



# Heartland National TB Center's Stop the Stigma Campaign

*Alysia Wayne*

*June 12, 2025*

TB Intensive • June 10 – 12, 2025 • Dallas, Texas



# Alysia Wayne

Has the following disclosures to make:

- No conflict of interests
- No relevant financial relationships with any commercial companies pertaining to this activity





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# Objectives

- ❖ Define Stigma
- ❖ Discuss the effect of stigma healthcare and preferred terminology
- ❖ Discuss Heartland National TB's Center's "Stop the Stigma" campaign within the TB Care Movement

# What is Stigma?

“Stigma is a mark of disgrace that sets a person apart from others. When a person is labelled by their illness they are no longer seen as an individual but as part of a stereotyped group. Negative attitudes and beliefs toward this group create prejudice which leads to negative actions and discrimination.”

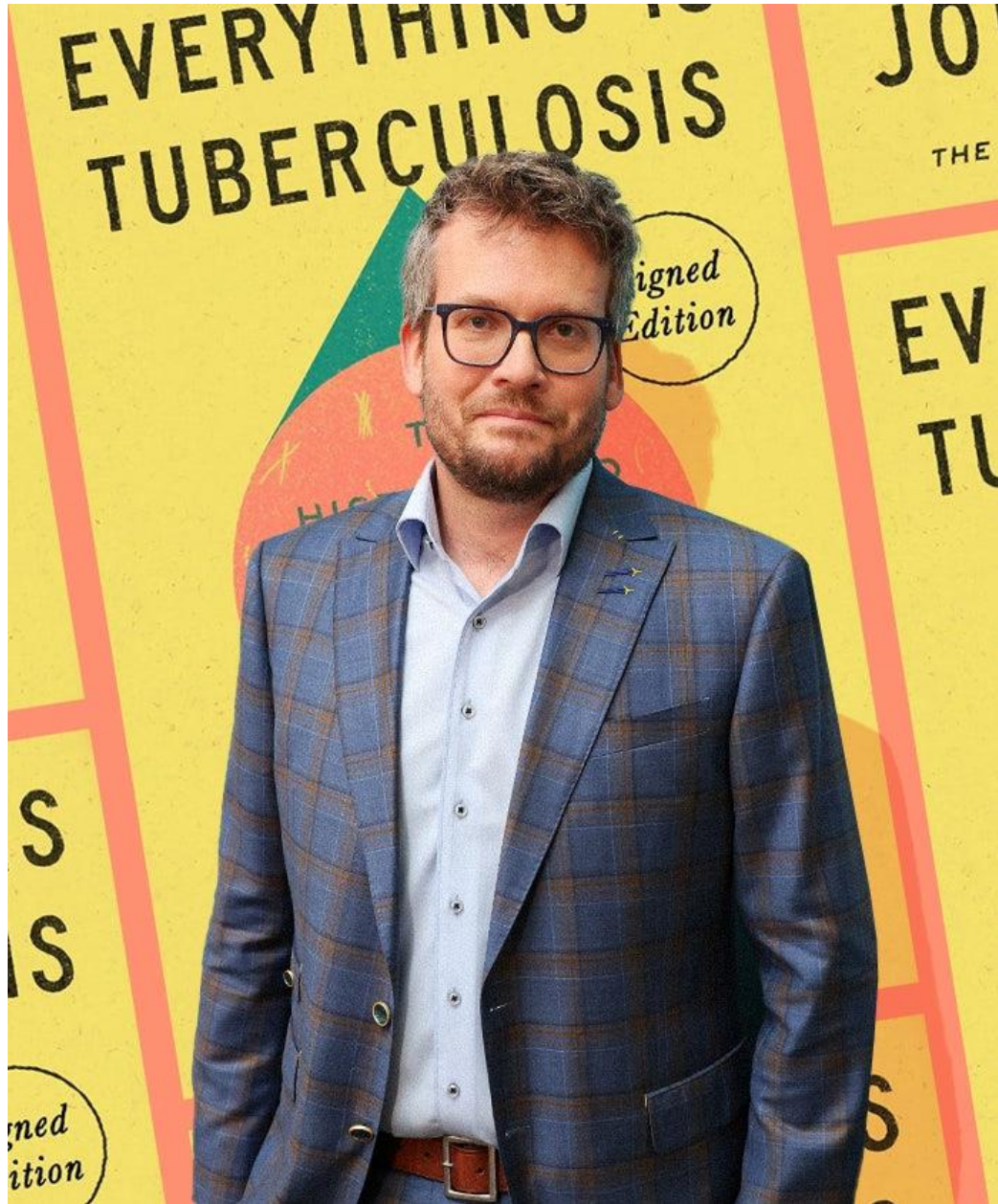
Stigma-Free Society. <https://stigmafreesociety.com/stigma/> Accessed June 16, 2020.

“A sign or a mark that designates the bearer as *spoiled* and therefore as valued less than *normal* people.” - Goffman E. (1963)



# ***Everything is Tuberculosis: The History and Persistence of Our Deadliest Infection,*** written by John Green

A compelling story about the science and history behind the world's deadliest infectious disease through the memoir of a patient he met in Sierra Leon, highlighting the social factors that allow a curable disease to prevail in the world.



# Food for Thought from Chapter 9: Not A Person

- “People who are treated as less than fully human by the social order *are* more susceptible to tuberculosis. But it’s not because of their moral codes or choices or genetics; **it’s because they are treated as less than fully human by the social order.**” (pg. 86)
- “Stigma is a way of saying, **‘You deserve to have this happen,’** but implied with the stigma is also, **‘And I don’t deserve it, so I don’t need to worry about it happening to me.’**” (pg. 86)
- “A young woman who was abandoned by her family told me, ‘To them I am not a person.’ **There were times that she wished she had died of TB rather than being cured of it,** because the ongoing stigma was so profound.” (pg. 88)



# How Can Stigma Affect Healthcare?

- Stigma is linked to poor health.
- Stigma is associated with greater social isolation.
- Social isolation increases risk for poor health outcomes.
- Stigma-health relationship is significantly strained after adjustment for social isolation.

Hatzenbuehler, M., Phelan, J., Link, B., Stigma as a Fundamental Cause of Public Health Inequalities, American Journal of Public Health, May 2013, Vol 103, No.5





# How Can Stigma Affect TB Care?

- Contributes to a delay in diagnosis
- “At-risk individuals report that fear of TB stigma and the social and economic impact of stigma affects their willingness to undergo TB screening and to seek medical care after the onset of symptoms associated with TB.”
- “Individuals with TB and their health-care providers also identify TB stigma as a cause of non-completion of treatment.”

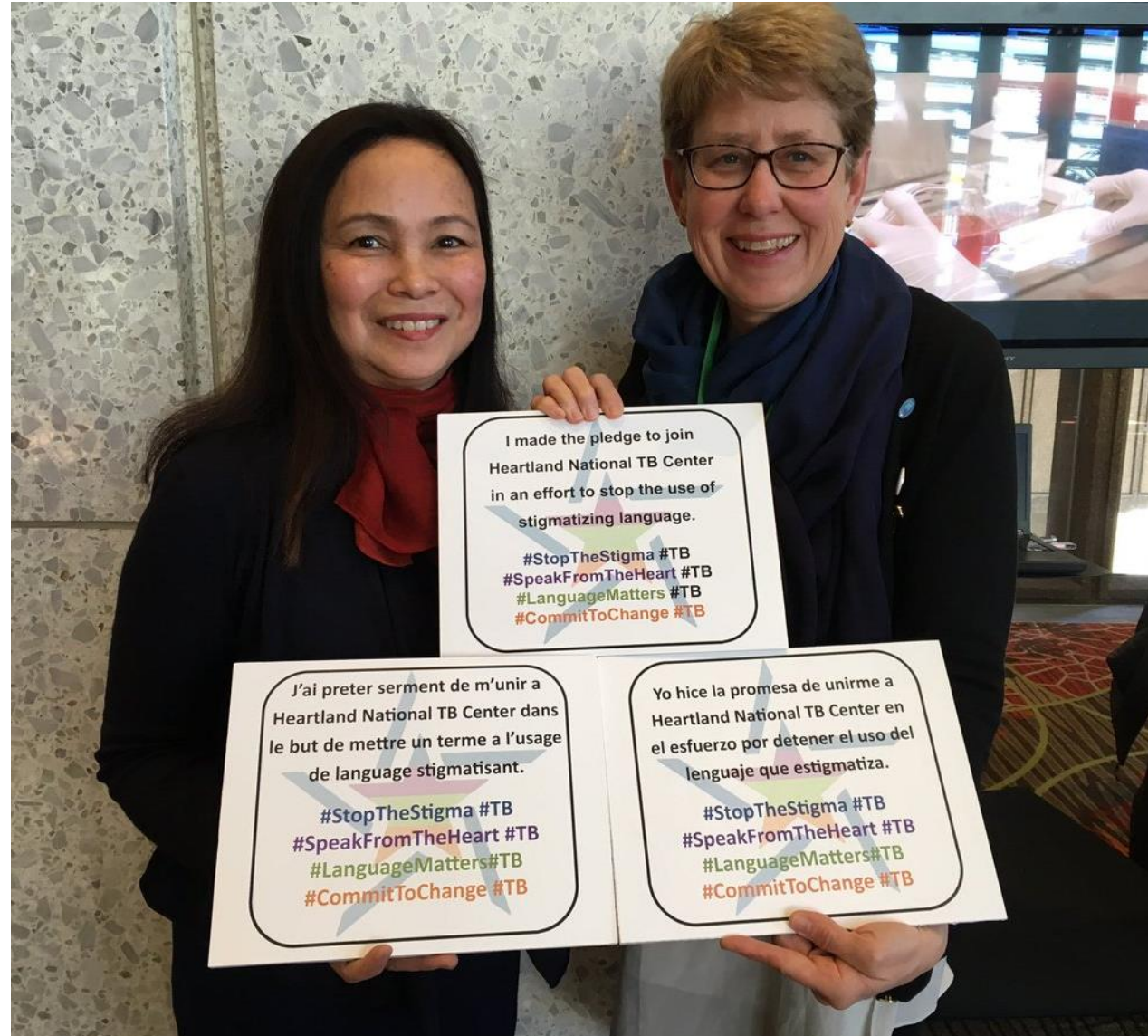
Courtwright, A., & Turner, A. N. (2010). Tuberculosis and Stigmatization: Pathways and Interventions. *Public Health Reports*, 125 (Suppl 4), 34–42.



# The Stigma of Tuberculosis

- “Fear of infection is the most common cause of TB stigma”
- By using non-stigmatizing language, we can begin to breakdown the stigma associated with TB.

Courtwright, Andrew, and Abigail Norris Turner. “Tuberculosis and Stigmatization: Pathways and Interventions.” *Public Health Reports* 125.Suppl 4 (2010): 34–42. Print.



# People First Language

For example:

When referring to a person with a disability, refer to the person first by using phrases such as:

- ✓ A person who ...
- ✓ A person with ...
- ✓ Person who has...



## Communicating With and About People with Disabilities



About 50 million Americans report having a disability. Most Americans will experience a disability some time during the course of their lives. Disabilities can affect people in different ways, even when one person has the same type of disability as another person. Some disabilities may be hidden or not easy to see.

### People First Language

People first language is used to speak appropriately and respectfully about an individual with a disability. People first language emphasizes the person first not the disability. For example, when referring to a person with a disability, refer to the person first by using phrases such as: "a person who ...", "a person with ..." or, "person who has..."

Here are suggestions on how to communicate with and about people with disabilities.



People First Language	Language to Avoid
Person with a disability	The disabled, handicapped
Person without a disability	Normal person, healthy person
Person with an intellectual, cognitive, developmental disability	Retarded, slow, simple, moronic, defective or retarded, afflicted, special person
Person with an emotional or behavioral disability, person with a mental health or a psychiatric disability	Insane, crazy, psycho, maniac, nuts
Person who is hard of hearing	Hearing impaired, suffers a hearing loss
Person who is deaf	Deaf and dumb, mute
Person who is blind/visually impaired	The blind
Person who has a communication disorder, is unable to speak, or uses a device to speak	Mute, dumb
Person who uses a wheelchair	Confined or restricted to a wheelchair, wheelchair bound
Person with a physical disability	Crippled, lame, deformed, invalid, spastic
Person with epilepsy or seizure disorder	Epileptic
Person with multiple sclerosis	Afflicted by MS
Person with cerebral palsy	CP victim
Accessible parking or bathrooms	Handicapped parking or bathroom
Person of short stature	Midget
Person with Down syndrome	Mongoloid
Person who is successful, productive	Has overcome his/her disability, is courageous

For more information about disability and health, visit [www.cdc.gov/disabilities](http://www.cdc.gov/disabilities)

National Center on Birth Defects and Developmental Disabilities  
Office of the Director



# Where It All Began

Roots of the Language Change Movement in TB Care



# Timeline

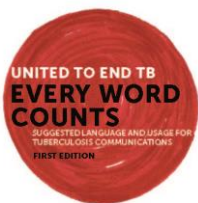
~~Defaulter~~

~~Suspect~~

~~Control~~

Every Word Counts TB Language Guide

2012



2012

Language in TB Services: can we change to patient-centered terminology and stop the paradigm of blaming the patients?

Open Letter Retire Stigmatizing and Criminalizing Language from Global TB Discourse

March 2015



Civil society calls for the retirement of stigmatizing and criminalizing language from the global TB discourse



2015

Civil Society Calls for Retirement of Stigmatizing and Criminalizing Language from Global TB Discourse

Heartland National TB Center creates the "Stop the Stigma" campaign.

2015



# A Call to Change

- ~~Defaulter~~ ✓ Person lost to follow-up
- ~~Suspect~~ ✓ Person with presumptive TB
- ~~Control~~ ✓ Prevention and care

## SUMMARY

The words 'defaulter', 'suspect' and 'control' have been part of the language of tuberculosis (TB) services for many decades, and they continue to be used in international guidelines and in published literature. From a patient perspective, it is our opinion that these terms are at best inappropriate, coercive and disempowering, and at worst they could be perceived as judgmental and criminalising, tending to place the blame of the disease or responsibility for adverse treatment outcomes on one side—that of the patients.

In this article, which brings together a wide range of authors and institutions from Africa, Asia, Latin America, Europe and the Pacific, we discuss the use of the words 'defaulter', 'suspect' and 'control' and argue why it is detrimental to continue using them in the context of TB. We propose that 'defaulter' be replaced with 'person lost to follow-up'; that 'TB suspect' be replaced by 'person with presumptive TB' or 'person to be evaluated for TB'; and that the term 'control' be replaced with 'prevention and care' or simply deleted. These terms are non-judgmental and patient-centred.

We appeal to the global Stop TB Partnership to lead discussions on this issue and to make concrete steps towards changing the current paradigm.

**KEY WORDS:** TB; language; defaulter; suspect; control; loss to follow-up



# Suspect

- ❖ Suspect (verb)
  - ❖ To believe or feel that (someone) is guilty of an illegal, dishonest or unpleasant act, without certain proof
- ❖ Suspect (noun)
  - ❖ Person thought to be guilty of a crime or offense
- ❖ Why did the TB community decide to transfer the 'suspicion' of the disease to the patient?

# Default/a defaulter

- ❖ Oxford English dictionary
  - ❖ A person who fails to fulfill a duty, obligation or undertaking
- ❖ Banking context
  - ❖ To fail to repay a loan
- ❖ Legal context
  - ❖ Failure to appear in court when summoned by a judge
- ❖ Context of competition
  - ❖ Failure to take part in or complete a scheduled contest
- ❖ Common feature:
  - ❖ blame is designated by someone in a decision-making position upon another in the community

# Control

- ❖ National TB 'Control' Programs
- ❖ Control
  - ❖ To limit, regulate or restrict an activity or a process
  - ❖ To maintain influence and authority over behavior
  - ❖ Synonymous terms:
    - ❖ power, to dominate, and be in charge of



# “Control”

- What is being controlled here?
  - TB? The patient? The affected community?
- ‘control of tuberculosis’ may inadvertently lead to programs trying to take control of patients with tuberculosis by infringing on their rights and autonomy
- May be interpreted as something done to, rather than something done for, the patient





# Tackling TB stigma – a necessary step toward humanizing TB

“I would like people who have been affected by stigma to be influencing decisions about how it should be addressed. There is no easy recipe for tackling stigma, it is about changing the behavior of society and that’s not going to happen overnight. It needs to start with, not only addressing TB in a way that upholds the rights of the person...”

“I want the TB world to recognize that, as long as we only focus on the bio-medical, that alone is not going to end TB...”



**Blessina (Blessi) Kumar**  
**Global Coalition of TB Activists**  
**The Union, 2018**



# Who are our patients, and what do we do for them?

- Are they defaulters?
  - ✓ Or are they lost to follow up?
- Are they TB suspects?
  - ✓ Or are they persons we suspect have TB disease?
- Do we 'control'?
  - ✓ Or do we 'care and prevent'?



# Heartland's “**Stop the Stigma**” Campaign

- Hearing the call and taking the initiative
- Officially launched in 2015
- Committing to change



I made the pledge to join  
Heartland National TB Center  
in an effort to stop the use of  
stigmatizing language.

**#StopTheStigma #TB**  
**#SpeakFromTheHeart #TB**  
**#LanguageMatters #TB**  
**#CommitToChange #TB**



# Stop the Stigma Fact Sheet

Heartland offers educational material on preferred language to help eliminate TB stigma.

If you would like a copy, please visit Heartland's website for a downloadable copy.



<https://heartlandntbc.org/>

Eliminating Stigmatizing Language	
Non-hurtful Replacement Language	
Key Terms suggested by the Stop TB Partnership	
Use this.....	Not that.....
Adherence / Non-adherence	Compliance / Non-compliance
Person lost to follow up	Defaulter
TB Prevention and Care	TB Control
Person to be evaluated for TB	TB Suspect
HIV-Positive	HIV-infected
HNTC Survey Results	
Language suggested by participants	
Use this.....	Not that.....
TB Infection	Latent TB
Lack of housing; Under-housed; People experiencing homelessness	Homeless/Homelessness
Immigrant	Alien
Undocumented	Illegal; Illegal alien
Person with TB disease	TB case
Treatment failed	Treatment failure
Missed doses/Non-adherent	Delinquent
Contact Analysis; Contact Elicitation; Contact Identification	Investigation; Investigate
Exposed to TB	TB contact
Tuberculosis	Consumption; White Plague

*Stigmatizing language and suggested replacements was identified by an HNTC survey requesting pledgers to identify language that they personally experienced or witnessed.  
\*\*This list is non-inclusive.*

Supported by Treatment Action Group (TAG)

# Stop the Stigma Speaker Letters

All speakers who collaborate with Heartland for training events are asked to review their content and materials for any stigmatizing language and are encouraged to join the “Stop the Stigma” campaign.



<https://heartlandntbc.org/>



June 3, 2015

Heartland National TB Center  
2303 SE Military Drive  
San Antonio, Texas 78223

Dear (speaker):

Thank you for your upcoming presentation at the upcoming (conference/training).

We would like you to be aware of HNTC's commitment to join forces with patient advocates from the Global TB Community, the International Union Against TB and Lung Disease, and the National Society of TB Clinicians' to eliminate stigmatizing language. The use of such language has been identified by TB survivors and others affected by TB as hurtful.

For additional information, please visit <http://www.heartlandntbc.org/stopthestigma> to find information including a related article published in the International Journal of Tuberculosis and Lung Disease, a document on Language from Stop TB, the open letter to the Union regarding retiring stigmatizing and criminalizing language, and the response by Executive Director of the Union Dr. Jose Luis Castro.

Heartland would like to thank you in advance for your effort to support HNTC's Commitment to eliminate the use of stigmatizing language. In parenthesis we have listed terms which have specifically been identified as hurtful and have noted suggested alternative language you may wish to use. Please review your slides and consider replacing the following terms: TB Control (TB Care or TB Care and Prevention), Suspect (Possible TB disease or suspected TB disease), Defaulter (Person lost to follow-up), Non-compliant (Non-adherent), and TB Case(s) (patient(s) with TB disease). If you have any questions or concerns, please contact one of us to discuss further. Please note we will also review presentations prior to the scheduled presentation date to look for this terminology.

Thank you for supporting HNTC in this effort.

*Barbara J. Seaworth*

Barbara J. Seaworth, MD, FIDSA, FACP  
Medical Director  
Heartland National TB Center,  
2303 Southeast Military Drive  
San Antonio, Texas 78223

2303 SE Military Drive • San Antonio, TX 78223 • Fax: (210) 531-4590 • Toll Free: 1-800-839-5864  
Equal Opportunity/Affirmative Action Institution

# Our commitment to you:

- **Use** language that is patient-centered, appropriate and sensitive and represents the dignity of people with TB and their families.
- **Implement** the use of non-stigmatizing language in the creation of our published materials including products, posters, marketing materials and speaking engagements.
- **Promote** the use of non-stigmatizing language by working with our speakers to ensure all presentations are free of words such as, “suspect,” “TB control,” “defaulter,” “noncompliant,” and “TB case”.



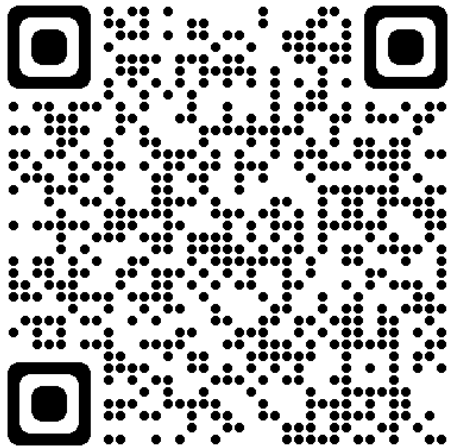
# Our challenge to you:

***Commit*** to using language that is patient-centered, appropriate and sensitive, and represents the dignity of people with TB and their families.



# Eliminating Stigmatizing Language in TB

Please be sure to visit our “Stop the Stigma” page for updates and additions to our “Stop the Stigma” Campaign!



<https://www.heartlandntbc.org/stopthestigma/>





# Thank You!

*A few testimonials from our campaign:*

“We have incorporated the requests to stop referring to our patients as ‘cases’ or ‘suspects’...”

“Instead of TB suspect, I use the term ‘patient with presumptive TB’”

“Increased awareness. Stronger review of materials and presentations. Changed language in trainings and communications of policies.”

“Being more respectful in addressing the needs of our patients”

“We all stop and think prior to calling an individual a ‘suspect’. It seems to be a trigger for pause and thoughtfulness before we speak.”