CHANGING THE LANGUAGE OF DIABETES

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OBJECTIVES

Upon completion of this activity, participants will be able to
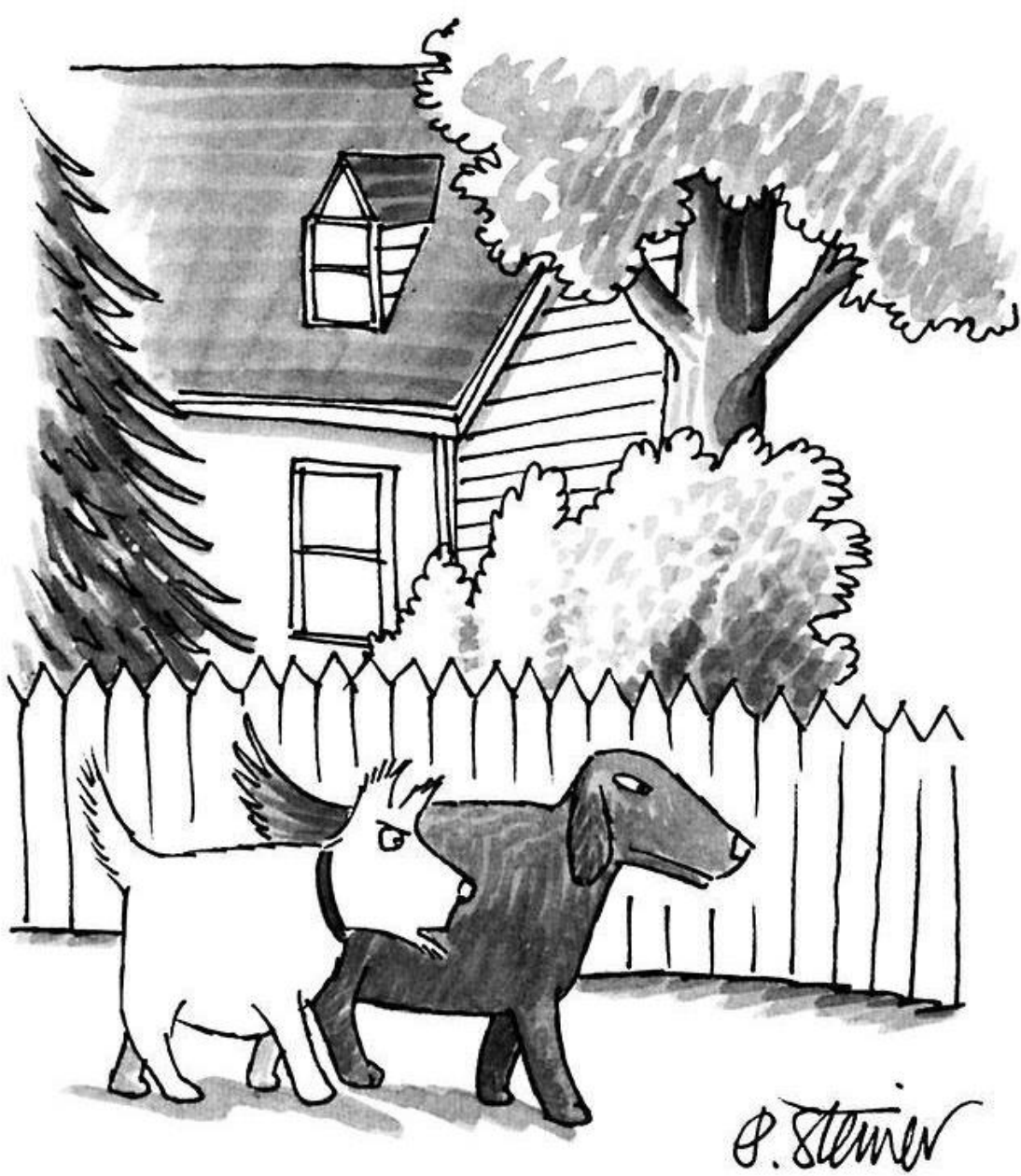
- Discuss why it's important to change the language of diabetes

- Identify words and phrases that are negative and ways to replace them

- Locate language resources for diabetes professionals

POLLING QUESTION

- Have you ever thought about the impact of language before right now?
  - Yes
  - No

"It's always 'Sit,' 'Stay,' 'Heel'—never 'Think,' 'Innovate,' 'Be yourself.'"

WORDS CANNOT BE SEPARATED FROM CONTEXT

- Words create meaning
- Words elicit feelings
- Words have an impact on self-esteem
- Words can lead to anger/frustration
- Words can lead to self-defeat
- Words can build someone up
- Words can empower

New Yorker P. Steiner

HOW THE LANGUAGE MOVEMENT GOT MOVING

- Writing Group

- Joint Paper
  - American Association of Diabetes Educators
  - American Diabetes Association

- Resources

- Language Movement

GUIDING PRINCIPLES

- Diabetes is a complex and challenging disease involving many factors and variables

- Stigma that has historically been attached to a diagnosis of diabetes can contribute to stress and feelings of shame and judgment

- Every member of the health care team can serve people with diabetes more effectively through a respectful, inclusive, and person-centered approach

- Person-first, strengths-based, empowering language can improve communication and enhance the motivation, health, and well-being of people with diabetes
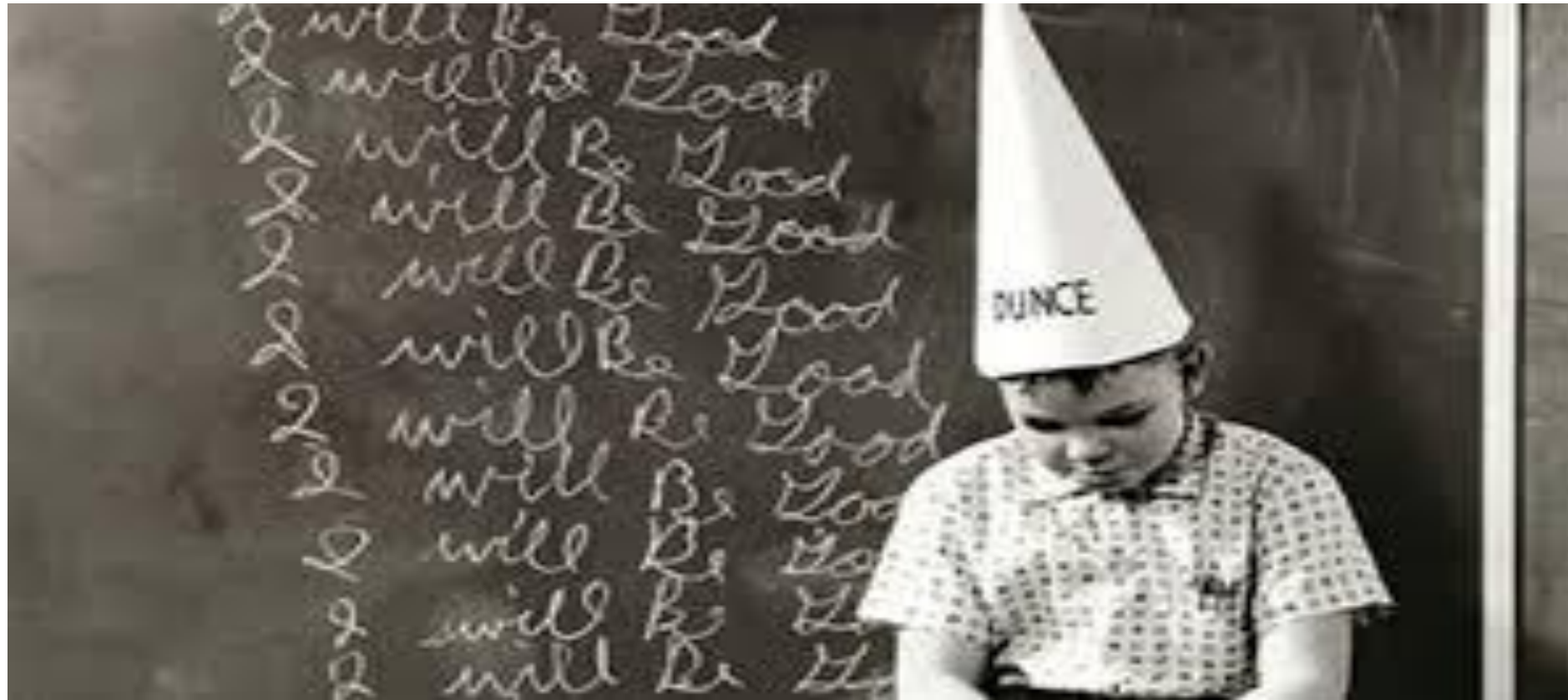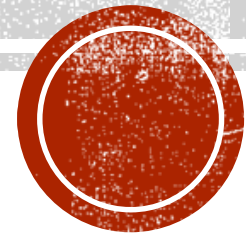
EXPECTANCY THEORY

Rosenthal & Fode, 1963; *Behavioral Science*

UNCONTROLLED, NON-COMPLIANT, NON-ADHERENT

REPLACING COMPLIANT WITH ADHERENT

RECOMMENDATION #1

USE LANGUAGE THAT IS NEUTRAL, NONJUDGMENTAL, AND BASED ON FACTS, ACTIONS, OR PHYSIOLOGY/BIOLOGY

- **Example:**

- Joe takes his medication about half the time.

- **Instead of**

- Joe is nonadherent with his medication. Joe has poor medication adherence.

LIVING WITH DIABETES FEELS LIKE...

- A failure
- A bad person
- Not good enough
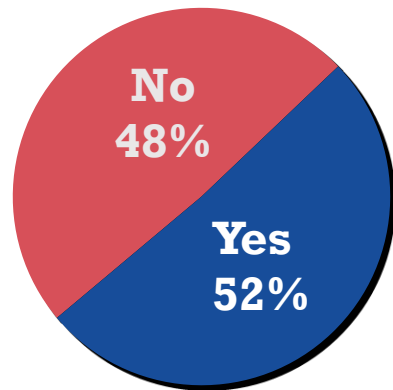- Shame
- Judgment

WHAT IS STIGMA?

- Negative mark
- Different
- Disapproval
- Stereotypes aren't always negative
- In diabetes, they often overlap

DOES DIABETES COME WITH SOCIAL STIGMA?

- People with diabetes perceived as being…
  - weak, fat, lazy/slothful, overeaters/gluttons, poor, bad, and not intelligent

Type 2

No 48%

Yes 52%

Type 1

No 24%

Yes 76%
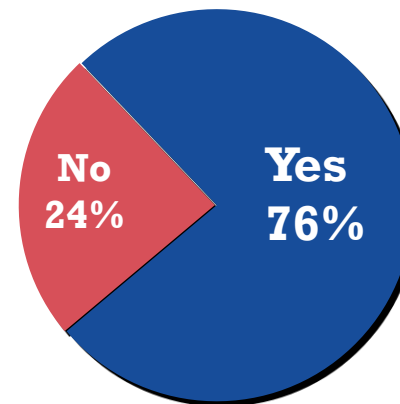
Tak-Ying SA, et al. *J Clin Nursing.* 2003;12:149-150. Browne JL, et al. *BMJ Open.* 18;3(11):e003384. Browne JL, et al. *BMJ Open.* 2014;4(7):e005625. Vishwanath A. *Health Communication. 2014;29*(5):516-526. Liu NF, et al. 2017. *Clin Diabetes.* 2017;35:27-34.

STIGMA AND DIABETES

- Guilt, shame, blame, embarrassment, isolation

- Higher BMI

- Higher A1C

- Self-reported blood glucose variability

FROM THE RESEARCH

Patients are "noncompliant"

- "I have no patience for people who cause themselves to become ill, lose limbs, and disregard their medication/diet regimen. I'd become overwhelmingly frustrated working with this group of patients all day every day."

- "From what I've seen thus far, many of those who have diabetes are noncompliant and don't take care of themselves. That would be extremely frustrating for me."

Dickinson, Lipman, & O'Brien, 2015; *The Diabetes Educator*

RECOMMENDATION #2
USE LANGUAGE THAT IS FREE FROM STIGMA

- **Example:**

- There are several factors that play a role in developing type 2 diabetes. It's not Cindy's fault that she got it.

- **Instead of**

- Cindy wouldn't have gotten type 2 diabetes if she had eaten better.

Change your mindset

Change your approach

Change your words/messages

WHAT WORDS NEGATIVELY AFFECT YOU?

▪ Six Themes

1. Judgment (non-compliant, uncontrolled, don't care, should, failure)

2. Fear/Anxiety (complications, blindness, death, diabetic ketoacidosis)

3. Labels/Assumptions (diabetic, all people with diabetes are fat, suffer)

4. Oversimplifications/Directives (lose weight, you should, you'll get used to it, at least it's not…)

5. Misunderstanding/Misinformation/Disconnected (cure, reverse, bad kind, you're fine)

6. Body Language and Tone (no eye contact, accusatory tone)

Dickinson, J.K., 2018; *Diabetes Spectrum*

CONTROL YOUR DIABETES!

- A failure
- A bad person
- Not good enough
- Shame
- Judgment

- "I've always felt like I'm the only one who can 'judge' my own feelings of control."

- "Sigh. Control. I think that's just an illusion."

RECOMMENDATION #3
USE LANGUAGE THAT IS STRENGTHS BASED, RESPECTFUL, INCLUSIVE, EMPOWERING, AND IMPARTS HOPE

- **Example:**

- Lucy is taking sulfonylureas and they are not bringing her blood glucose levels down enough.

- **Instead of**

- Lucy is poorly controlled. Lucy has uncontrolled diabetes.

POLLING QUESTION

- Why do you think the language of diabetes hasn't changed across the board?

    - It's too hard to change
    - These words are too engrained in health care communication
    - There's nothing wrong with the language of diabetes the way it is
    - It's impossible to erase the stigma of diabetes
    - It's not the most important problem in diabetes
    - We need more work on recognizing the emotional side of diabetes
    - There isn't time

DO SCARE TACTICS WORK?

MESSAGES AT DIAGNOSIS

- ## Factors
  - Encouraging
  - Collaborative
  - Discouraging
  - Recommending other resources

Polonsky, W.H., et al. 2017; *Diabetes Res Clin Pract*

MESSAGES AT DIAGNOSIS

- Impact on
  - Emotional distress
  - Diabetes distress
  - Wellness
  - Healthy eating
  - Exercise
  - Medication taking

Polonsky, W.H., et al. 2017; *Diabetes Res Clin Pract*

PATIENT ENGAGEMENT

Hospitals/Clinics	Language Movement
Tools	Interest
Programs	Value
Technology	Participation/Involvement

FROM THE RESEARCH

- Partnership:
  - Changing language would lead to trust, partnership
  - Less emphasis on disease, more emphasis on the person
  - Hope

Dickinson, J.K., 2018; *Diabetes Spectrum*

RECOMMENDATION #4

USE LANGUAGE THAT FOSTERS COLLABORATION BETWEEN PATIENTS AND PROVIDERS

- **Example:**

- More and more people are living long and healthy lives with diabetes. Let's work together to make a plan that you can do in your daily life.

- **Instead of**

- You are going to end up blind or on dialysis.

TOP TEN REASONS TO ELIMINATE 'DIABETIC' FROM OUR VOCABULARY

10. It's often used incorrectly

9. Some people don't relate

8. It's a label

7. It's what we *have*, not what we *are*

6. The person is more important than the disease

5. It's not helpful

4. There is stigma attached to the word

3. It limits recognizing the emotional side of diabetes

2. It's not empowering

1. The only way to get rid of the word, is to get rid of the word

RECOMMENDATION #5
USE LANGUAGE THAT IS PERSON CENTERED

- **Example:**

- Lonnie has diabetes. Lonnie has lived with diabetes for ten years.

- **Instead of**

- Lonnie is a diabetic. Lonnie has been a diabetic for ten years.

LANGUAGE WILL CONTINUE TO EVOLVE

- "…whatever words we use to replace the "problem words" will grow to associate with the same issues."

- "Focus on the person, not the diagnosis. You'll treat both more effectively that way."

Dickinson, J.K., 2018; *Diabetes Spectrum*

Change your mindset

Change your approach

Change your words/messages

BODY LANGUAGE MATTERS TOO!

- What does your tone imply?
- What message does your face send?
- What is your body telling someone?

RESOURCES

- AADE has developed the following resources:

  - Two-page handout (for patients, families, friends, students, colleagues, members of society)

  - Media guide (for anyone who writes about diabetes)

  - www.diabeteseducator.org (click on *practice* then *educator tools* then *practice resources* then *diabetes language guidance*)

WORDS TO LIVE BY

- Words convey meaning that can determine expectations

- Expectations can lead to bias that affects outcomes (even if we aren't aware of it)

- Messages that convey judgment, fear, and misunderstanding can lead to disengagement, avoidance, and distress

- Healthcare professionals have an important role in transforming this experience by communicating collaborative and encouraging messages

"HOW DO WE MAKE LIFE BETTER, NOT JUST LONGER, FOR PEOPLE WITH DIABETES?"

- Robert Ratner, MD

QUESTIONS?

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- www.tc.edu/diabetes
- www.facebook.com/DiabetesBalance

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