for detection and management of eating disorders with an eye toward leveraging the power of electronic medical record systems. This protocol will equip frontline clinicians with the necessary training and tools to engage in early detection and intervention for eating disorders.

⁵⁵Important Contacts: Thinktank of people who represent various stakeholder groups and have knowledge in these types of processes (e.g., smoking cessation; depression screening, etc.).

⁵⁶Important Contacts: Department of Health and Human Services; National Eating Disorders Association; Eating Disorders Coalition; State Boards of Education; Superintendent’s Associations; and Parent Teacher Associations.

⁵⁷One such study already is underway led by Project HEAL and EAT Lab.

⁵⁸Notably, NCEED was designed to provide training and education for healthcare providers, trainees of all sorts, and even non-professional caregivers.

⁵⁹Those organizations include, among others: the National Eating Disorders Association (NEDA), the Academy for Eating Disorders (AED), The Alliance for Eating Disorders Awareness, the Eating Disorders Coalition (EDC), Families Empowered and Supporting Treatment for Eating Disorders (F.E.A.S.T.), the International Association of Eating Disorders Professionals (iaedp), the National Association of Anorexia Nervosa and Associated Disorders (ANAD), Project HEAL, the Multi-Service Eating Disorders Association (MEDA), and the Residential Eating Disorders Consortium (REDC).

⁶⁰Some of those resources include: ATDTfb – Eating Disorder Family and Carer Support (<https://www.facebook.com/groups/ATDTCarerSupportGroup>); Mothers Against Anorexia Nervosa and Bulimia Nervosa (<https://www.facebook.com/Mothers-Against-Anorexia-and-Bulimia-1578282975793738>); Eating Disorder AN, BED BN & EDNOS Recovery Support Group (<https://www.facebook.com/groups/edrecoverymentalhealthsupport>); Sockit To ED (<https://www.facebook.com/groups/SockitToEDglobal>); and World Eating Disorders Day (<https://www.facebook.com/WorldEatingDisordersDay>) – to name only a few.

⁶¹If passed, that Act would have required the National Institutes of Health (“NIH”) to take myriad steps, the most notable of which included: (1) compiling statistics on the economic cost of eating disorders; (2) consulting with eating disorder researchers to implement a comprehensive long term plan for research on eating disorders; (3) annually submitting to Congress a scientifically-justified budget on eating disorders research; (4) establishing “Centers of Excellence” for the purpose of training researchers and conducting research; and (5) creating a clearinghouse for eating disorder research information at the Center for Disease Control and Prevention.

⁶²Like its predecessor, the 2011 version of the Act contemplated sweeping initiatives coordinated through NIH in the areas of: (1) eating disorder research aimed at identifying and classifying eating disorders, ferreting out the causes of eating disorders and establishing guidelines for their diagnosis, early detection, and treatment; (2) the development and evaluation of new treatment protocols and best practices; (3) a comprehensive assessment of existing eating disorders prevention programs and the development of reliable prevention and screening programs; (4) a strategic plan for the conduct of, and support for, eating disorder research, including proposed budgetary recommendations, an award of federal grants for the purpose of improving the collection, analysis and reporting of State epidemiological data on eating disorders, and a joint study on the impact eating disorders have on educational advancement and achievement beginning in elementary schools.

⁶³The 2013 Act had a heavy emphasis on research aimed at better understanding, diagnosing, and treating eating disorders and how to more quickly identify and intervene in them in the lives of those afflicted.

⁶⁴The 2015 bill, dubbed the Anna Westin Act, marked a notable shift in focus away from research and collaboration. Instead, broadly construed, it sought “clarification” that, pursuant to the Mental Health Parity Act of 2008 (“MHPAEA”), a group health plan or policy that afforded coverage for eating disorders necessarily had to include residential treatment.

⁶⁵NCEED is one avenue that may be particularly effective for dissemination of research findings and data given its ties to federal partners and its collaborative relationships across academic medicine, organizations represented in REDC, and advocacy/policy groups like the Eating Disorders Coalition, NEDA, Project HEAL, and The Alliance for Eating Disorders Awareness.

⁶⁶NOTE: NCEED is already poised to do this work (and funded to do so). It would welcome the opportunity to work from a place of consensus with the larger field to help disseminate critical messaging to various stakeholder audiences. And to the larger point re: needing professional help to do so. In fact, NCEED has hired a communications firm with experience in health communications to help achieve KPIs and we could easily incorporate this work into those KPIs.

⁶⁷NCEED is situated to have a crucial impact here. Since its inception, NCEED has pivoted its educational and training efforts to focus on primary care/frontline clinicians (with a still present but less emphasized effort on stakeholders who already constitute the eating disorders field). Given its established relationships with stakeholders outside the eating disorder community, NCEED is a natural fit for fostering these lines of communication.

⁶⁸UNC CEED and NCEED partnered with their colleagues in the Netherlands (Eric van Furth and Jet Termorshuizen) to launch the COVID-ED study. The baseline results of that study have been published in IJED and the authors will be collecting data over the next year to longitudinally explore the impact of COVID on eating disorders. The preliminary findings can be found at <https://doi.org/10.1002/eat.23353>

⁶⁹<https://www.nytimes.com/2020/06/05/health/eating-disorders-coronavirus.html>

⁷⁰<https://www.healthline.com/health-news/what-covid-19-is-doing-to-our-mental-health>

⁷¹Paige Winfield Cunningham. “The Stories About Protests Are Also The Stories About COVID-19 And Racism Says One Epidemiologist.” Washington Post. The Health 202. June 2, 2020.

⁷²Puhl, R., Suh, Y. Stigma and Eating and Weight Disorders. *Curr Psychiatry Rep* 17, 10 (2015). <https://doi.org/10.1007/s11920-015-0552-6>; Neumark-Sztainer, D., Falkner, N., Story, M., Perry, C., Hannan, P., & Mulert, S. (2002). Weight-teasing among adolescents: correlations with weight status and disordered eating behaviors. *International Journal of Obesity*, 26(1), 123–131.

⁷³www.scientificamerican.com/article/the-racist-roots-of-fighting-obesity2/

⁷⁴SOURCE: <https://www.kff.org/1e5d13d/>

⁷⁵Early impact of COVID-19 on individuals with self-reported eating disorders: A survey of ~1,000 individuals in the United States and the Netherlands, Jet D. Termorshuizen MSc, Hunna J. Watson PhD, Laura M. Thornton PhD, Stina Borg MSc, Rachael E. Flatt MA, Casey M. MacDermod BA, Lauren E. Harper BS, Eric F. van Furth PhD, Christine M. Peat PhD, Cynthia M. Bulik PhD, July 28, 2020 (<https://doi.org/10.1002/eat.23353>).

⁷⁶ www.eatingdisorders.org.au/find-support/covid-19-and-eating-disorders

⁷⁷Becker, C. B., Middlemass, K., Taylor, B., Johnson, C., & Gomez F. (2017). Food Insecurity and Eating Disorder Pathology. *International Journal of Eating Disorders*, 50, 1031-1040. DOI: 10.1002/eat.22735 and Lydecker, J. A., & Grilo, C. M. (2019). Food Insecurity and Bulimia Nervosa in the United States. *International Journal of Eating Disorders*, 52, 735-739. DOI: 10.1002/eat.23074.

⁷⁸Smith, A. R., Zuromski, K. L., & Dodd, D. R. (2017). Eating Disorders and Suicidality: What We Know, What We Don't Know, and Suggestions for Future Research. *Curr Opin Psychol*, 22, 63-67.

⁷⁹Source: The Center for Eating Disorders at Sheppard Pratt <https://www.eatingdisorder.org/the-center> (accessed November 20, 2019).

⁸⁰<https://www.nationaleatingdisorders.org/learn/by-eating-disorder/arfid>; see also Table 3 Bourne L, Bryant-Waugh R, Cook J, Mandy W. Avoidant/restrictive food intake disorder: A systematic scoping review of the current literature. *Psychiatry Res*. 2020 Jun;288:112961. doi: 10.1016/j.psychres.2020.112961. Epub 2020 Apr 4. PMID: 32283448, which summarizes the clinical characteristics of ARFID, as well as the treatment interventions and clinical outcomes, as reported in the current literature.