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**How Stigma Affects Health Outcomes:
How To Reduce Stigma Effects**

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Learning Objectives

1. Describe the process by which a group becomes stigmatized
2. Explain 3 mechanisms through which stigma harms health
3. For each of 3 stigmatized patients, discuss one action to decrease stigma effects.

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Today's Outline

- What is stigma?
- How does stigma harm health?
- Personal stigma stories & thoughts on decreasing stigma
 - Eileen Ley, blindness
 - Tristan Conor Murphy, sexual and gender minority
 - Laurie Klipfel, weight
- Q & A

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Definition of Stigma

- An old, classic definition:
 - Stigma is “an attribute that is deeply discrediting” that reduces someone “from a whole and usual person to a tainted, discounted one” (p. 3).
 - Stigmatized people are perceived as having a “spoiled identity” (p. 3).

Reference: Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs NJ: Prentice Hall; 1963.

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A modern definition in wide use today:

- Stigma is defined as “the co-occurrence of its components: labeling, stereotyping, separation, status loss, and discrimination” in a context in which power is exercised.
- Stigma overlaps with racism and discrimination, but is different.

Reference: Link BG, Phelan JC. Conceptualizing stigma. *Annu Rev Sociol.* 2001;27:363–385

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Social process by which a group is stigmatized

- Labeling
- Stereotyping
- Separation
- Loss of status
- Discrimination + Power

Reference: Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. *Am J Public Health.* 2013;103(5):813–821. doi:10.2105/AJPH.2012.301069

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A few assumptions

- Stigma is a social, i.e., interpersonal, process
 - But it can become self-perpetuating when internalized as self-stigma
- Stigma can operate on individual or societal levels
 - Unequal treatment by an individual
 - Structural stigma, unequal treatment embedded in laws or societal norms

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What is a “fundamental cause”?

- A social factor that is persistently associated with health inequalities through differing times, places, and circumstances
 - Example: socioeconomic status

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A few important traits of a fundamental cause

- Influences multiple disease outcomes through multiple risk factors
- Involves access to resources that could help diminish risks or minimize consequences of a disease
 - Examples: knowledge, money, beneficial social connections
- Robustly related to health inequalities in many different times and places

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What are the processes through which stigma affects health?

- Resource allocation
- Status loss
- Social isolation
- Loss of social support
- Stress

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**Eileen Rivera Ley,
MBA**

Blind Disability & Health Advocate

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Why does it matter whether we pay attention to stigma?

“The difference between a lady and a flower girl is not how she behaves, but how she is treated.

I shall always be a common flower girl to Professor Higgins, because he always treats me like a common flower girl, and always will. But I know that I shall always be a lady to Colonel Pickering, because he always treats me like a lady, and always will.”

- Eliza Dolittle, from My Fair Lady

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My Story:
Eileen Rivera Ley

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My Story



My husband Tom
Person with Type 1 diabetes



Tom and me
with daughter Maria
and son JonCarlos as a baby

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Myself, Tom, and JonCarlos

My husband Tom had type 1 diabetes and was totally blind. I was also legally blind. Our 4-year-old son was diagnosed with type 1 diabetes.



What do you think happened next? Who learned to do blood glucose testing and insulin administration for the child?

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JonCarlos with His school nurse

Maria, JonCarlos, myself and Tom

Myself with JonCarlos at graduation this year

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How did stigma affect diabetes self-management for Tom, me, & JonCarlos?

- Resource allocation
- Status loss
- Social isolation
- Loss of social support
- Stress

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To decrease effects of stigma from visual impairment:

Learn the common courtesies to observe when working with people who don't see well

- Speak directly to your patient
- State your name when encountering the person
- Use a normal tone of voice
- Describe equipment using nonvisual senses
- Use correct sighted guide techniques

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To decrease effects of stigma always ask:

“What can we do to make this easier for you?”

?

- Sometimes people know, sometimes not
 - *Example:* Access to learning materials in nonvisual format is a major result of stigma
 - *Example:* Some people with low vision do better with specific lighting
 - Needs can vary greatly between individuals

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To Fight Stigma Provide Equal Access to Information

Don't Worry with E-Files it's Simple and Affordable to Create Accessible:

- Large print
- Braille
- Audio
- Digital Information

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To Fight Stigma Make Good Referrals:

- **Low Vision Rehabilitation**
- **Blindness Skills Training**
 - Every state has a state agency
 - Many areas also have a private agency
- **Positive role models and peer support:** National blindness organizations have many local chapters
 - American Council of the Blind www.acb.org
 - National Federation of the Blind www.nfb.org

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**To fight stigma, remember:
One Size fits One**

- We are all unique individuals
- Every person's needs are different

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A few valuable resources:

- **AADE Practice Paper on Diabetes and Disabilities, 2017**
<https://www.diabeteseducator.org/docs/default-source/practice/practice-documents/practice-papers/diabetes-and-disabilities.pdf?sfvrsn=4>
- **ADA Checklist for Healthcare Facilities:**
<https://webhost.westernu.edu/hfcdhp/wp-content/uploads/AFB-full-ADA-Checklist.doc>

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- **Bridging the Gap: Living with Blindness and Diabetes** – in audio and print:
https://www.nfb.org/images/nfb/publications/books/bridgegap_diabetes.htm
- **Guide to Living with Diabetes and Vision Loss** – in audio and print:
<https://www.afb.org/blindness-and-low-vision/eye-conditions/diabetes-and-vision-loss>

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For more information...

Come to the session:
"A treasure trove of technological tools for individuals with vision loss"
Sunday, August 11, 10:30 AM, room 370

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Tristan Conor Murphy

Transgender Person with Diabetes
Phoenix, AZ

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**Tristan's
Story:
In
transition**



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**Being both LGBTQ+
AND
A healthcare provider**

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How does stigma affect diabetes self-management for Tristan?

- Resource allocation
- Status loss
- Social isolation
- Loss of social support
- Stress

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To decrease stigma for LGBT people:

- Be real about whether you have your own discomfort with LGBT people.
- Normalize LGBT status by including it on your intake forms.
- Have all-gender bathrooms in your office
- For transgender people, use preferred name & pronouns

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Educate yourself

- Educate yourself.
 - Attend educational workshops for professionals
 - For example: “Inclusive Care for LGBTQ People with Diabetes”, Saturday, August 10, 1:00-2:00 PM
 - See the Resource List in that presentation
 - Consider attending support groups that include allies

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What healthcare providers often say...

- “Obesity” is related to....
- Just small changes make a big difference
- If you lose weight.....
- “Obesity” is growing at an alarming rate and it is causing an explosion of diabetes.....

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What many patients hear....

- Having Diabetes, HTN, HLD is all my fault
- This is easy. If I just made small changes I wouldn't be this size and I would be cured.
- I must be a total failure, I should be able to cure this with lifestyle changes
- Everything is all my fault

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Healthcare providers and public

- Justify discrimination
- "Just trying to help"
- Idea that they must not be trying or don't care about health
- Cost to the economy/societal burden
- Contempt

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Services denied due to weight

- Orthopedic procedures
- Transplants
- Weight loss surgery
- Many other surgical procedures
- Fertility procedures

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**What comes first?
"Obesity"??? Insulin Resistance???
What if we have it backwards???**

Insulin Resistance



Dr. Atia <http://www.youtube.com/watch?v=U3ol1045Tzs#at=101> #AADE19

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Insulin – An Anabolic Hormone

- Helps get sugar (glucose) from the blood stream into the cells where it is used for fuel.
- Helps store sugar in the form of triglyceride which can be turned into fat.
- Prevents the breakdown of fat.

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My story



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Hippocratic Oath: Too much focus on weight can cause harm

- Repeated weight loss and regain
- Distraction from other health goals/frustration
- Decreased utilization of health services
- Reduced self esteem-motivation
- Eating disorders
- Weight stigmatization and discrimination
- Decreased quality of life
- Stress and depression
- Weight gain

Tylka, T.L., Annunzio, R.A., Burgard, D., et al. Review Article: The Weight-Inclusive versus Weight-Normative Approach to Health: Evaluating the Evidence for Prioritizing Well-Being over Weight Loss. (2014) Journal of Obesity. Volume 2014, Article ID 189496. <https://doi.org/10.1155/2014/189496>
 Bacon, L. & Apramior, L. Body Respect: What Conventional Health Books Get Wrong, Leave Out, and Just Plain Fail to Understand about Weight. Dallas: BenBella Books 2014
 Neumark-Sztainer, Journal of Adolescent Health 2009, 44:208-213
 Hatzenbuehler, M. L., Phelan, J. C. & Link, B. G. Stigma as a Fundamental Cause of Population Health Inequalities. American Journal of Public Health, (2013) 103(5), 813-821.

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What can healthcare providers do to help?

- Do not place blame – even rewarding weight loss
- Do not focus on weight
- Evaluate/treat depression
- Set a “SMART” realistic goal
- Explain benefits of healthy behavior with or without weight loss
- Measure success in ways other than the scale
- Keep it simple
- Empowerment/encouragement

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Words matter!!

- 48 y/o “obese” female vs 48 y/o female with a BMI of 40 - you would not say 48 y/o diabetic female or 48 y/o tall female
- Reclaiming the term “fat”
- Diet vs. meal plan
- Prevention/cure vs. delay/treatment

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Summary

- Very strong evidence supports the "obesity paradox" – it is NOT a paradox!!
- Even IF there is a relationship between obesity and health, it does not mean there is a causal relationship.
- We have no evidence that weight loss itself helps (some evidence that weight loss even decreases health). Studies that show benefit do not separate benefit of healthy behavior vs. the weight loss itself.
- Obese fit people are twice as likely to live longer than unhealthy thin people.
- People are very willing to do healthy behavior, but they need to know what that is AND it has to work.
- We don't have anything that consistently works for weight loss. Weight that is lost is often regained, and weight cycling has significant decrease in health.
- Weight focus often leads to stigma, discrimination, lack of motivation, depression, eating disorders, decrease in seeking healthcare.

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Most important message:

- Fitness DOES make a difference for ALL people
- Focusing on individualized behavior that is achievable is more motivating and more likely to be continued
- Patients are more likely to continue medical follow-up
- Focusing on weight loss takes away energy for healthy behavior
- Even if weight loss is a focus, what are you recommending other than healthy behavior????
- Weight loss is NOT a behavior!!
- Patients deserve stigma/discrimination free care!!

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