



dStigmatizing Diabetes:

Addressing diabetes stigma and its impacts

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April 16, 2025

diaTribe

Making Sense of Diabetes

dStigmatize



Disclosures

- No personal disclosures
- The diaTribe Foundation has received funding from Abbott, AstraZeneca, BI-Lilly, Genentech, Insulet, Lilly, and One Drop for the dStigmatize Program.

Who are we?

The diaTribe Foundation: We're a small nonprofit focused on helping people with diabetes through education and advocacy.

We have three main programs:

- diaTribe Learn - www.diatribefoundation.org
- dStigmatize - www.dstigmatize.org
- Time in Range Coalition - www.TimeinRange.org





Objectives

- I. Examine what diabetes stigma is and how it impacts people with diabetes.
- II. Identify examples of healthcare professionals and medical centers that might contribute to diabetes stigma and strategies to avoid this.
- III. Determine the ways language contributes to stigma and recognize the subtle language and conversation shifts that can reduce stigmatizing experiences



What is diabetes stigma?

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Diabetes stigma refers to negative social judgments, stereotypes, and prejudices about diabetes, or about a person due to their diabetes.¹

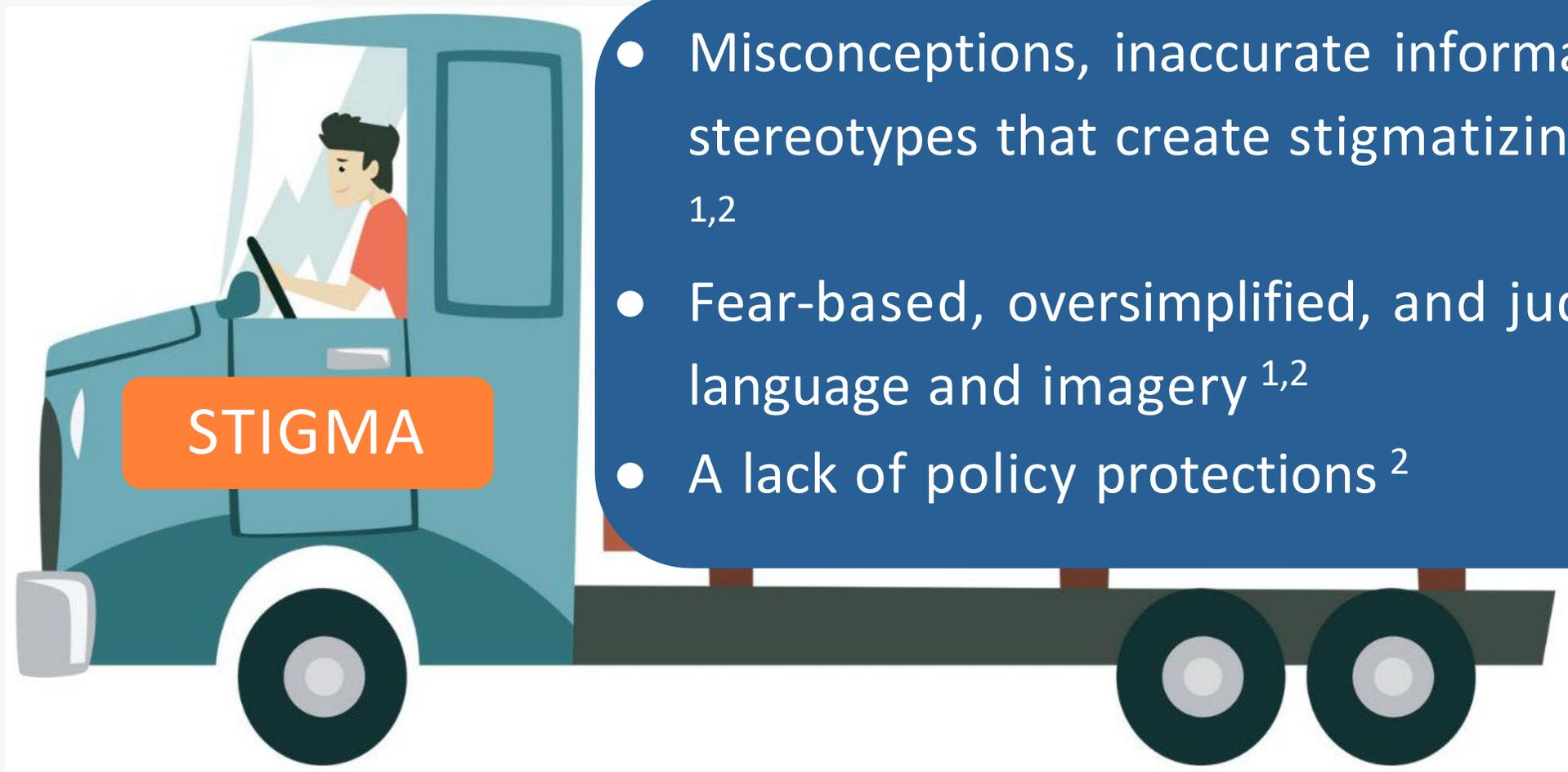
Diabetes stigma becomes **discrimination** when it is used in unfair or prejudicial treatment towards a person with diabetes.¹



**ADDRESSING DIABETES
STIGMA IS AN ESSENTIAL
MISSING ELEMENT OF
EFFECTIVE DIABETES CARE**



The drivers of diabetes stigma



- Misconceptions, inaccurate information, and stereotypes that create stigmatizing narratives^{1,2}
- Fear-based, oversimplified, and judgmental language and imagery^{1,2}
- A lack of policy protections²

The manifestations of diabetes stigma ^{1,2}

Internalized Stigma



External Stigma: Enacted, Anticipated, and Perceived



The manifestations of diabetes stigma ^{1,2}

Internalized Stigma



External Stigma: Enacted, Anticipated, and Perceived





Intersecting stigmas

- For many, the experience of diabetes stigma converges with other stigmatized conditions (eg, obesity or schizophrenia) or characteristics (eg, race or ethnicity).¹
 - This is of particular concern for indigenous communities who face unique challenges including:
 - increased poverty and discrepancies in education/employment³
 - marginalized racial identity, violence and trauma³
 - lack of access to health care and reduced coverage³
 - increased risk for additional health conditions.³
- Diabetes stigma may not be someone's #1 concern, but we can't ignore how it might interact with other biases.



How does stigma show up in healthcare?



Unique challenges for Indigenous communities

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- Indigenous people often face discrimination and implicit bias within the healthcare system – they are “treated differently” and labeled as “difficult,” “non-compliant,” and “drug-seeking.”⁴
- As a result they are more likely to avoid or miss crucial healthcare appointments, including prevention and treatment services to avoid experiencing racism and bias.⁴
 - 1 in 6 avoided healthcare due to anticipated unfair treatment/discrimination.⁵
 - Those who experience discrimination are more likely to express experiencing an unmet health need within the previous year.⁶



Research shows that diabetes and weight stigma are common amongst healthcare professionals:

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- A survey of 208 US medical students showed 29% reported harboring stigma towards people with diabetes (especially those with type 2) because they “brought it on themselves.”⁸
- A 2015 narrative review found that healthcare professionals have less respect for people with obesity,⁹ spend less time with them in the clinic,¹⁰ and over-attribute symptoms and problems to obesity while failing to refer people to diagnostic testing or to consider treatment options.¹¹

How does diabetes stigma affect

Psychological well-being



Diabetes stigma is associated with:

- Increased depressive and anxiety symptoms,
- Increased diabetes distress
- Decreased quality of life
- Decreased self-esteem, self-efficacy, and resilience



Social well-being



Diabetes stigma is associated with:

- Social withdrawal or isolation,
- Worse interpersonal relationships with family, friends, and health professionals,
- Concealing diabetes from others.

How does diabetes stigma affect people? ^{1,2}

Physical well-being and self-care

Diabetes stigma is associated with:

- Higher HbA1c,
- Higher BMI,
- More frequent severe hypoglycemia, diabetes-related ketoacidosis (DKA), retinopathy,
- Avoiding diabetes self-care behaviors including monitoring glucose levels, delivering insulin, and taking diabetes medications,
- Avoiding healthcare appointments and screenings (for diabetes or diabetes-related complications).





I have developed large complications and I have had medical professionals say to me 'well it's your own fault because you're diabetic' which is not what you really want to hear.

***Woman with type 1 diabetes,
Australia***¹²

The way that [the dietitian] was talking about diabetes kind of made me feel that it was my fault that I actually had it – that I wasn't watching what I was doing to begin with, and this is how I developed it.

Woman with GDM, Canada¹³

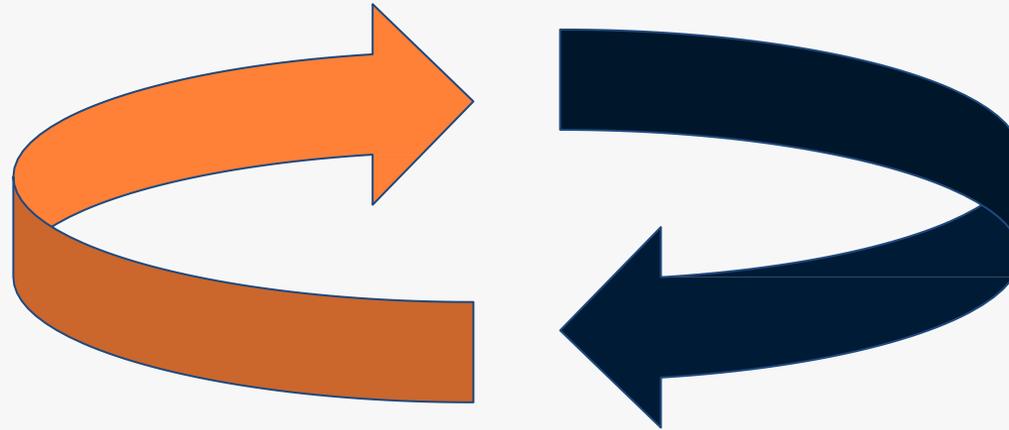
I wish [my healthcare team] would focus on what works for me and not push for things that are unrealistic. With my family's schedule, not every meal is going to be at the same time around a table. If I have to adjust, so do you.

***Man with type 2 diabetes,
United States***¹⁴

Harmful cycle

Which positively reinforces the idea that they will face stigma or judgment due to poor health outcomes.

Person experiences or anticipates stigma from healthcare professionals



Encounters worse mental, physical, and social health outcomes due to reduced self-management and isolation

Avoids healthcare appointments, prevention and screening efforts, and treatment.



Addressing diabetes stigma



Effective strategies for reducing stigma

- Education and awareness^{1,2, 15}
- Empathy building¹⁵
- Narrative shifting and language choices^{1,2}
- Creating a clinic free from stigma; using a weight-inclusive approach^{2,15}

Co-create interventions with (Indigenous) people with diabetes!



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Changing the narrative: #LanguageMatters

- We must shift the prevailing social narrative surrounding diabetes

From a focus on blame, responsibility, control and compliance...

To a more balanced focus on the genetic, biological, sociocultural, environmental, and behavioral factors, as well as the social inequities influencing health.^{16,17}



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- This starts with changing the language and imagery we use to talk about and portray people with diabetes. ^{1-2, 16,17}



Language Matters^{16,17}

Choose language that is:

Neutral,
nonjudgmental,
and based on
facts, actions, or
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Fostering
collaboration
between people
with diabetes and
their healthcare
teams



Discussing diabetes-related medications

Be mindful of the unique stigma associated with insulin use.

Avoid using overly technical language or language commonly used in electronic health records in conversations with people with diabetes.

Emphasize that medications are just one tool in a person's toolbox.



Discussing diabetes devices and technology

Ask lots of questions, be an active listener, and share in the decision-making.

Avoid “gatekeeping” certain devices or diabetes-related technology.

Acknowledge the psychosocial impact of using diabetes-related technology.



Discussing diabetes-related complications

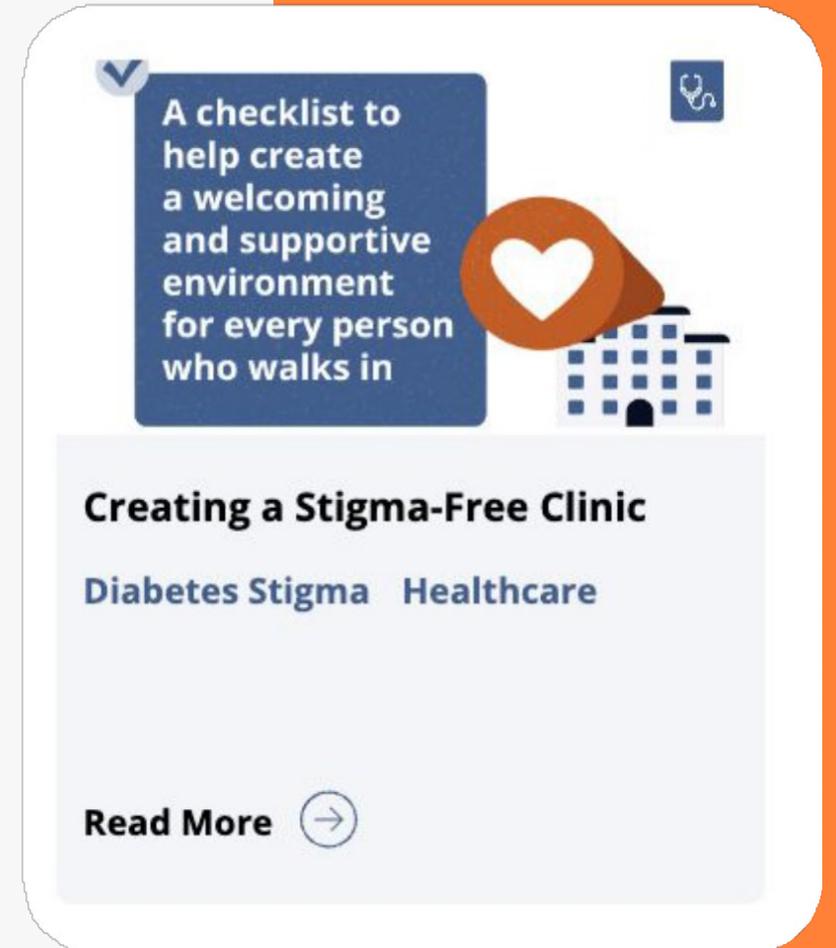
Be aware that certain complications can be particularly scary: eye complications, neuropathy and amputation, and kidney complications.

Avoid using fear or scare tactics to motivate behavior changes.

Enter conversations with respect, hope, and positivity. Often, people are looking for simple explanations and clear directions that highlight collaboration.

Setting up a stigma-free clinic

- Avoid fear based imagery and messaging¹⁵
- All seating and equipment should be size-inclusive and inclusive of people with disabilities or diabetes-related complications¹⁵
- Encourage privacy¹⁵
- Have supplies to assist during hypo or DKA¹⁵
- Resources on mental health providers¹⁵



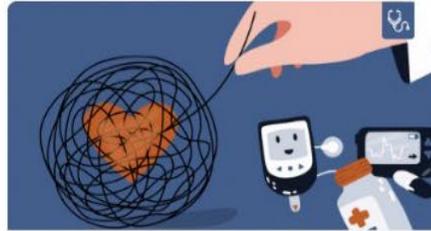
Weight-inclusive care



© Obesity Action Coalition

- Place emphasis on overall health goals that are sustainable, not weight loss.¹⁸
- Avoid discussions around appearance.¹⁸
- De-emphasize BMI & pay attention to overall weight trajectory over time, looking for signs of disordered, emotional, and/or binge eating.¹⁸
- As needed, refer patients to other health professionals such as dietitians and mental health providers.¹⁸

dStigmatize Resource Library:



What is Diabetes Stigma?

Diabetes Stigma Healthcare

Read More →

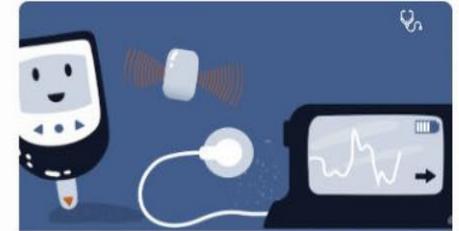


Diabetes Stigma in Healthcare

Diabetes Stigma Healthcare

Language

Read More →



How to Talk About Diabetes-Related Technology

Diabetes Stigma Healthcare

Language

Read More →



How to Talk About Diabetes-Related Medications

Diabetes Stigma Healthcare

Language

Read More →



Checking Our Bias: Removing Stigma in the Clinical Setting

Diabetes Stigma Healthcare

Language

Read More →



A checklist to help create a welcoming and supportive environment for every person who walks in

Creating a Stigma-Free Clinic

Diabetes Stigma Healthcare

Read More →

An international call to action

- 51 expert panelists
- Rapid Systematic Search / Evidence Summary
- Consensus (3 rounds, Delphi-like survey)
 - Statements of Evidence
 - Recommendations
 - Pledge
- Published in Lancet D&E

Review

Bringing an end to diabetes stigma and discrimination: an international consensus statement on evidence and recommendations



Jane Speight*, Elizabeth Holmes-Truscott*, Matthew Garza, Renza Scibilia, Sabina Wagner, Asuka Kato, Victor Pedrero, Sonya Deschênes, Susan J Guzman, Kevin L Joiner, Shengxin Liu, Ingrid Willaing, Katie M Babbott, Bryan Cleal, Jane K Dickinson, Jennifer A Halliday, Eimear C Morrissey, Giesje Nefs, Shane O'Donnell, Anna Serlachius, Per Winterdijk, Hamzah Alzubaidi, Bustanul Arifin, Liz Cambron-Kopco, Corinna Santa Ana, Emma Davidsen, Mary de Groot, Maartje de Wit, Phyllisa Deroze, Stephanie Haaack, Richard I G Holt, Walther Jensen, Kamlesh Khunti, Karoline Kragelund Nielsen, Tejal Lathia, Christopher J Lee, Bridget McNulty, Diana Naranjo, Rebecca L Pearl, Suman Prinjha, Rebecca M Puhl, Anita Sabidi, Chitra Selvan, Jazz Sethi, Mohammed Seyam, Jackie Sturt, Mythily Subramaniam, Helle Terkildsen Maindal, Virginia Valentine, Michael Vallis, Timothy C Skinner

People with diabetes often encounter stigma (ie, negative social judgments, stereotypes, prejudice), which can adversely affect emotional, mental, and physical health; self-care, access to optimal health care; and social and professional opportunities. To accelerate an end to diabetes stigma and discrimination, an international multidisciplinary expert panel (n=51 members, from 18 countries) conducted rapid reviews and participated in a three-round Delphi survey process. We achieved consensus on 25 statements of evidence and 24 statements of recommendations. The consensus is that diabetes stigma is driven primarily by blame, perceptions of burden or sickness, invisibility, and fear or disgust. On average, four in five adults with diabetes experience diabetes stigma and one in five experience discrimination (ie, unfair and prejudicial treatment) due to diabetes, such as in health care, education, and employment. Diabetes stigma and discrimination are harmful, unacceptable, unethical, and counterproductive. Collective leadership is needed to proactively challenge, and bring an end to, diabetes stigma and discrimination. Consequently, we achieved unanimous consensus on a pledge to end diabetes stigma and discrimination.

Lancet Diabetes Endocrinol
2024; 12: 61–82

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Specific items pertaining to Indigenous communities

- Statement of evidence:

“There is very little research about the experiences of diabetes stigma and its impact among disadvantaged, minority, and diverse populations (eg, Indigenous people, refugee and asylum seekers, migrants).” ¹

- Recommendation:

“Culturally sensitive research is needed to understand diabetes stigma and its impacts among disadvantaged, minority, and diverse populations, eg Indigenous people, refugee and asylum seekers, migrants.” ¹

The Pledge to End Diabetes Stigma

- The Pledge has received
 - 3000+ Individual endorsements
 - 335+ Organizational endorsements
- People in over 110 countries have signed on!
- Learn more at EndDiabetesStigma.org and share on social media using [#EndDiabetesStigma](https://twitter.com/EndDiabetesStigma)



Join the growing movement – it's easy!

- At diaTribe, we are creating a **culture of compassion** that helps people with diabetes live well with a serious but manageable condition.
- Contact me: matthew.garza@diaTribe.org

Take the Pledge to End Diabetes Stigma
EndDiabetesStigma.org



Visit the dStigmatize Resource Library
dStigmatize.org/resources





Q&A

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Making Sense of Diabetes

dStigmatize



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