What have you done?

• Text 22333
• With the message: ICED2019
Niche Dialogue

An exchange of ideas within a homogenous group
Do you identify as being a part of any of these groups?

• Vote

How much do you feel that you are in dialogue with people in the other groups?

• Vote (Likert)
Cultural dialogue

An exchange of ideas throughout different groups in a society

Why do we want a cultural dialogue?

- We NEED the public. We need people outside of the ED community to care and help.
- Consumer demand drives change:
  - Regulations
  - Funding
  - Access
  - Screening
Cultural dialogue is already happening

But do we like the message?

What will the message be?

- Challenge old messages vs. add new messages
- Consensus on messages?
- Quantity and brevity of messages?
- Source of messages
- Are there still experts?
Learning from autism

- Challenge old messages vs. add new messages

Learning from autism

- Consensus on messages?
Learning from autism

• Consensus on messages?

Learning from autism

• Quantity and brevity of messages?

AUTISM FACTS

FACT

IS AUTISM AN EPIDEMIC?

A PROBLEM THAT HAS ALWAYS BEEN AROUND, WHAT HAS CHANGED IS OUR UNDERSTANDING OF THE DELIGHTFUL DIVERSITY OF OUR PEN AND SKULL?

NEURODIVERSITY!

WE ARE NOT AN ILLNESS. WE ARE NOT AN APPENDIX. WE ARE BEAUTIFUL. EXACTLY AS WE ARE.

neurodiversityloveyou.org

HOW TO END THE AUTISM EPIDEMIC

J.B. HANDLEY

FACTS ABOUT AUTISM

AUTISM AFFECTS 1 in 68 INDIVIDUALS (2014)

AUTISM CAN BE ACCURATELY DIAGNOSED BY TV PREDICTORS

ENVIRONMENTAL, BIOLOGICAL & GENETIC FACTORS ARE SUSPECTED TO CAUSE AUTISM, BUT THERE IS NO EXACT CAUSE KNOWN YET.

THERE IS NO MEDICAL CURE FOR AUTISM AND APPLIED BEHAVIORAL ANALYSIS (ABA) IS CURRENTLY THE ONLY APPROACH APROPRIATE TREATMENT.

ALMOOST 90% OF CHILDREN WITH AUTISM SHOW INCREASED QUOTIENT (IQ) PROGRESSIONAL ANALYSIS (ABA) TREATMENT ARE ABLE TO CATCH UP WITH THEIR PEERS IN DEVELOPMENT.

AUTISM IS A SPECTRUM DISORDER AND CAN AFFECT INDIVIDUALS ON DIFFERENT HIERARCHY LEVELS: - MODERATE, MODERATE-SEVERE

FACT

FACT

FACT
Learning from autism

- Source of messages

Learning from autism

- Are there still experts?
No perfection, lots of success

- Increased funding
- Wide-spread screening
- Common lexicon
- Funded services

What do YOU want the messages to be?
Survey responses

- What do you want the message to be?

How do you want to spread the word?

- Talking Hollywood
- Social media
- Blogs
- Press
- Laws
- Podcasts
- Screening
- Film & TV
Our panel

- Documentary Filmmaker
- Media Owner & Podcaster
- Blogger and Speaker
- Health & Science Journalist

- What is your message?
- How do you get society listening, and talking?

Heather Hower, MSW, LICSW, QCSW, ACSW

- NEDA Board Member, EDC advocate
- Grant reviewer (DOD), proposal reviewer (iaedp), and manuscript reviewer (JED)
- Research Project Director at Brown University and treatment development at UC San Diego
- Presenter, researcher, and author

- NEDA: https://www.nationaleatingdisorders.org/blog
- Project HEAL: http://theprojectheal.org/blog/
- Medium: https://medium.com/libertased
Blogger: Heather Hower

- Blogging is a medium that allows you to convey your message in a succinct format, and in a timely manner. The intent is to grab your attention, focus on the most important information, and if it is applicable, provide links to references and further resources.
- I blog about Eating Disorders (EDs) from both a personal and professional perspective, including translating research findings into layman's terms. In these blogs, I define the terminology used in the studies, and explain them in a way that is understandable.
- My blogs have been posted on the websites of the National Eating Disorder Association (NEDA), Project HEAL, and Jenni Schaefer. I also have my own Medium page, where I publish stories instantly.
- I have also been able to use the blogs and my corresponding bio to note cross-postings, as well as separate content (e.g., podcasts).

Blogger: Heather Hower

- My goals in sharing messages with the public via blogs include: increasing awareness of EDs, providing education on research and treatment in layman's terms, opening up a dialogue for further communication, and decreasing the stigma related to EDs.
- My blogs have thus incorporated aspects related to busting myths and clarifying facts about EDs, reporting what we know about research and treatment findings, noting how this can be helpful, inviting others to comment on the blogs, sharing their thoughts, and reaffirming that EDs are worthy of being discussed in public.
Blogger: Heather Hower

• What has worked for my blogs has involved a combination of content, audience, pictures, and also the timing of my posts.
• For example, the piece that I wrote on EDs and Complex PTSD that was posted by NEDA developed while I was attending the AED Conference in April 2018. I was reflecting on the fact that it was also Sexual Assault and Awareness Month, and I was inspired to write based upon my intersection of Anorexia (AN) and trauma.
• I included recent research, but I also disclosed my personal trauma for the first time. I had actually just presented on my AN publically at the conference, so I was in the frame of mind to share my story.
• I got an overwhelming response to this blog, as the message seemed to hit home with many people. I had several comments, cross-posts, and requests to write follow-up pieces.
• I am assisting Jenni Schaefer with research for her new book on EDs and trauma, and it will similarly include professional references, as well as anecdotes from my personal story. She was the one that suggested to me that pictures help people connect more to the blog.

Blogger: Heather Hower

• What has not worked in terms of lack of response were blogs that were too specific to individual aspects of my personal experience.
• For example, I have had chronic nightmares related to my AN and traumas, and I actually meet the DSM 5 definition for Nightmare Disorder. I am not sure if this is an issue that others are not dealing with, or something that they have not yet connected to their EDs or PTSD. In any case, I moved away from submitting those types of pieces for public consumption, but I continue to publish them on my personal Medium blog, mostly as thought exercises.
• This reaffirms the related points of making sure that you connect with your audience, your content is relevant to them, and you communicate a succinct take-home message that will hopefully move them to learn more, as well as personally reflect upon it.
EDs & Complex PTSD

Complex PTSD is the result, not of a small number of dramatic events, but rather a prolonged series of abusive events, which take place as part of an asymmetric relationship, often during childhood, due to a parental figure. Perhaps the most characteristic signs of Complex PTSD are having a negative self-image and an inability to cope with strong feelings of anger or sadness. PTSD is noted to have a specific onset, with the memory of the trauma intact. By contrast, Complex PTSD is frequently characterized by absences of memory. Indeed, one way of understanding Complex PTSD is an elaborate strategy by the brain to force out memories that are too painful to bear.

The comorbidity between PTSD and EDs is well established; the relationship appears to be largely related a form of ‘self-medicating’ behavior. People who have been through traumatic experiences often feel a sense of powerlessness, brought on to them by their inability to prevent the traumatic incident from happening, or prevent themselves from being traumatized by it. The act of consciously starving oneself in order to change one’s body shape is a method the victim uses to reassert control over his/her or own body.

References

Brain Based Treatment

Wierenga and UCSD colleagues developed an intensive 5-day multifamily treatment for adult AN. The treatment includes psychoeducation to emphasize the key role of neurobiological (brain) factors in the development of AN, teaching the patient and Support (SU) age-appropriate skills to manage disorder-related temperament.

They reported that the patients rated the intervention as highly acceptable, and the clinicians noted it was easy to implement. At post-treatment, patients demonstrated significantly increased BMI, reduced eating disorder symptoms, and improved family function. Benefits were maintained in the patients who completed follow-up assessments, with 62% reporting full or partial remission.

Reference
Research indicates that people with AN and BN have difficulty with identifying and describing their feelings (known as “alexithymia”). This may lead to a tendency to focus on logical, external thoughts (vs. creative, internal thoughts), and trouble with distinguishing between emotions and bodily sensations. Correspondingly, people with this trait often are not able to control their emotional responses to negative events (known as “emotional dysregulation”). Brown and UCSD colleagues conducted a study on adults with AN and BN, assessing for alexithymia at the beginning of a day treatment program, and emotion regulation at the end of the program. They found that the who had higher levels of alexithymia at the beginning had equal levels of emotion dysregulation at the end, however, when the adults had lower levels of alexithymia in the beginning, the AN adults had lower levels of emotion dysregulation at the end (compared to the BN adults). These findings suggest that difficulties with alexithymia have a greater impact on emotion dysregulation in AN adults.

Reference:

There is a particular stigma against EDs, compared to other Disorders such as Schizophrenia (viewed as more serious, and biologically based). EDs are considered a “lifestyle choice,” for “vain” people, who could decide to “just eat.” Extensive research has shown, however, that psychological disorders (including EDs) are based on genetic and environmental influences (as with physical disorders), and should be considered as severe.

There is a similar stigma towards recovered ED professionals. Some are viewed as “less qualified” compared to others who do not have personal experience of EDs. There is an ongoing question of whether the professional is truly recovered, or will relapse.

In contrast to EDs, there is an acceptance of recovered Substance Abuse professionals. Given their usually extensive experience with abusing (sometimes multiple) substances, there is a level of understanding, and credibility, that they bring to the role which others widely respect.
Stigma Towards ED Professionals

• We have also seen in other Disorders that disclosures by recovered professionals can be very helpful to decrease stigma. This is particularly powerful when the professional has been involved with research/clinical work that is based on their personal experience, and they have cultivated a career despite (or rather, because of) their Disorder. A recent example is Marsha Linehan, Ph.D., who disclosed that she created Dialectal Behavior Therapy (DBT) in response to her own Borderline Personality Disorder, which had previously not been properly treated.

• The field of EDs is relatively new, small, and under-funded compared to other Disorders. There is a need for continued research, novel interventions, a next generation of professionals, and fresh perspectives on understanding EDs. Recovered ED professionals are able to contribute to all of these goals, and provide a unique “inside look” as to what it is like to experience the transition from serious illness to well-being.

~Posted by Jenni Schaefer

Heather Hower,
MSW, LICSW, QCSW, ACSW
Blogger
Michael Cortese

- Owner of Gurze/Salucore
- Publishes the Gurze/Salucore Eating Disorders Resource Catalogue
- Podcast: ED Matters

- Website: https://EDcatalogue.com
- Email: mike@edcatalogue.com
Marketing: Michael Cortese

Reading Level

https://readable.com/blog/the-flesch-reading-ease-and-flesch-kincaid-grade-level/
• Writing documents intended for the general public at the 9th-grade level, health and safety information at the 5th-grade level.

• Knowing the average reading level of your audience, however, is not the same as writing for that audience.

http://www.impact-information.com/impactinfo/literacy.htm

Who are you presenting to?
Marketing: Michael Cortese

[Image of a shareable writing chart]


Marketing: Michael Cortese

[Image of a meme: "WAS NAUGHTY: SANTA LEFT PRESENTS ANYWAY"]
Marketing: Michael Cortese

- General marketing statistics for 2018:
- In North America the average email open rate is 19.49%
- For all other countries it is 22.86%
- The average click through rate for North America is 3.32%
- For all other countries it is 3.71%
Images

Stats for webtraffic

Where are they from?
– 75% from the US
– 12% from Great Britain
– Canada and Australia next highest

edcatalogue.com
Stats for edcatalogue.com

• 78% female
• 21% male

How old are they?
- 36% 25-34
- 23% 18-24
- 16% 35-44
- 13% 45-54
- 7% 55-64
- 5% 65+

Stats for edcatalogue.com

How do they visit?
- 63% on mobile
- 31% desktop
- 5% tablet
Stats for webtraffic

edcatalogue.com

Most visited articles:
– Medical symptoms and complications associated with bulimia
– How to stop abusing laxatives
– Anorexia and hair loss

Questions?

What does this mean for you?

ASK QUESTIONS!
Michael Cortese

THANK YOU!
mike@edcatalogue.com

Lisa Sabey,
Documentary Film Maker

- Anorexia—Parents to Parents: What We Wish We’d Understood
- Going Sane
- American Tragedy
Carrie Arnold

Health & Science Writer

- National Geographic
- Scientific American
- Discover
- New Scientist
- The Atlantic
- Nature
- Women’s Health
As we were cooking dinner, my husband asked me,

“Did you hear they cured cancer with the measles?!?”

The original press release
Getting the Whole Story

Woman’s cancer killed by measles virus in unprecedented trial

Daily Mail
Could measles cure cancer? Experimental virus treatment leaves 49 year old woman in complete remission

...But are you really?

Could measles cure cancer? Uh, not exactly...

But while the story is dramatic – a 49-year old US woman's myeloma blood cancer seems to have completely disappeared following treatment – the actual science is a lot more complex than simply injecting her with an armful of measles. A number of the stories implied that the woman had been treated with an extremely high dose of the regular measles vaccine, but we need to be absolutely clear here:

This treatment did not involve a standard measles vaccine or virus – the researchers used a genetically modified virus, and there's no evidence that the regular measles or MMR jab can cure, prevent or cause any type of cancer.

Stacy's story is certainly an impressive result from an exciting field of research, and we look forward to seeing more results from the Mayo Clinic team’s trial as they come through.

But these are just two patients, only one of whom had a strong response to the therapy, and one success story does not make a miracle cure. We need to see results from many more patients to know whether the virus is safe and effective at treating cancer and that Stacy’s incredible outcome wasn’t just a fluke.
Other things to note...

Check out the date on the original press release!!

Mayo Clinic First to Show Virotherapy is Promising Against Multiple Myeloma (pkg)

May 14, 2014

ROCHESTER, Minn. — May 14, 2014 — In a proof of principle clinical trial, Mayo Clinic researchers have demonstrated that virotherapy — destroying cancer with a virus that infects and kills cancer cells but spares normal tissues — can be effective against the deadly cancer multiple myeloma. The findings appear in the journal Mayo Clinic Proceedings.

Conflicts of Interest

- The Primary Investigator (PI) on the trial was Stephen J. Russell, MD, PhD of the Mayo Clinic
- Russell is ALSO the CEO of Vyriad, a biotech firm working to develop cancer vaccines and treatments, including one derived from measles
- **NONE** of the articles mentioned or disclosed a potential conflict of interest in these trial results
So what about eating disorders?

- Beware of what isn’t in the headlines
- Ask yourself if the publication has a history of sensationalizing news stories (*cough* Daily Mail *cough*)
- Consider the financial conflicts of interest of researchers and others quoted
  - *Do they have a financial incentive to believe certain things?*
- CHECK THE DATE of the article you’re reading or sharing

YOUR elevator pitch

YOU can start to socialize your research, clinical work, and lived experience.

- Get the confidence and desire to be the medium of your message.
- Know your audience—make your message meaningful
- Use conversational language
- Remove jargon
- Practice – on the airplane, in the elevator!
The Elevator Pitch

I just published a study that is the first to show that a history of BN is associated with heightened anticipatory brain activation before a prolonged, unpleasant internal experience, but an abnormal decline in brain activation over the course of this experience. This combination of exaggerated predictive signaling and aberrant adjustment over time to aversive body states may help explain why individuals with BN try to avoid them and why they engage in behaviors that result in alternating over- and under-shooting of a stable baseline (i.e., binge eating, purging).

Make it meaningful

“People do not enjoy feeling guilty, or dizzy, or worried, or short-of-breath—these are all different internal experiences (emotions and/or body sensations) that are unpleasant for most everyone.”
Use conversational language

“People with bulimia have said that the behaviors of binging (extreme over-eating) and purging (through vomiting, laxatives, excessive exercise, or fasting) help them to “numb out” to avoid negative internal experiences. But if everyone experiences the same negative internal experiences, why doesn’t everyone binge and purge?”

Remove jargon

“We are now closer to answering that question. This is the very first study to show that the brains of people who have had bulimia, respond differently to unpleasant internal experience.”
"Their brains activate differently in two ways at two different times: first, before the negative internal experience even begins, their brain anticipates the upcoming event and has increased brain activation and second, during the negative internal experience, they have an abnormal decline in brain activation."