OBJECTIVES

1. Identify problem language in diabetes
2. Locate resources for changing diabetes messages.
3. Discuss strategies for changing messages in diabetes.
Special Diabetes Program for Indians
Changing the Course of Diabetes: Charting Remarkable Progress

Tremendous improvements in diabetes outcomes are happening for American Indian and Alaska Native people. Read the Special Diabetes Program for Indians 2020 Report to Congress to learn more.

Diabetes Prevalence
Diabetes decreased from 15.4% in 2013 to 14.6% in 2017 in adults

Diabetes-Related Deaths
↓ 37% Decreased 37% from 1999 to 2017

Diabetes-Related Kidney Failure
New cases decreased by 54% from 1996 to 2013 in adults

Diabetic Eye Disease
↓ 50% Decreased by >50% since 1990s in adults

Hospitalizations for Uncontrolled Diabetes
Decreased 84% between 2000 and 2015 in adults

These improvements have huge implications for quality of life and health care costs. The Special Diabetes Program for Indians has been, and continues to be, key to this remarkable progress.” — Ann Bullock, MD (Ojibwe)

Indian Health Service
Division of Diabetes Treatment and Prevention
Common messages in diabetes:

- Rules
- Judgment
- Blame/shame
INACCURATE BELIEFS ABOUT “POOR ADHERENCE”

(“strongly agree” endorsements by physicians)

- Poor self-discipline: 53.2%
- Poor willpower: 50.0%
- Not scared enough: 36.9%
- Not intelligent enough: 16.3%

Polonsky, Boswell, Edelman, 1996
WHAT HCPS SAY ABOUT “POOR CONTROL”

HCP top complaints:

1. Patients say they want to change but not willing to make the necessary changes
2. Not honest/only tell me what they think I want to hear
3. Diabetes not a priority/ “in denial”/don’t care
4. Don’t listen to my advice

Edelman et al, 2012
Effective HCP communication is built on a better understanding of the real problem.
Feelings
Messages
Labels
Trust
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)
### Messages at Diagnosis (INTRODIA)

<table>
<thead>
<tr>
<th>Type of message</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encouraging</td>
<td>Positive impact</td>
</tr>
<tr>
<td>Collaborative</td>
<td>Positive impact</td>
</tr>
<tr>
<td>Discouraging</td>
<td>Negative impact</td>
</tr>
<tr>
<td>Recommend resources</td>
<td>No impact</td>
</tr>
</tbody>
</table>

Polonsky, et al, 2017
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
IF HCPS STOPPED USING JUDGMENTAL, SCARY, LABELING, OVERSIMPLIFIED, DISCONNECTED, AND DIRECTIVE WORDS . . .

They would feel respected, listened to, supported, and comfortable.

They would trust their HCPs and feel more confident and willing to work with them.
# Problem Language in Diabetes

<table>
<thead>
<tr>
<th>High (more negative feelings)</th>
<th>Neutral</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-compliant</td>
<td>Diabetic</td>
</tr>
<tr>
<td>Preventable (T1)</td>
<td>Preventable (T2)</td>
</tr>
<tr>
<td>In denial</td>
<td>Suffered (just above neutral)</td>
</tr>
<tr>
<td>Unmotivated</td>
<td></td>
</tr>
<tr>
<td>Failed</td>
<td></td>
</tr>
<tr>
<td>Should</td>
<td></td>
</tr>
<tr>
<td>Uncontrolled</td>
<td></td>
</tr>
<tr>
<td>What did you do wrong?</td>
<td></td>
</tr>
<tr>
<td>You could end up blind or on dialysis</td>
<td></td>
</tr>
</tbody>
</table>

Dickinson, Guzman, Wooldridge, 2023
EXPERIENCE OF STIGMA IN T2D

T2D Not on insulin 49%

T2D on Intensive Insulin 61%

Liu, et al, 2017
GUILT, SHAME, BLAME, FEAR, EMBARRASSMENT

- Avoidance/Hiding
- Additional Barriers
- Disengagement
- Isolation
- Depression
- Health Outcomes
MESSAGES AND THERAPEUTIC INERTIA

The evidence...

Expectancy Theory

Rosenthal & Fode, 1963
MESSAGES AND THERAPEUTIC INERTIA

thoughts → ideas → behaviors → outcomes
PROBLEM WORDS TO REMOVE/REPLACE

- suffer
- diabetic
- control
- regimen
- adherence
- compliance
- good
- bad
## Emotional Impact of Negative Messaging

**Uncontrolled (%)**

<table>
<thead>
<tr>
<th></th>
<th>M (SD)</th>
<th>( ^p )</th>
<th>% positive</th>
<th>% neutral</th>
<th>% negative</th>
<th>Emotion</th>
</tr>
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<tbody>
<tr>
<td>T1DM</td>
<td>5.8 (1.4)</td>
<td>0.001</td>
<td>8.4</td>
<td>11.2</td>
<td>80.4</td>
<td>Hopeless</td>
</tr>
<tr>
<td>T2DM</td>
<td>5.3 (1.9)</td>
<td></td>
<td>19.1</td>
<td>11.8</td>
<td>69.1</td>
<td></td>
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<td>T1DM</td>
<td>5.5 (1.5)</td>
<td>0.052</td>
<td>9.3</td>
<td>20.6</td>
<td>70.1</td>
<td>Not trusting</td>
</tr>
<tr>
<td>T2DM</td>
<td>5.0 (1.8)</td>
<td></td>
<td>20.9</td>
<td>18.2</td>
<td>60.9</td>
<td></td>
</tr>
<tr>
<td>T1DM</td>
<td>5.9 (1.3)</td>
<td>&lt;.001</td>
<td>6.5</td>
<td>8.4</td>
<td>85.1</td>
<td>Blamed</td>
</tr>
<tr>
<td>T2DM</td>
<td>5.4 (1.9)</td>
<td></td>
<td>19.1</td>
<td>10.9</td>
<td>69.9</td>
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<tr>
<td>T1DM</td>
<td>5.9 (1.4)</td>
<td>&lt;.001</td>
<td>5.6</td>
<td>13.1</td>
<td>81.4</td>
<td>Misunderstood</td>
</tr>
<tr>
<td>T2DM</td>
<td>5.1 (1.9)</td>
<td></td>
<td>21</td>
<td>13.6</td>
<td>65.4</td>
<td></td>
</tr>
<tr>
<td>T1DM</td>
<td>6.0 (1.4)</td>
<td>&lt;.001</td>
<td>6.6</td>
<td>7.5</td>
<td>86</td>
<td>Judged</td>
</tr>
<tr>
<td>T2DM</td>
<td>5.4 (1.9)</td>
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<td>20.1</td>
<td>8.2</td>
<td>71.8</td>
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<tr>
<td>T1DM</td>
<td>5.6 (1.4)</td>
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<td>19.6</td>
<td>72.9</td>
<td>Not motivated</td>
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<td></td>
<td>21.9</td>
<td>15.5</td>
<td>62.7</td>
<td></td>
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</tbody>
</table>

Dickinson, Guzman, Wooldridge, 2023
### EMOTIONAL IMPACT OF NEGATIVE MESSAGING

**You could end up blind or on dialysis (%)**

<table>
<thead>
<tr>
<th></th>
<th>M (SD)</th>
<th>*p</th>
<th>% positive</th>
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<tbody>
<tr>
<td><strong>T1DM 6.0 (1.4)</strong></td>
<td>0.001</td>
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<td>3.8</td>
<td>8.4</td>
<td>87.9</td>
<td>Hopeless</td>
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<tr>
<td><strong>T2DM 5.6 (1.9)</strong></td>
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<td></td>
<td>16.4</td>
<td>7.3</td>
<td>76.4</td>
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</tr>
<tr>
<td><strong>T1DM 5.7 (1.4)</strong></td>
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<td>3.8</td>
<td>19.6</td>
<td>76.6</td>
<td>Not trusting</td>
</tr>
<tr>
<td><strong>T2DM 5.2 (1.9)</strong></td>
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<td></td>
<td>19.1</td>
<td>14.5</td>
<td>66.3</td>
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<tr>
<td><strong>T1DM 6.1 (1.4)</strong></td>
<td>&lt;.001</td>
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<td>85</td>
<td>Blamed</td>
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<td><strong>T2DM 5.6 (1.9)</strong></td>
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<td>16.4</td>
<td>10.0</td>
<td>73.6</td>
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<tr>
<td><strong>T1DM 5.9 (1.5)</strong></td>
<td>0.002</td>
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<td>5.6</td>
<td>16.8</td>
<td>77.5</td>
<td>Misunderstood</td>
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<tr>
<td><strong>T2DM 5.3 (1.9)</strong></td>
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<td>18.2</td>
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<td>&lt;.001</td>
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<td>5.7</td>
<td>14.0</td>
<td>80.3</td>
<td>Judged</td>
</tr>
<tr>
<td><strong>T2DM 5.5 (2.0)</strong></td>
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<td>19.1</td>
<td>7.3</td>
<td>73.6</td>
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<td>Not motivated</td>
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<tr>
<td><strong>T2DM 5.1 (2.1)</strong></td>
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<td>26.4</td>
<td>7.3</td>
<td>66.4</td>
<td></td>
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SAMPLE REPLACEMENTS

Control  ➔  A1C; Time in Range

Adherence   ➔  medication taking

Diabetic  ➔  person with diabetes; diabetes-related

Suffer  ➔  experience; live with

Regimen  ➔  plan; approach
CHANGING WORDS VS. CHANGING MINDSET

Compliance to adherence vs. compliance/adherence to engagement

Control to management vs. defining “control” neutrally and factually
Fred’s A1C is 9.5%; Fred’s time in range is 35%
• Fred has poor glycemic control.
• Fred is uncontrolled.
• Fred is poorly controlled.

Fred’s A1C is 9.5% and he lost his job last month
Fred takes his meds about half the time
- Fred is nonadherent.
- Fred is noncompliant.

*Fred takes his meds about half the time because he lost his job and can't afford them.*
LANGUAGE GUIDANCE RESOURCES


General handout (Quick Guide for Health Care Providers)

Style guide for writers/speakers (Media Guide)

https://www.languagemattersdiabetes.com/

www.dstigmatize.org
STRATEGIES FOR MORE EFFECTIVE PATIENT-PROVIDER COMMUNICATION

- Use language/messages that are person-centered and strengths-based.
- Use language/messages that are neutral and factual
- Practice radical acceptance and avoid judgment
- Acknowledge that diabetes is hard; ask how the person is doing
- Come from a place of partnership and curiosity
- Share the language guidance paper widely!
- Remove problem language/messages from your EHR
QUESTIONS?

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REFERENCES


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