



MORE than a
DSM Code



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***Addressing Stigma
Experienced by
Families***



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Network



Carol Dickey

*We know how difficult parenting can be.
We've been there and we understand!*

A Family-Run 501(c)(3) Organization

**Serving Families Across
Oregon**

1:1 Peer Support
Parent Support Groups
Systems Navigation
Training & Education



A Support Team
of Families & Friends

**Reach Out
Oregon**

1-833-REACH-
OR
Warmline
Forum
Email
Live Chat

and advocacy.

Every family deserves to be heard and understood

SUPPORT EDUCATE ADVOCATE EMPOWER

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***“Everyone
hears only
what he
understands.”***

Johann Wolfgang von Goethe

- What is stigma?
- What is the family experience of stigma?
- How does stigmatization become business as usual?
- How does implicit bias contribute to stigma?
- How can we elevate context expertise?
- How can we work together to minimize stigma?



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Stigma

"Stigma is a process by which the reaction of others spoils normal identity."

Erving Goffman (1963) Stigma: Notes on the management of spoiled identity.

- Stereotypes : *the way we think*
- Prejudice : *the way we feel*
- Discrimination : *the way we act*



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What do we have in common?



- A group of human beings
- Interested in the family experience of stigma
- Fearful that I may not meet expectations

FACT

JUDGMENT

FEAR

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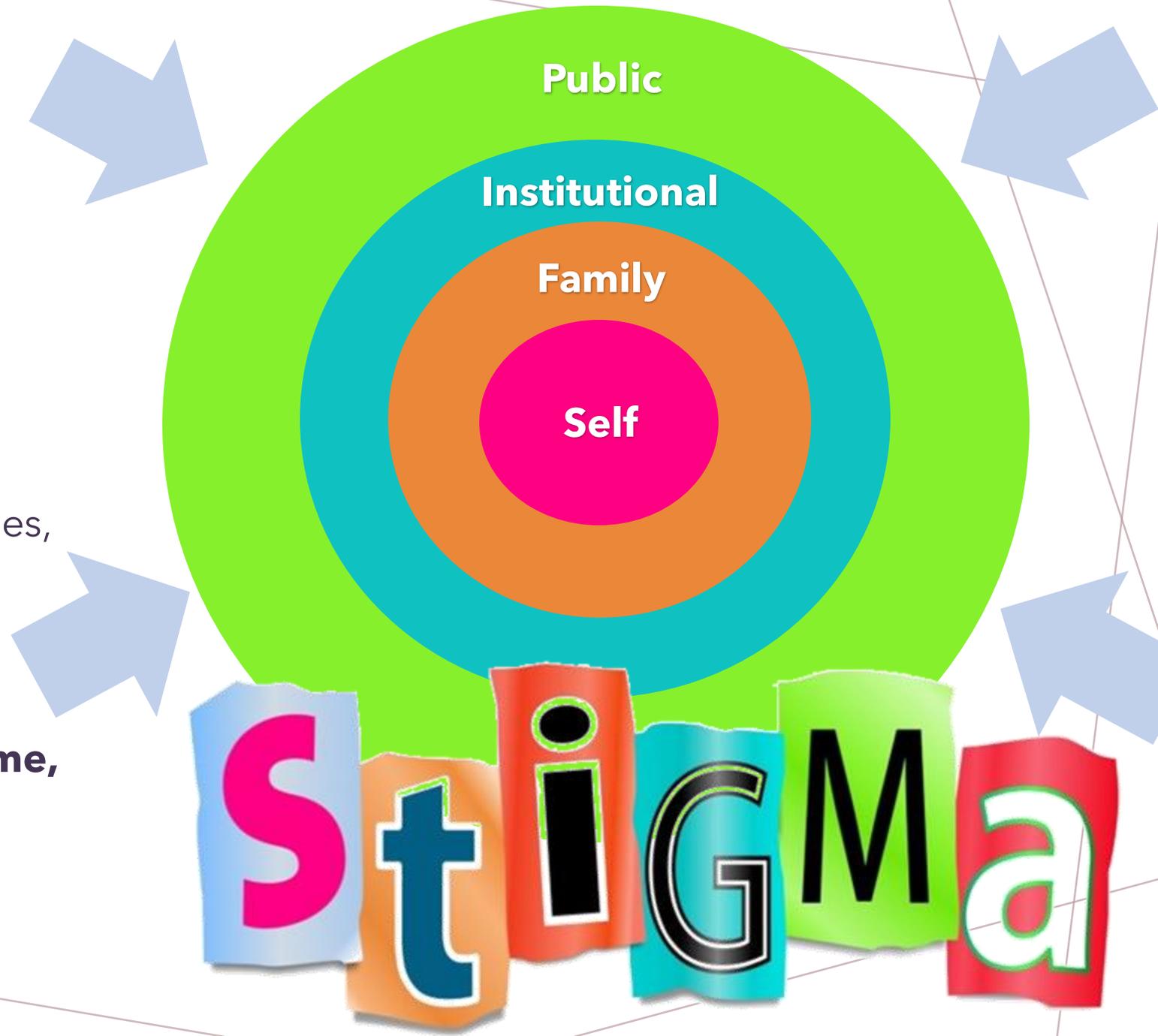
What do we have in common?

- Capacity for judgment
- Capacity for fear
- Need for belonging - social identity

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Types of stigma

- Public Stigma: stereotypes, discriminatory attitudes
- Institutional stigma: systemic, policies, limited opportunities
- Self-stigma: internalized shame, negative attitudes
- **Family stigma: associational, blame, shame**
- Societal norms

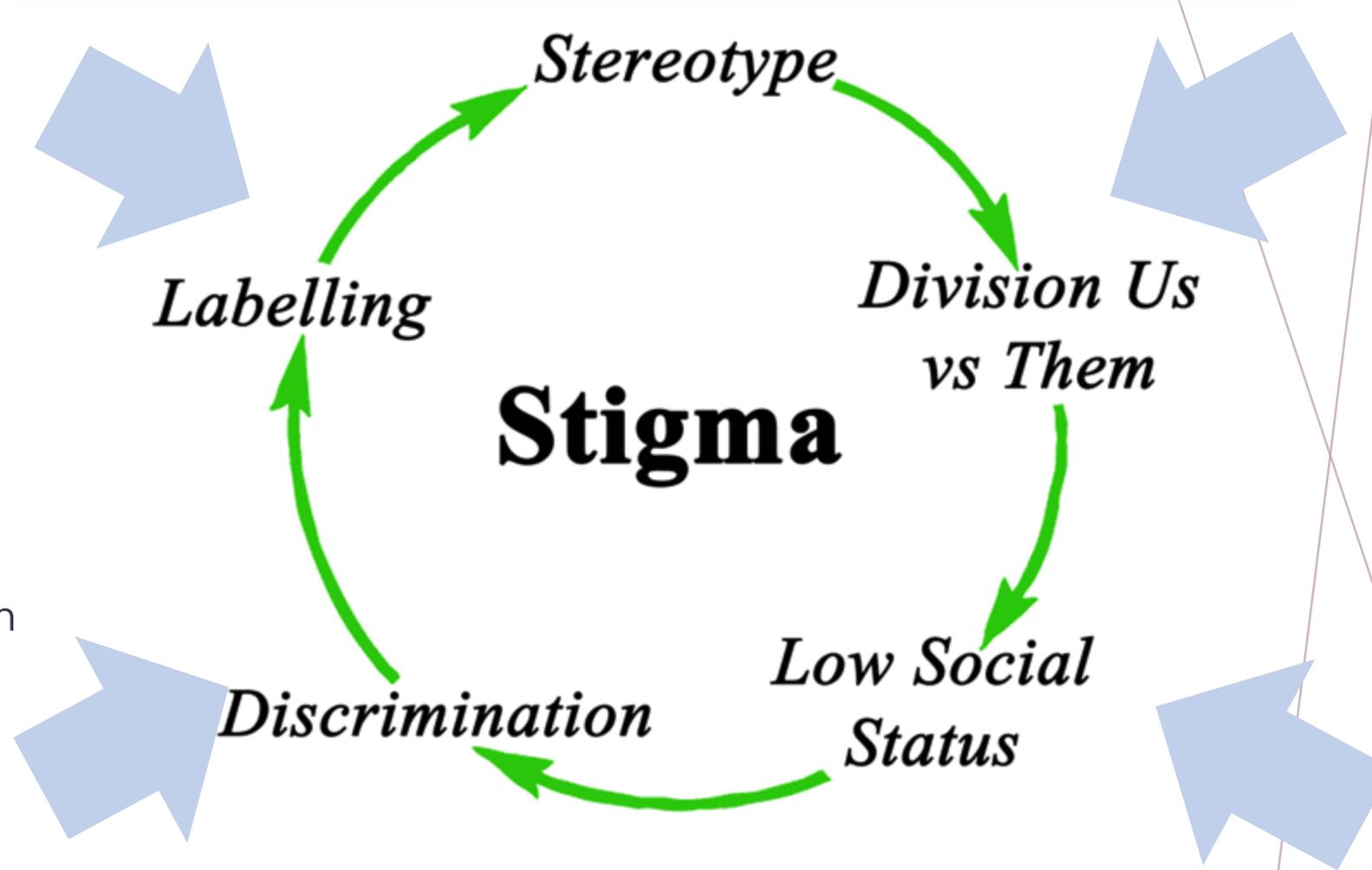


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"Undesired Differentness"

Stigma exists in the relationship
between an *attribute* and an
audience

It is felt in the disconnect between
identity and *perception*



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**What do we NOT
have in common?**

POWER

- Capacity for judgment
- Capacity for fear
- Need for belonging



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“Undesired Differentness”

- They’re “different”
- There’s something *wrong* with them
- That isn’t wrong with me
- I need to distance myself



Stigma

The word "Stigma" is rendered in a colorful, 3D, cut-out style. Each letter is on a separate, slightly overlapping piece of paper or card. The letters are: 'S' (pink on a light blue background), 't' (dark blue on an orange background), 'i' (black on a red background), 'G' (black on a cyan background), 'M' (black on a lime green background), and 'a' (white on a red background). The letters have a slight shadow and are arranged in a slightly wavy line. Four light blue arrows point towards the word from the corners of the slide.

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The Family Experience

"Until you have a kid with special needs you have no idea of the depth of your strength, tenacity, and resourcefulness."

Unknown



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Experience of family stigma

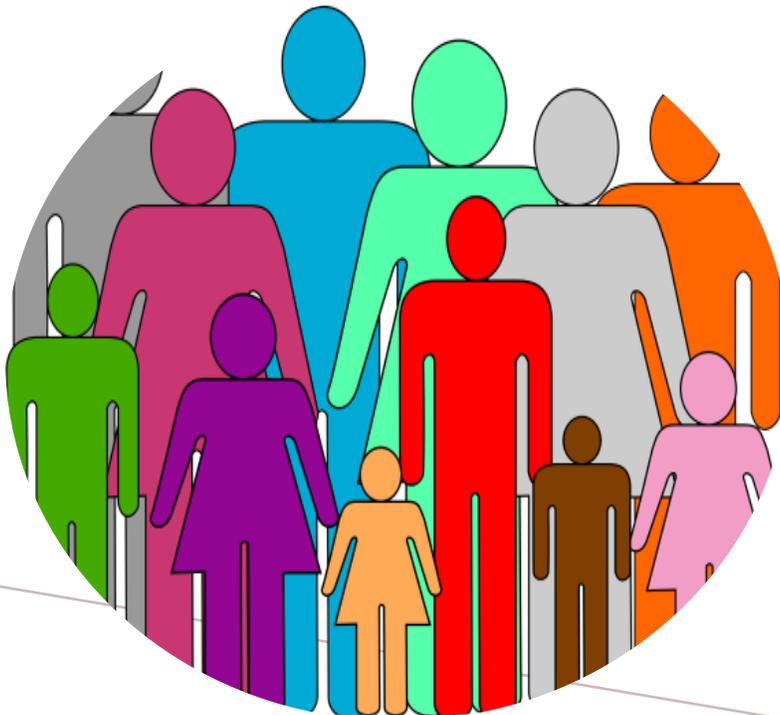


Conversations with nearly 300 parents & caregivers of children with complex needs

Families are not seen in context

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Experience of family stigma



"He assumed I was an addict."

JUDGMENT

"She told me I should discipline my child."

PRESCRIPTION

"So much baby talk! She spoke to me like I was three."

INFANTALIZATION

"She announced to the group that, 'This is therapy 101.'"

SUBORDINATION

"He always said, 'families like yours' but he didn't know my family."

IGNORANCE

"His diagnosis was ODD and we were the ODD parents."

STEREOTYPING

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Experience of family stigma



“Stigma often comes from lack of understanding or fear.”

American Psychiatric Association, 2020

“His diagnosis was _____ and we were the _____ parents.”

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Experience of family stigma

“Stigma often comes from lack of understanding or fear.”

American Psychiatric Association, 2020

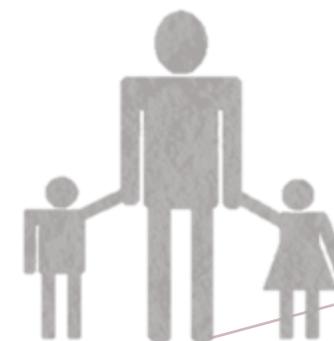
- Family
- Friends
- Neighbors
- Strangers
- Pediatric providers
- Preschool & Early childhood programs
- School





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Experience of family stigma



**What didn't
you do?**

Those people

**That
parent!**

*Piece of
work*

**What did
you do?**

*Bad
Parent?*



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Implicit Bias & Stigma

"a negative attitude, of which one is not consciously aware, against a specific social group."

American Psychological Association

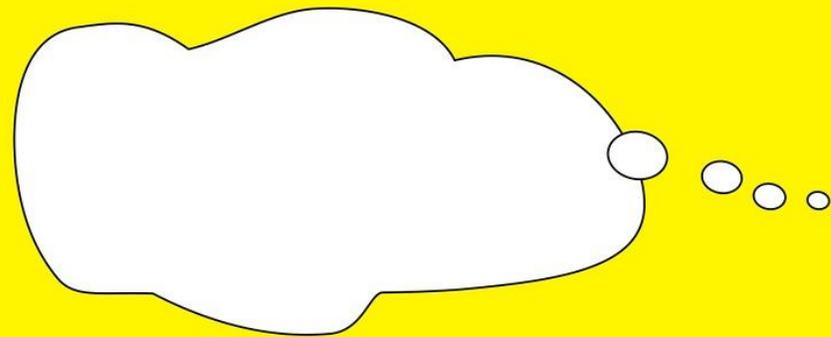


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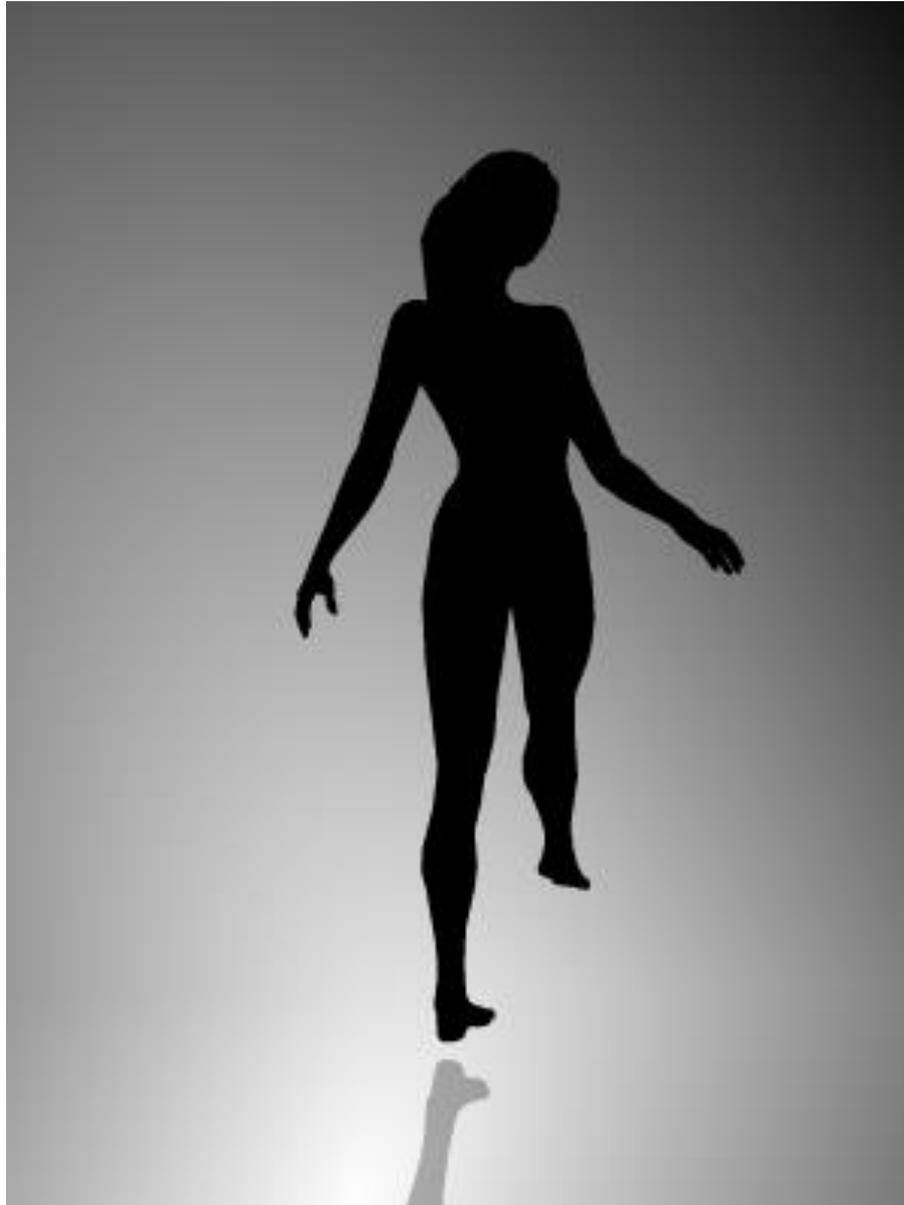
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Implicit bias



MINDBUGS

“Bias is the thumbprint of culture on our minds and we are reflecting what our culture is teaching us.”

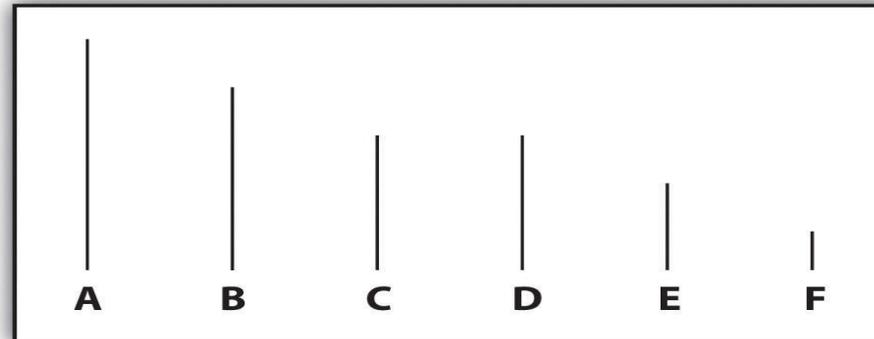


By Nobuyuki Kayahara - Procreo Flash Design Laboratory, CC BY-SA 3.0, <https://commons.wikimedia.org/w/index.php?curid=3526328>

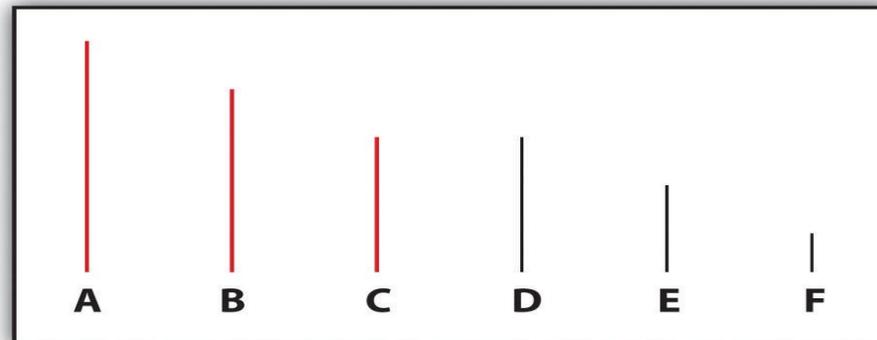
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Implicit bias

No categorization condition:



Categorization condition:



Tajfel (1970).

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The Normalization of Stigma

"Social processes through which ideas and actions come to be seen as normal and become taken-for-granted or 'natural' in everyday life."

Gunderson, R. (2021). How Do Social Structures Become Taken for Granted? Social Reproduction in Calm and Crisis



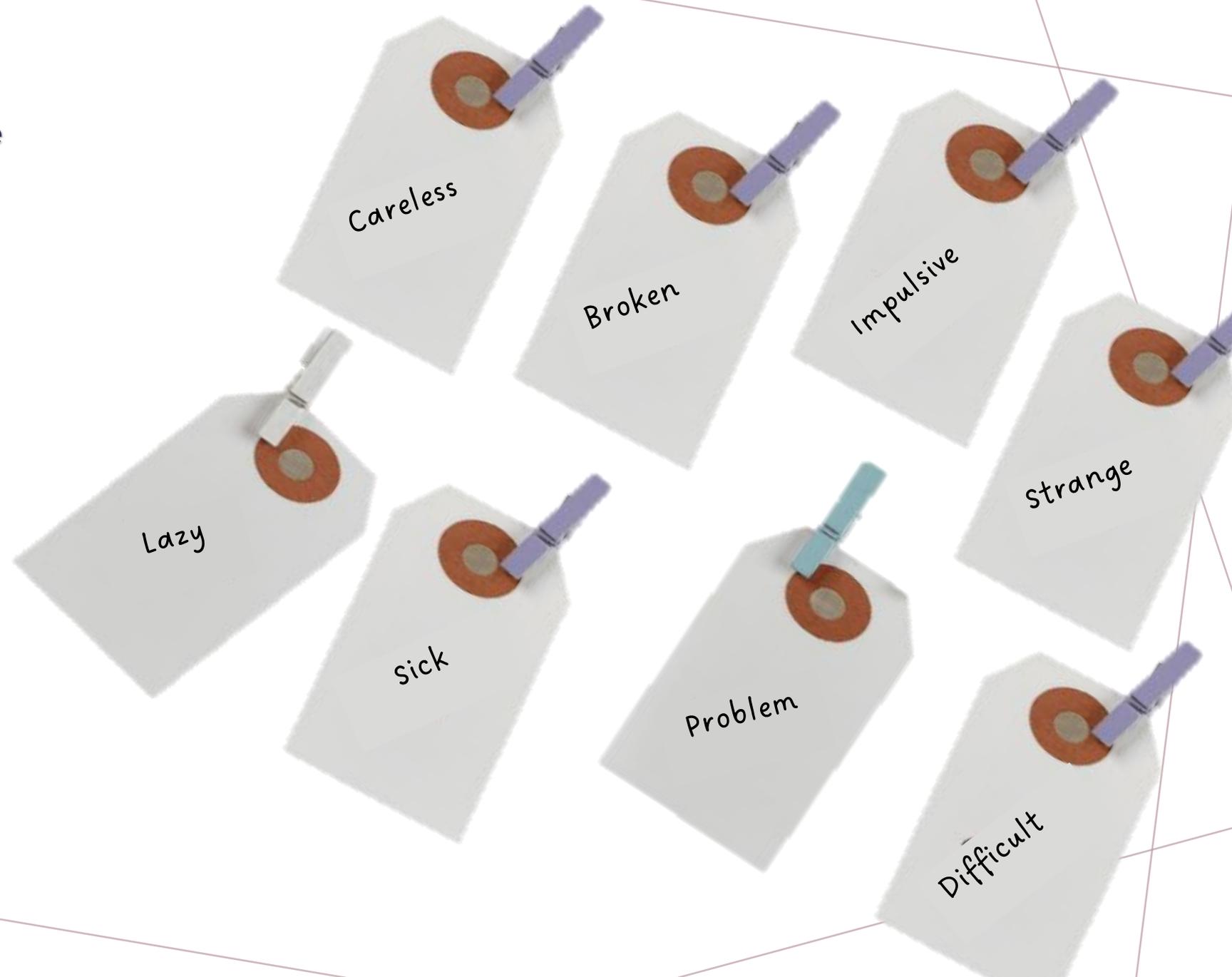
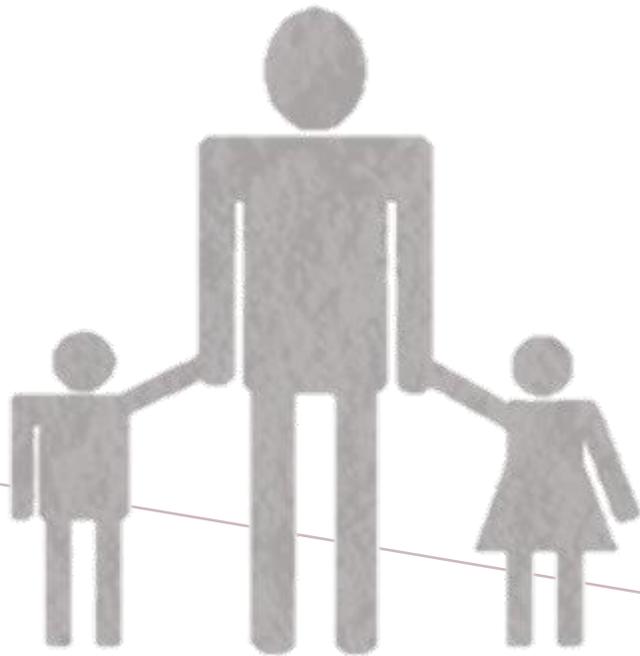
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Normalization of Stigma

Person reduced to label

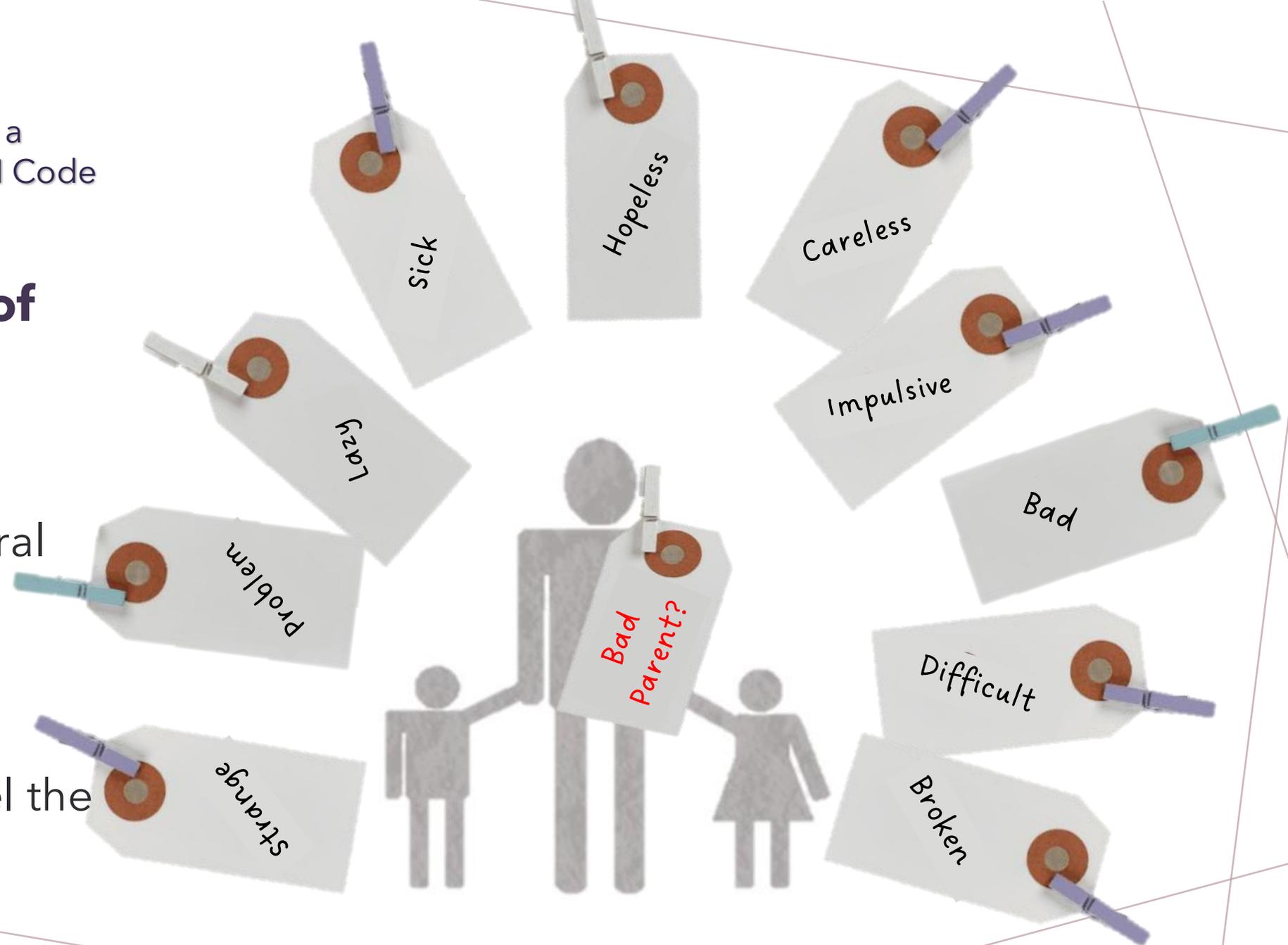


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Normalization of Stigma

Stigmatizing language has an immediate, visceral adverse reaction

When we hear certain words we immediately label the person as "bad"



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Context Experts

"I've seen hundreds of kids
like him."

"But you've never seen him!"



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Boy

Notice physical sensations

Picture living environment, family, neighborhood, cultural attributes, SES

How closely do you relate to this experience?

- Disruptive in school
- Took food out of garbage
- Excluded from extracurricular activities
- Frequently excluded from school
- Aggressive behavior resulted in school lock-downs
- Ran away from school and home
- Fashioned weapons from household objects & hid them
- Frequent aggression toward family
- Destruction of property
- Police called to home

Girl

Notice physical sensations

Picture living environment, family, neighborhood, cultural attributes, SES

How closely do you relate to this experience?

- Good student
- School Athlete
- Musician - Played flute with a youth symphony
- Worked as a camp counselor
- Student advocate & leader
- Majored in international politics and psychology
- Founded and hosted a podcast
- Numerous honors & awards
- Hired by a major financial institution
- Applying to graduate schools

- 
- The background is a vibrant watercolor illustration. It features a silhouette of a human head in profile, facing right, rendered in various shades of green and blue. The rest of the image is filled with colorful, swirling watercolor patterns in shades of blue, purple, pink, red, and yellow, creating a dynamic and artistic feel.
- Affinity Bias
 - Halo/Horns Effect
 - Confirmation Bias
 - Conformity Bias
 - Authority Bias
 - Perception Bias
 - Illusory Correlation
 - Affect Heuristic
 - Attribution Bias
 - Status Quo Bias

**WHAT
DO YOU SEE?**



feel, observe,
describe

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**That's just the way
we do it...**



The Essence of Dehumanization

To respond

To a significant degree...

To a human being

As if he were not what he is...

Or could never be...

What he might be

William G. Bronston, M.D., Concepts and Theory of Normalization

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Be the Change

- Build awareness
- Examine assumptions
- Challenge stereotypes
- Reframe your thinking
- Build community through empathy

<https://hbr.org/2021/09/unconscious-bias-training-that-works>



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Implicit bias trainings fail in reducing bias when

- Trainings are a one-time event
- Not part of a larger strategy
- Participants are not receptive
- There is a lack of focus on behavioral change

https://diversity.nih.gov/sites/coswd/files/images/NIH_COSWD_SWDSS_Implicit_Bias_Proceedings_508.pdf

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Thank you!

***Carol Dickey, MBA, MS
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