Editor: Melissa Munn-Chernoff

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# THE Forum

Promoting excellence in research, treatment, and prevention of eating disorders.

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## Message from the President



S. Bryn Austin, ScD, FAED

If I recall correctly, it was about one nanosecond into my presidency that Executive Director Elissa Myers began to regale me her inimitable blue-sky visions for the AED. For any of you who have had the pleasure to meet Elissa, you all know that she does not waste any time in making valuable connections and sharing inspired ideas.

So perhaps it was around Day 2 of my time in office when Elissa came to me with one of her bluest of blue-sky ideas yet – for the AED to follow the lead of true pioneers with the <u>Australian Butterfly</u> <u>Foundation</u> and the <u>United Kingdom charity Beat</u> to have a comprehensive report commissioned on the social and economic impact of eating disorders in the United States. It had never been done before for the United States, we had no funds to cover the cost, and we are not economists. But Elissa did have one thing – a connection with Lynne Pezzullo, a lead person at the economic consulting firm Deloitte involved with producing the now legendary <u>Butterfly report</u>. Did I mention that Elissa has connections?

When we reached out to Lynne, she was thrilled. She then painstakingly walked us through how they achieved this for Australia and what we would need to put in place to do the same for the United States. It was not going to be easy. The healthcare systems and available healthcare costs data to work with in Australia and the United Kingdom are more centralized than in the United States, a nation with healthcare and health data systems that tend more toward, shall we say, chaos and cacophony.

The report produced by Deloitte for <u>Butterfly</u> and another by economic consulting firm PwC for <u>Beat</u> set a high standard for us, but Elissa and I were determined to create a similar report for the United States. Why? We both knew how critical solid economic data can be for advocacy efforts to increase government and foundation commitment to and funding for eating disorders research and treatment access. Since the Butterfly report came out a few years ago, advocates have been able to successfully leverage the findings to motivate the Australian government to commit substantial additional funding for <u>eating</u> <u>disorders treatment access</u>. What this advocacy success story shows us is that you do not have to be an economist to impact government health funding decisions, but it does not hurt to have a few friends who are. (If you have not had a chance to check these out yet, I highly recommend taking a quick look at the <u>Australian</u> and <u>United Kingdom</u> reports.)

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## Message from the President continued

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The AED is a global professional society – with the emphasis increasingly on *global* – rather than a single-nation research organization, so we are not in a position to fund research efforts like this. But what we are in the position to do is bring a global perspective on the state of science and policy on eating disorders around the world. We can share success stories, for instance, in health policy innovations and research funding that we find in one part of the world and use them to inspire action elsewhere. So Elissa and I began sleuthing for every opportunity we could find for funding from outside the AED to support the new project idea.

We were greeted by lots of enthusiasm and clear recognition of the need, but for any of you who have spent your career trying to raise funds for research, you know how these efforts end most of the time – a string of strikeouts with nary a penny to support your brilliant idea. But this was not like most times. As luck would have it, all the stars aligned a couple of months ago when I was able to secure the funds to hire Deloitte through my research and training program, the <u>Strategic Training Initiative for the Prevention of Eating Disorders: A Public Health Incubator (STRIPED)</u>, based at Boston Children's Hospital and the Harvard T.H. Chan School of Public Health. (At this point in the story, if this were a vlog or a GIF instead of a Forum essay, you would be seeing a repeating loop of ecstatic happy dancing. But you get the picture.)

For the project, we have assembled a stellar line-up of advisors who bring a wide range of expertise and perspectives. Their expertise includes health policy, health economics, decision sciences, psychology, medicine, public health systems, and lived experience with eating disorders. Most are AED members, including a past president, but also, several have spent most of their careers outside of the field and so will bring fresh perspectives and approaches to the guidance they offer.

Our goal for this <u>new AED-STRIPED collaboration with Deloitte</u> is to conduct a rigorous and comprehensive study estimating the economic and social costs of eating disorders in the United States. A top priority for us in crafting the final report will be to engage a wide range of audiences. These audiences will include research scientists. We will also reach out to policymakers and their staff in government, key decision makers in the healthcare and other sectors, grant-making foundations, and community members with lived experience who are the heart and soul of advocacy efforts to raise awareness and move decision makers to action. This study represents a critical step toward more fully understanding the social and economic burden of eating disorders in the United States, as well as making it possible to estimate the costeffectiveness, improved quality of life, and, most importantly, lives to be saved by scaling up effective prevention, early detection, and treatment interventions.

Once the United States report is done, that leaves just a little more than 190 countries left to go. But heck, we are up for a challenge. If I have learned anything from my time working with Elissa, it is to keep on cultivating those connections and dream big. Really big. Sometimes those connections might be all you need to bring a dream to life.



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# Message from the Editor



Melissa Munn-Chernoff

Welcome to the latest edition of the *Forum*! The issue begins with a message from President S. Bryn Austin about a new collaboration for the AED to assess the social and economic impact of eating disorders in the United States. Executive Director Elissa Myers discusses early efforts to define best practice and practical treatment for eating disorders. You will also find updates from various committees, including information and pictures about Sydney, Australia, where the International Conference on Eating Disorders will be held next year. Finally, Abigail Matthews reviews the book *"Loving Someone with an Eating Disorder: Understanding, Supporting, and Connecting with Your Partner"* written by Dana Harron. I hope you will enjoy reading these articles and seeing the pictures as much as I did.

Thank you to everyone who submitted articles to this issue of the *Forum*. Please submit your articles, letters, announcements, and suggestions (no more than 250 words per entry) for the next issue of the *Forum* by **January 15, 2020** to Melissa Munn-Chernoff at Forum@aedweb.org.

# **Greetings** from the Executive Director



Elissa Myers, MA, CAE, IOM

The Wikipedia definition of psychotherapy is "the use of psychological methods, particularly when based on regular personal interaction, to help a person change behavior and overcome problems in desired ways. Psychotherapy aims to improve an individual's well-being and mental health, to resolve or mitigate troublesome behaviors, beliefs, compulsions, thoughts, or emotions, and to improve relationships and social skills. Certain psychotherapies are considered evidence-based for treating some diagnosed mental disorders. Others have been criticized as pseudoscience."

Pseudoscience. Ouch.

In a provocative article, **Obtaining Consensus in Psychotherapy: What Holds Us Back?**, Marvin R. Goldfried, psychologist at Stony Brook University, wrote, "Although the field of psychotherapy has been in existence for well over a century, it nonetheless continues to be preparadigmatic, lacking a consensus or scientific core. Instead, it is characterized by a large and increasing number of different schools of thought. In addition to the varying ways in which psychotherapy has been conceptualized, there also exists a long-standing gap between psychotherapy research and how it is conducted in actual clinical practice. Finally, there also exists a tendency to place great emphasis on what is new, often rediscovering or reinventing past contributions."

The lack of precision in treatment choices is not unique to the field of eating disorders. It permeates the entire field of mental health. The Coalition of Associations to Advance Psychological Science (of which the AED is a member) is devoted to promoting the principle of evidence-based practice. The AED, along with most other psychological and psychiatric associations in the United States and elsewhere, have <u>endorsed a statement of commitment to evidence-based care</u>.

While committing to the principle, however, the statement itself acknowledges that in many situations, the evidence is missing or inconclusive. In evidence-based practice, "the limitations of the available empirical evidence are also considered, especially given contextual factors such as developmental level, community/cultural needs, the settings in which the services occur, barriers to services, and the strengths and assets of individuals and communities."

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## Greetings from the Executive Director continued

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To an incomparably greater extent, if you have a heart attack, there is a defined and commonly agreed upon protocol for treatment. Indeed, there are different forms and causes of a heart attack and therefore, different treatment options based on the form. However, these treatment options are carefully defined and their success or failure can (and is) empirically documented. Similarly, if you have pneumonia, there is a highly detailed <u>set of protocols</u> for treatment.

But with mental illness in general, and for eating disorders in particular, as the <u>Mayo Clinic</u> says: "Sometimes it's difficult to find out which mental illness may be causing your symptoms. But taking the time and effort to get an accurate diagnosis will *help* determine the appropriate treatment."

As noted in an <u>article</u> in <u>The Globe and Mail</u>, "One of the challenges for mental-health professionals is that they don't have the benefit of definitive tests, such as blood tests or X-rays, to confirm a diagnosis."

Great progress has been made in describing and defining mental illness, as evidenced by, for example, the American Psychiatric Association Diagnostic and Statistical Manual. Yet, as well-respected and remarkably valuable as that tool is, it is also the subject of a significant amount of <u>criticism</u>. "The new edition of the DSM-5, suffers from a scientific lack of validity, according to <u>Professor Allen Frances</u>, author <u>Gary Greenberg</u>, <u>Dr. Thomas R. Insel</u>, former director of the National Institute of Mental Health, and others," said an article in <u>Psychology Today</u>.

Even in the presence of an accurate diagnosis, there is likely to be significant disagreement as to the appropriate treatment, as well as disagreement among professionals.

The shortcomings of our certainty in both diagnosis and treatment are daunting. However, given how far we have come, there is no doubt that things are, and will continue to get, better. In fact, several AED initiatives are attempting to address and define the state-of-the-art of knowledge in treating eating disorders based on input from the best insights from around the world. I am so proud of the efforts. There are no less than four AED Committees and Task Forces and Special Interest Groups working to define best practice and practical treatment advice, and you will see the results of their work in the coming months.

But real progress will be based on our methodic, detailed, sustained, and consistent tracking of treatment outcomes – and the amalgamation of that data into a universal database. And, of course, improved funding for inclusive and carefully crafted research.

We can do this. We need to do this. As the French philosopher Moliere said, "The greater the obstacle, the more glory in overcoming it." Or as Robert Kennedy said, "Only those who dare to fail greatly can ever achieve greatly."

The call for the AED volunteers will be coming out shortly. We need voices and thinking from every corner of the world. I hope we can count on you to step up and volunteer to help us achieve great things!



# **SIG and Committee Updates**

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## Electronic Media Committee Update

## Danyale McCurdy-McKinnon & Kielty Oberlin

Welcome new and sustaining AED members! On the Electronic Media Committee (EMC), we continue to work on our webpage in order to make the community a more interactive place! We just finished our first "how-to" videos! Two video tutorials: "Navigate the online community" and "Update your profile" can be found on the 'My AED' page of the website (last tab of the main page toolbar). We hope you like them!

We would like to remind everyone about posting guidelines for post-doc opportunities and research studies. Posting under both of these community forums requires prior approval from the EMC. For post-doc opportunities, please email your request to: <u>info@aedweb.org</u>. For research studies, please follow the instructions listed <u>here</u>. We look forward to working together with you to help meet your needs!

The EMC would also like to remind you about the 'Find a Job' feature on the website. This is an excellent resource if you are looking to hire employees, staff, or faculty, and if you are looking for a new job opportunity in the field of eating disorders. You will find this tab on the very top right toolbar on the AED homepage. Check it out!

Lastly, we want to remind you of some of your wonderful membership benefits (including this *Forum* newsletter)! We would also like to remind you that your membership includes access to the <u>International Journal of Eating Disorders</u>, the official journal of the AED. This academic publication is released monthly online and bi-monthly in print. You can even earn continuing education <u>credits</u> for reading certain featured articles. Take advantage of this amazing perk by going to the 'Membership' tab on the homepage and clicking the 'Member Benefits' tab on the dropdown menu. See what your talented colleagues are up to!



## Research-Practice Committee Update

#### Gina Dimitropoulos and Kelsey Clark

#### Engaging Youth in a Meaningful Way in Co-Designing Research and Program Development

We have recently observed an increase in youth involvement and activism (e.g., LGBTQ/Two-Spirit youth and Indigenous youth working against discrimination/marginalization, youth conveying urgency for governments and the private sector to address climate change). In many countries (e.g., Australia, United Kingdom, and Canada), mental health service providers have engaged youth to solicit input on ways to build or restructure services to be empowering, youth positive, and responsive to their diversity of identities or experiences. Researchers have begun to include carers and individuals with lived experience in identifying and setting priorities for eating disorders research.<sup>1-3</sup>

Youth-Led Participatory Action Research (YPAR)<sup>4</sup> is an approach to work with youth to identify and address critical causes by using their lived experiences, expertise, knowledge, and skills. Adolescents use their insider perspective to identify salient issues to study and evaluate programs and services through a youth lens. Building on this exciting direction in our field, we would like to provide some "food for thought" on how to meaningfully engage youth in research and programming:

- Promote a positive youth development framework (i.e., recognize adolescents' knowledge, skills, and resources that should be leveraged to support those affected by eating disorders).
- Establish Youth Advisory Councils for providers to consult with adolescents on various topics (e.g., program changes, reducing barriers to services, and increasing or maintaining youth engagement).
- Engage youth meaningfully post-treatment to facilitate adoption of a positive identity as an agent of change.
- Create forums for youth to meet other youth in recovery to promote belonging, social support, and group cohesion.
- Collaboratively communicate a shared vision of recovery, heath, and youth-friendly messages to reach youth ambivalent about treatment.
- Include youth in communication about the importance of familial involvement in prevention and treatment.

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Stay connected with fellow eating disorders professionals and advocates from around the world when you renew your AED membership!

Renew today at www.aedweb.org

## Social Media Committee Update

#### Mirjam Mainland and Millie Plotkin

Sydney 1: We are counting down for ICED 2020 in Sydney, Australia!



Sydney 2: While you are in Sydney, visit the Taronga Zoo. The zoo is super easy to get to by ferry. Koalas, kangaroos, and tigers, oh my!





Sydney 3: This is Darling Harbor Theater at the International Convention Center Sydney, where we will hold the <u>#ICED2020</u> keynote, plenaries, and workshops.



Sydney 4: Views of Cockle Bay at Darling Harbor showing the International Convention Center Sydney and nearby hotels.



## Social Media Committee Update (cont.)

Sydney 5: In the spotlight: Paddington. This neighborhood in Sydney is filled with art galleries, cozy boutiques, wine bars, restaurants, and bookstores.



Royal National Park

Sydney 7: Spot whales or go for a hike in Royal National Park.



Photo Credit: https://www.nationalparks.nsw.gov.au

Photo Credit: <u>www.sydney.com</u>

Sydney 6: The Bondi to Coogee Beach walk is a six-kilometer coastal walk offering beautiful coastline vistas, beaches, and cafes.



For more exciting hotspots and conference information, visit our Instagram account at https://www.instagram.com/aed\_iced/.





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# **Association Updates and Other News**

## **Book Review Corner**



#### Abigail Matthews

Loving Someone with an Eating Disorder: Understanding, Supporting, and Connecting with Your Partner written by Dana Harron (New Harbinger Publications, Inc., 2019, 161 pages)

This book is a new resource for partners of individuals struggling with eating disorders (EDs). Comprehensive in scope, the book includes a full range of useful content, including psychoeducation about ED development and treatment; materials to improve insight into their partner's experience with an ED; and concrete skills to navigate challenges that may arise. Importantly, the reader's needs are prioritized throughout, with an emphasis on identifying personal needs and wants in the context of the relationship. Important topics include creating a self-care plan, setting healthy boundaries, and even when to consider ending the relationship.

From the outset, *Loving Someone with an Eating Disorder* fosters a personal connection with the reader via straightforward, easy-to read language and relatable content. Case vignettes portray "real" couples in the midst of challenging situations, featuring individuals with diverse ED symptoms at various relationship stages. The vignettes aim to allow the reader to identify with others, facilitating less alienation and normalization of their experience. Further, writing prompts and perspective-taking exercises encourage the reader to gain insight into their partner's experience with an ED. For example, the reader is asked to consider the emotional underpinnings of his or her partner's ED, identify times when the reader has used maladaptive strategies in response to their partner's ED, and to determine triggers of his or her partner's ED. An additional strength is Harron's use of analogies in her writing, which sheds light on the experience of ED symptoms. At one point, she compares ED cognitions to the "world's worst (and meanest) translator," skilfully allowing the reader to better understand how well-intended comments like "You look healthy!" can be interpreted by someone with an ED as evidence for weight gain.

An additional strength of *Loving Someone with an Eating Disorder* is that the book provides the reader with concrete recommendations for specific scenarios that often arise when a partner has an ED. The rationale for recommendations is also provided, fostering greater empathy and compassion for the individual with an ED. Harron tackles a wide range of topics, such as responding to a partner's requests for weight-related feedback; inadvertently hearing a partner purging; fertility; parenting in the context of having a partner with an ED; and navigating sexual intimacy. Tables are placed throughout the text that present the reader with suggested "do's" and "don't's" in the context of specific scenarios. The book also offers couples an invaluable opportunity to connect. Though not directly suggested by the author, it would be appropriate for some couples to read the book together and mutually complete exercises. This would undoubtedly prompt communication about topics that can be challenging to initiate and could facilitate the identification of needs and wants in the context of the relationship.

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## Book Review Corner continued

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Beyond its strengths, *Loving Someone with an Eating Disorder* has some shortcomings. First, Harron's book may be *too* comprehensive, as the sheer number of topics covered may at first feel overwhelming and intimidating to the reader. Additionally, the reader is encouraged to implement strategies that are often challenging to use in any relationship, and may be slightly more difficult when someone in the relationship is impacted by an ED. Skills are often presented in a few short paragraphs, potentially misleading the reader to believe that mastery should be easy.

In summary, *Loving Someone with an Eating Disorder* is a helpful resource for partners of individuals with ED. Its compassion-focused approach, relatable content, comprehensive scope, and use of concrete recommendations will be an asset to people experiencing the challenges of navigating a relationship with a partner with an ED.

## Association Updates

The August virtual gathering of the Eating Disorders Leadership Summit (EDLS) again highlighted the importance of unity, communication, and collaboration across the field of eating disorders.

The EDLS consists of executive leaders from the following organizations: the AED, Alliance for Eating Disorders, Eating Disorders Coalition (EDC), Families Empowered and Supporting Treatment for Eating Disorders (F.E.A.S.T.), International Association of Eating Disorders Professionals (iaedp), National Association of Anorexia Nervosa and Associated Disorders (ANAD), National Eating Disorders Association (NEDA), Project HEAL, and Residential Eating Disorders Consortium (REDC). The mission of the EDLS is to promote open dialogue, collaboration, and unity across diverse organizations in the United States and internationally that are committed to reducing suffering of people with eating disorders and their families.

Topics of discussion at the August meeting included a joint project called "Eating Disorders by the Numbers," which will outline a common set of eating disorder related statistics and talking points. Once finalized and adopted, this outline will be published and housed on the AED website. Also discussed was the importance of respectful and direct engagement with each other and with others across the eating disorders field, to further propel the field forward and diminish the distraction of disrespectful and unproductive dialogue.

"The passion that infuses those who are exposed to eating disorders – either as sufferers, family members, or in our case professionals and researchers seeking to alleviate the suffering – has led to the creation of a large group of associations addressing eating disorders. Each of the associations represented in this community has a unique role to play, and comes at the issues from a slightly different perspective. But while we don't always have 100% agreement on the details, we stand together in mutual support and admiration and seek common ground through the EDLS," said Elissa Myers, Executive Director of the AED.

Eating disorders are a public health problem in the United States, and there is a compelling need for improved awareness, decreased stigma, and access to quality care. An estimated 30 million Americans will struggle with an eating disorder, and approximately one person dies every hour from eating disorder complications. More than 70% of those affected will not seek treatment because of stigma, access barriers, or misinformation.

EDLS collaborators meet in-person annually, as well as via periodic virtual meetings, to discuss collaboration, communication, and maintain a strong and allied voice to the public and the media. Since all organizational participants are EDC members, EDC is the coordinating body of EDLS meetings, with various initiatives led by members facilitating collaboration across organizations. Each organization is welcome to share regular updates from EDLS meetings with their constituents via their social media and governance channels.

## **Upcoming Conferences**

## The AED European Chapter Conference is quickly approaching!

Faculty of Eating Disorders Psychiatry Annual Conference

December 4-5, 2019 | London, United Kingdom

## **Click here to learn more**

## International Conference on Eating Disorders (ICED)

For the first time, the International Conference on Eating Disorders (ICED) will be held in Sydney, Australia. The ICED will be co-hosted by AED and the Australia and New Zealand Academy for Eating Disorders (ANZAED) on June 11-13, 2020.

- The ICED will be based in Sydney. Take the opportunity to climb the Harbour Bridge, see the Sydney Opera House, and soak up some sun at Bondi Beach.
- The venue for the ICED 2020 is the new International Convention Centre Sydney. A welcome reception will be held at the Convention Centre on Thursday, June 11, and catered lunches will be provided each day of the conference.
- We are very lucky that the ICED 2020 coincides with the Sydney Vivid Festival. Incredible laser light art installations will be displayed throughout the city each evening. The ICED 2020 closing event will be a harbour cruise. This is a great opportunity to network, celebrate all of the work that has been highlighted at the ICED, and see famous icons of Sydney illuminated.
- Three days not enough? Want to understand the Australian and New Zealand eating disorders field in more detail? Sign up for the <u>ICED 2020 Observer Program</u> and visit a service or research centre for up to a week.
- Finally, post-conference workshops will be taking place in Sydney on Monday, June 15, and in Cairns, a city in northern Australia, on Tuesday, June 16. A small educational component is being made available in Cairns to afford you the opportunity to visit one of the nearby wonders of the world the Great Barrier Reef (and to be able to claim it as a tax deduction!). Experience the wonder of the Reef during the day, and learn and network in the evening.



## **Upcoming Webinars**

## AED Webinar: Parent-Based Prevention: Empowering and Guiding Parents with Eating Pathology Tuesday, December 3, 2019 at 1:00 PM EST Speaker: Shiri Sadeh-Sharvit, PhD

Eating disorders are highly heritable and affected by environmental factors. Parents with histories of eating psychopathology and weight concerns are especially worried about their children's weight trajectories and these concerns might lead to more stressful feeding interactions. Many parents with eating disorders also feel that their own history hinders their knowledge, skills, and self-efficacy in developing healthy habits in their children, potentially precipitating future problems. The goal of this webinar is to bridge the research-practice gap regarding parents with eating disorders and provide the healthcare providers (psychologists, nutritionists, physicians, and other clinicians) working with these families strategies to communicate with concerned parents in a validating, engaging, and empirically-supported way. This webinar will offer important information, ideas, and skills for professionals working with families in which a parent struggles with body image and/or eating concerns. Parent-Based Prevention will be discussed, including guidelines to determine which parents may benefit from a focused parenting program and techniques to increased engagement and adherence.

#### Register here.

# AED 5-Part Webinar Series: Evidence-Based Treatment and Eating Disorders: A General Practitioner's Guide

*Previously Recorded: Tuesday's October 8, 15, 22, 29, and November 5, 2019* Speaker: Lucene Wisniewski, PhD, FAED

Eating disorders (EDs) are serious and difficult to treat psychiatric illnesses which frequently co-occur with medical complications, psychiatric conditions, and ambivalence toward recovery. Early diagnosis and prompt intervention, based on a developmentally appropriate and evidence-based multidisciplinary team approach is the ideal standard of care. However, if you are not an ED specialist, identifying and assessing the ED, deciding among the various treatments available and knowing when you need to refer to a higher level of care can be overwhelming. The good news is that there is a vast literature to guide these decisions!

During this webinar series, AED Fellow Lucene Wisniewski, PhD, will emphasize integrating cutting edge research and evidence-based protocols into real-world clinical practice to help the general practitioner feel more confident treating EDs.

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