

Stronger Than Stigma:  
What People with Living Experience  
Have Told Researchers Over the Past  
20 Years



Lauren Perovsek, MS  
Kaitlyn Drafton, PhD  
Leayh Abel, Ed.S.  
Michelle Kuhn, PhD



Prenatal alcohol/substance exposure is associated with complex lifelong outcomes



Individuals and families experience significant stigma



Stigma impacts:

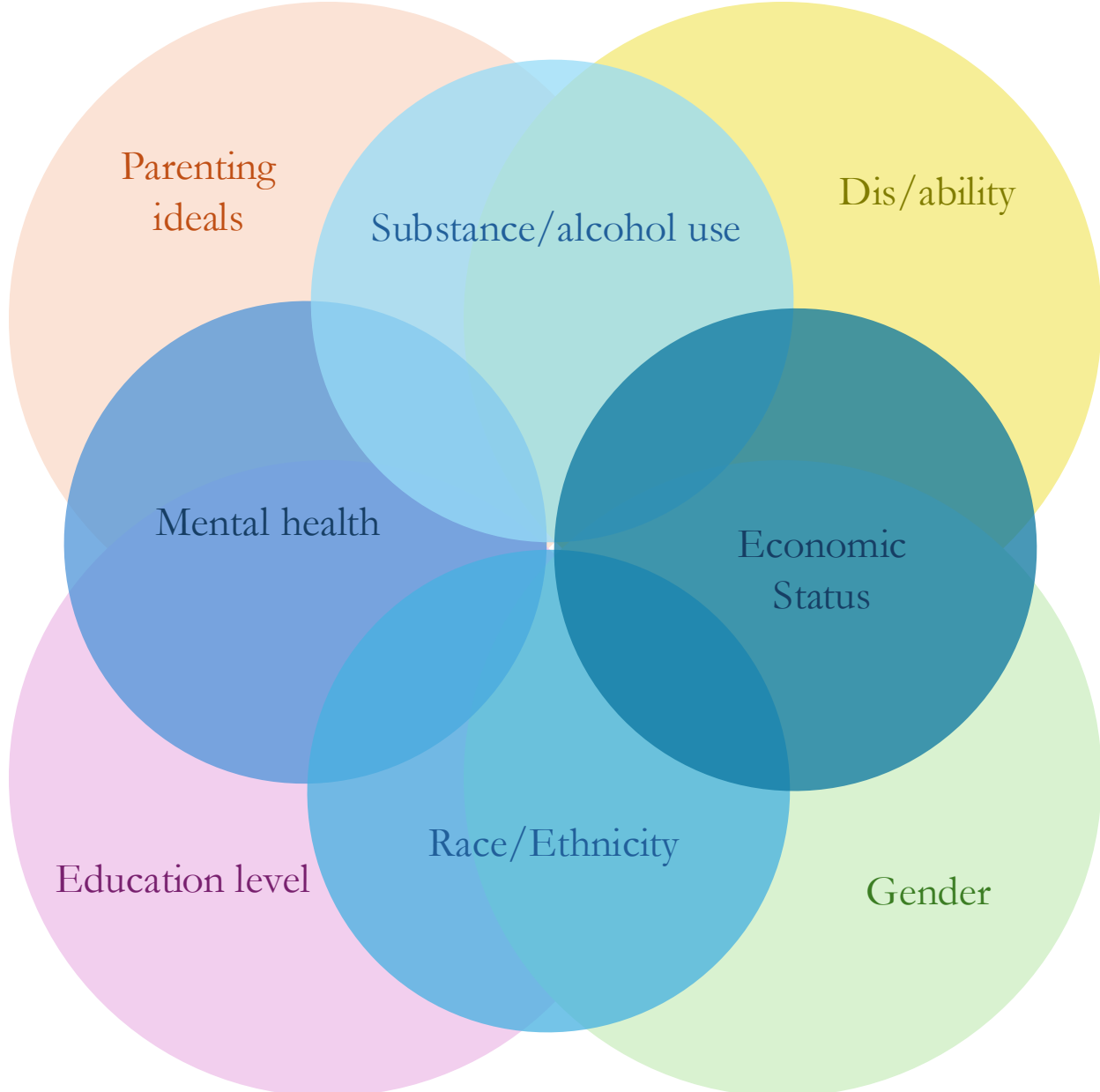
Well-being

Education

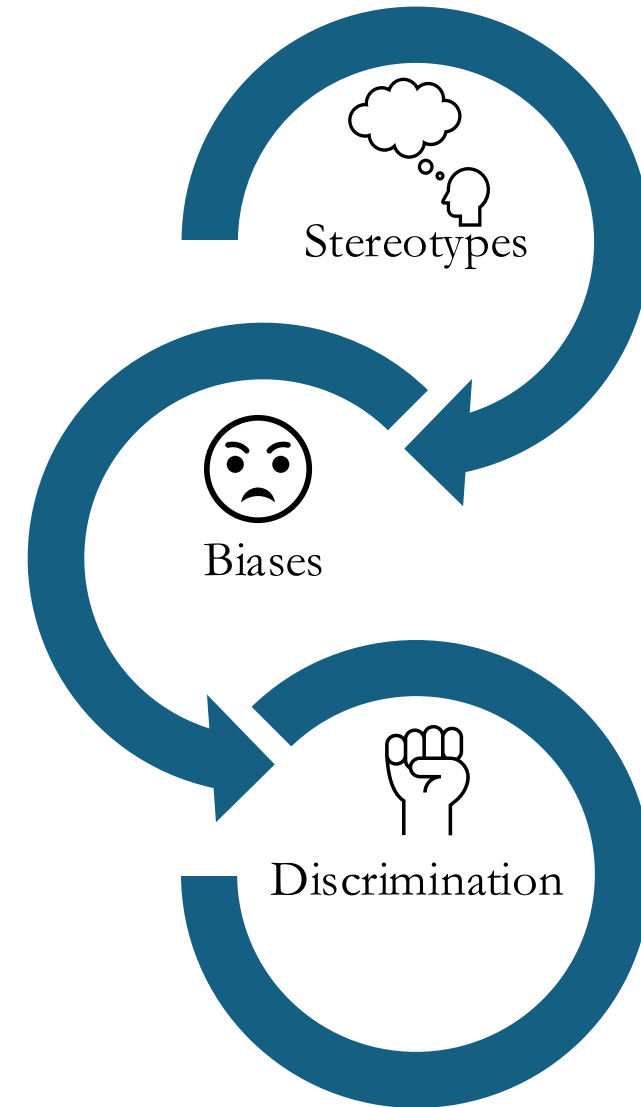
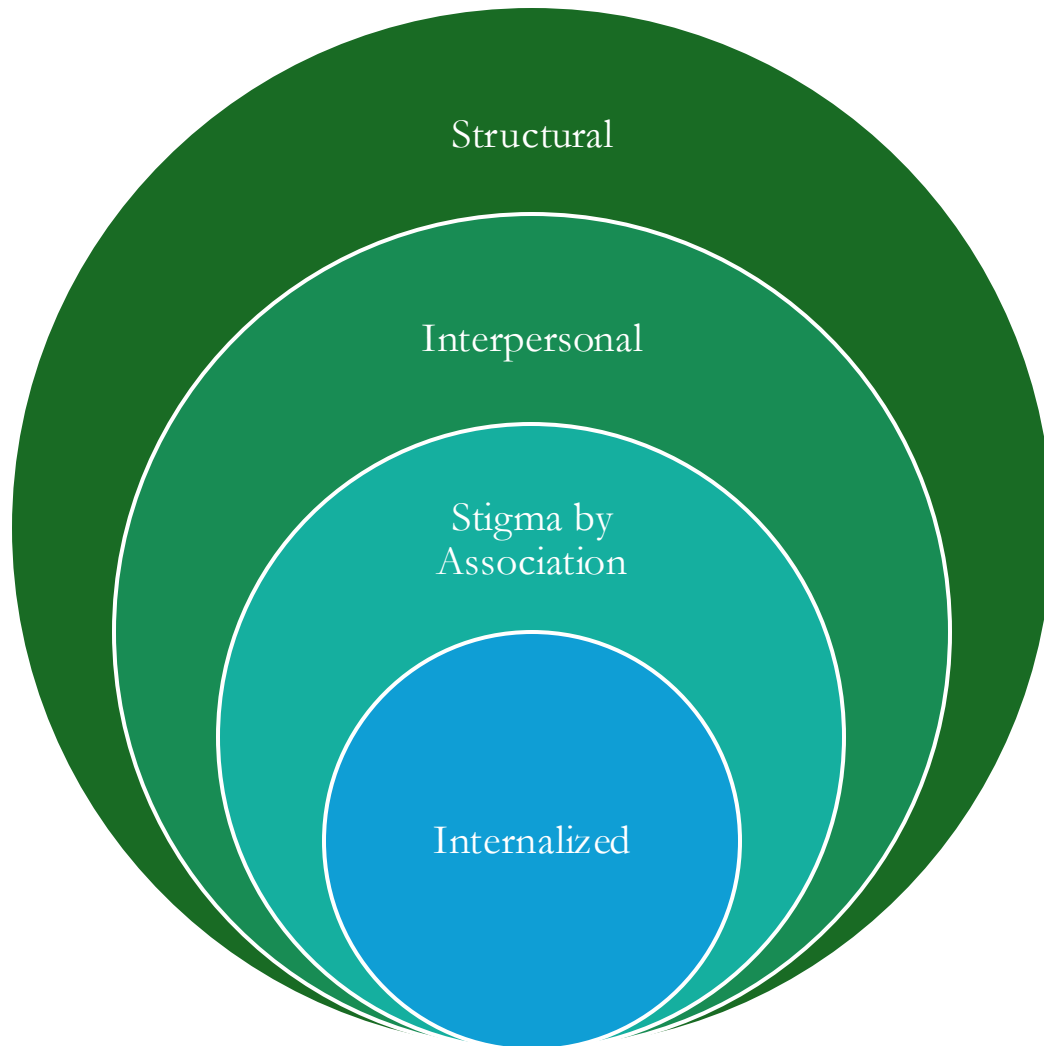
Access to medical and psychological care

Prenatal  
Alcohol &  
Substance  
Exposure

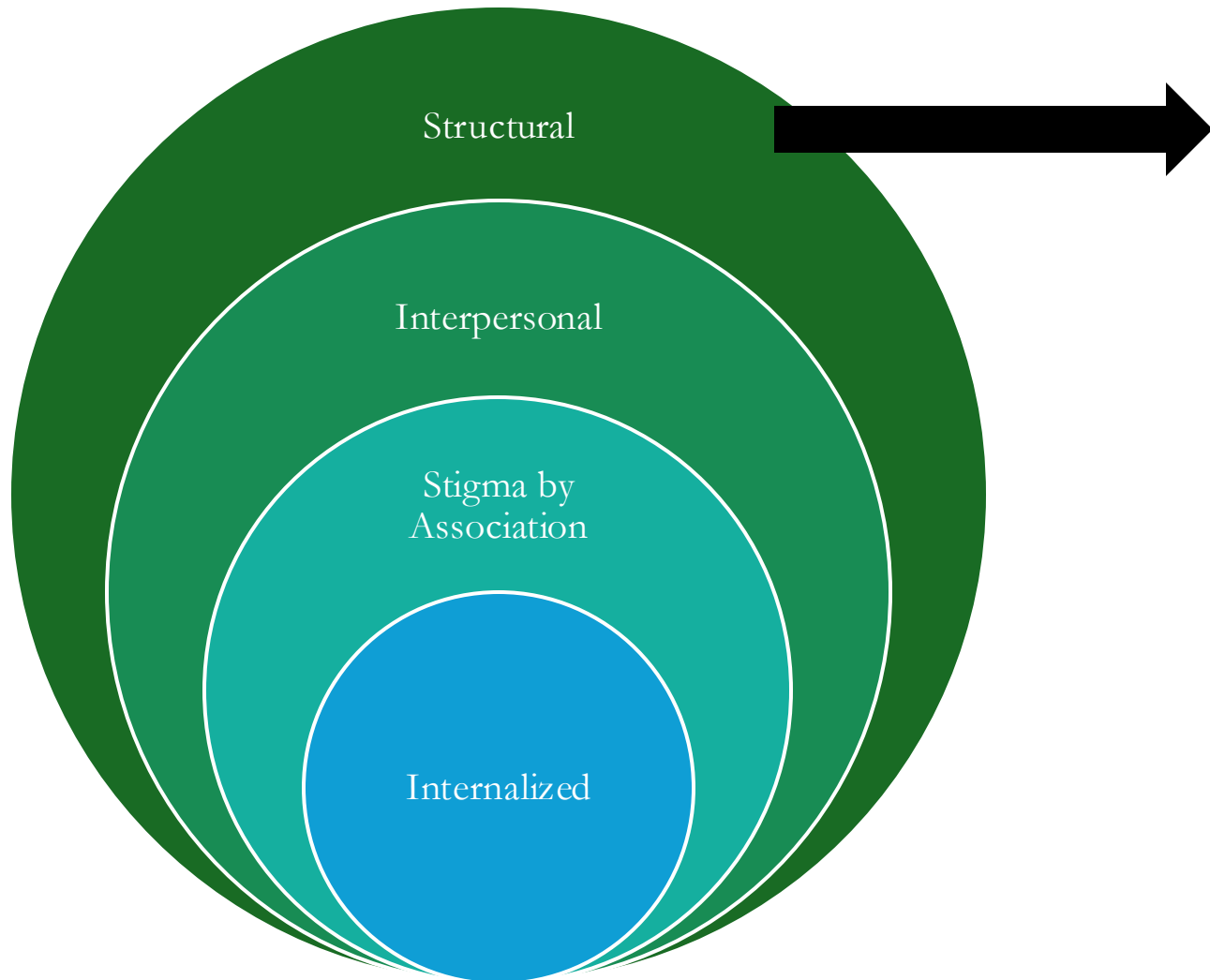
# Stigma is multifaceted



# Defining Stigma



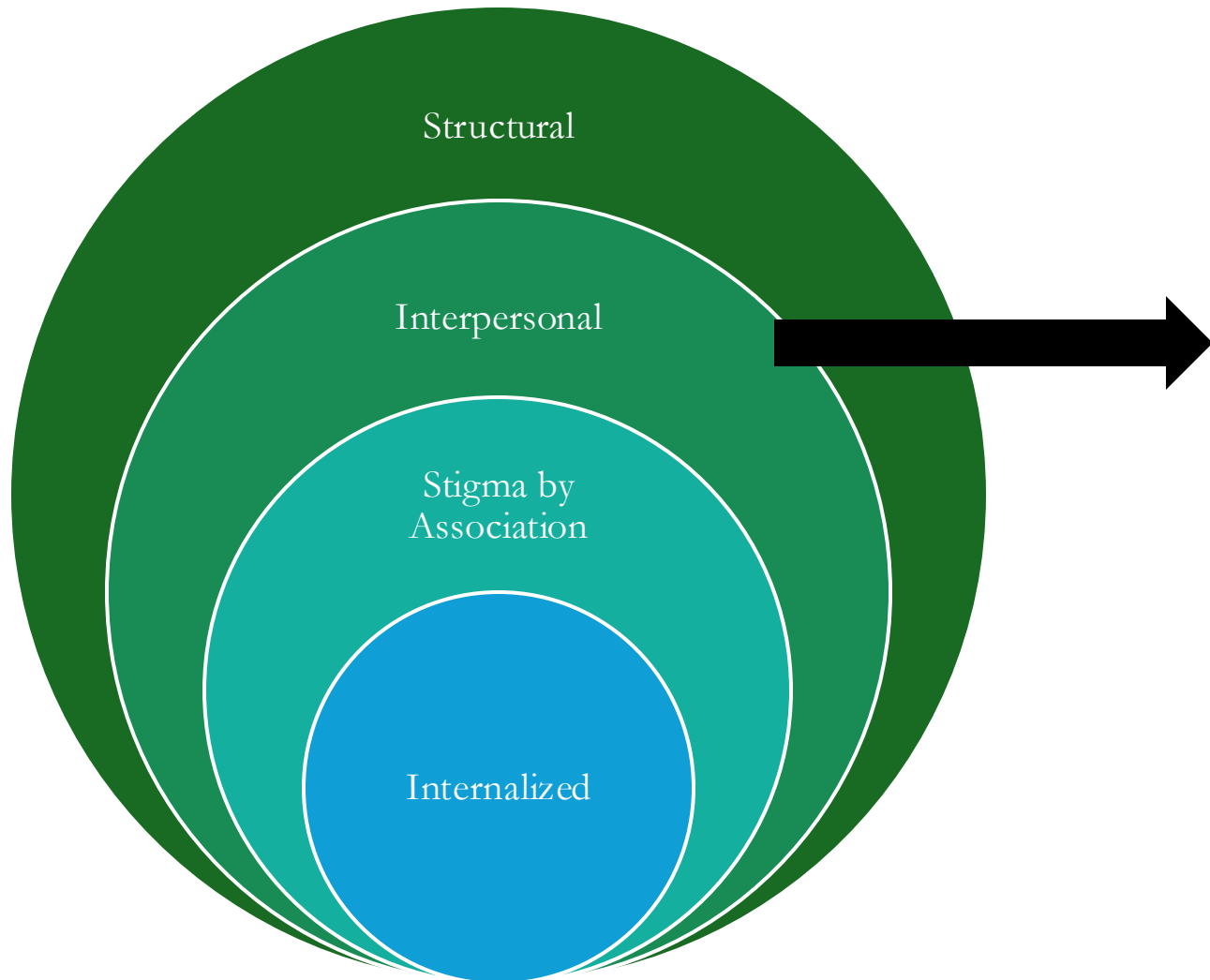
# Defining Stigma



**System-level policies,  
laws, and practices**

- Increased punitive measures
- Limited care options

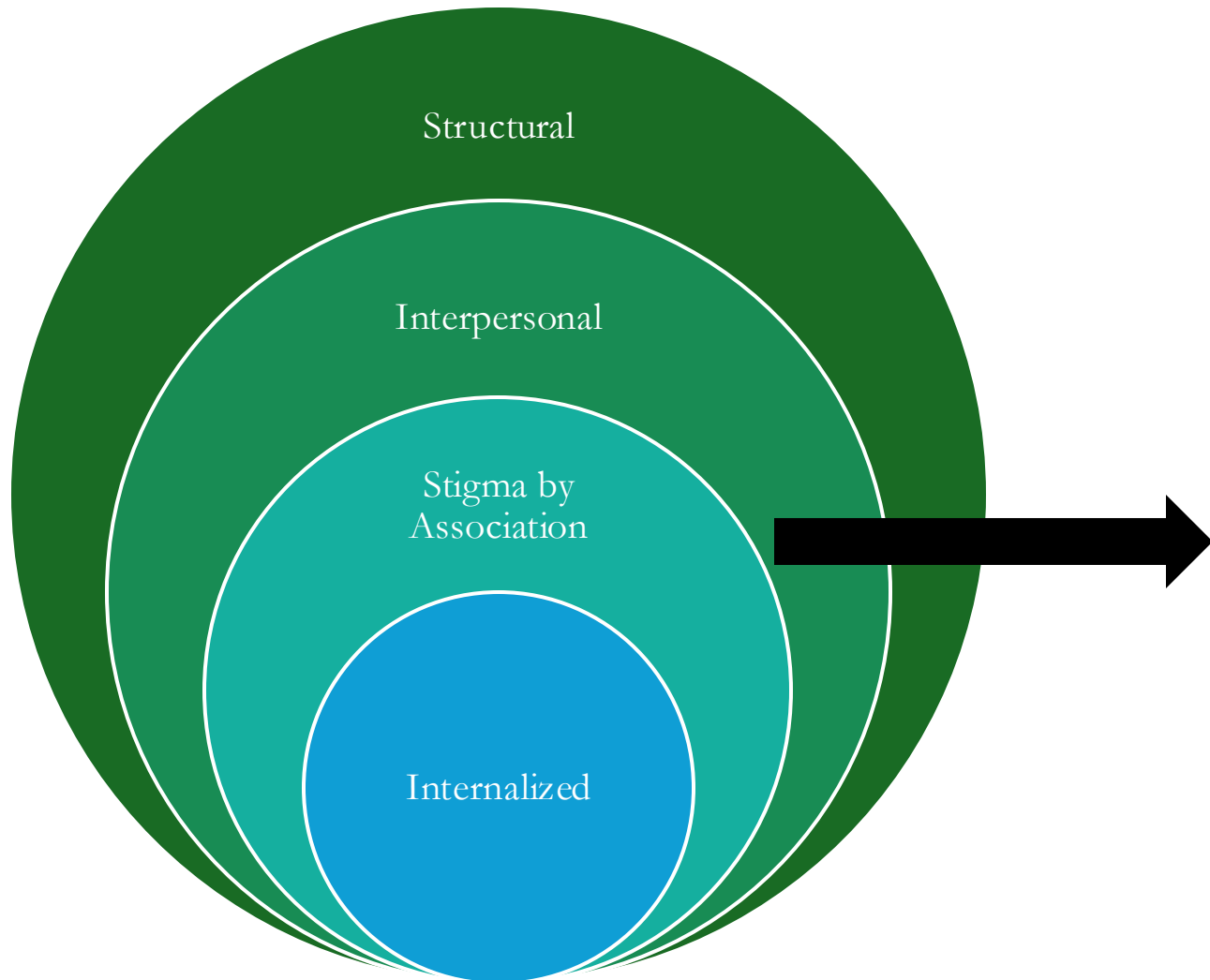
# Defining Stigma



**Between individuals  
(providers, family,  
community members)**

- Negative Labels
- Judgement

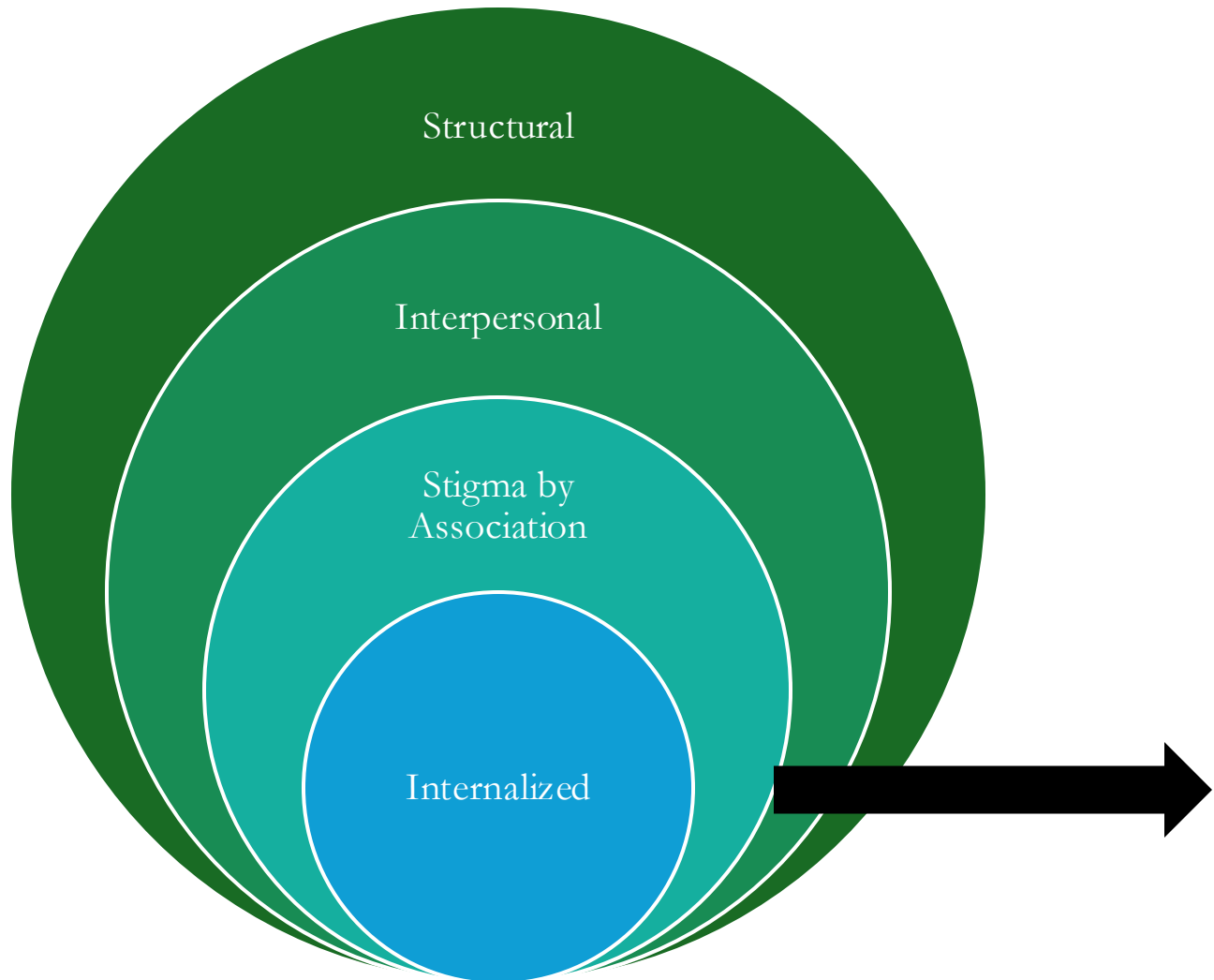
# Defining Stigma



**Stigma toward those  
connected to the  
stigmatized person**

- Negative Labels
- Caregivers excluded from community support

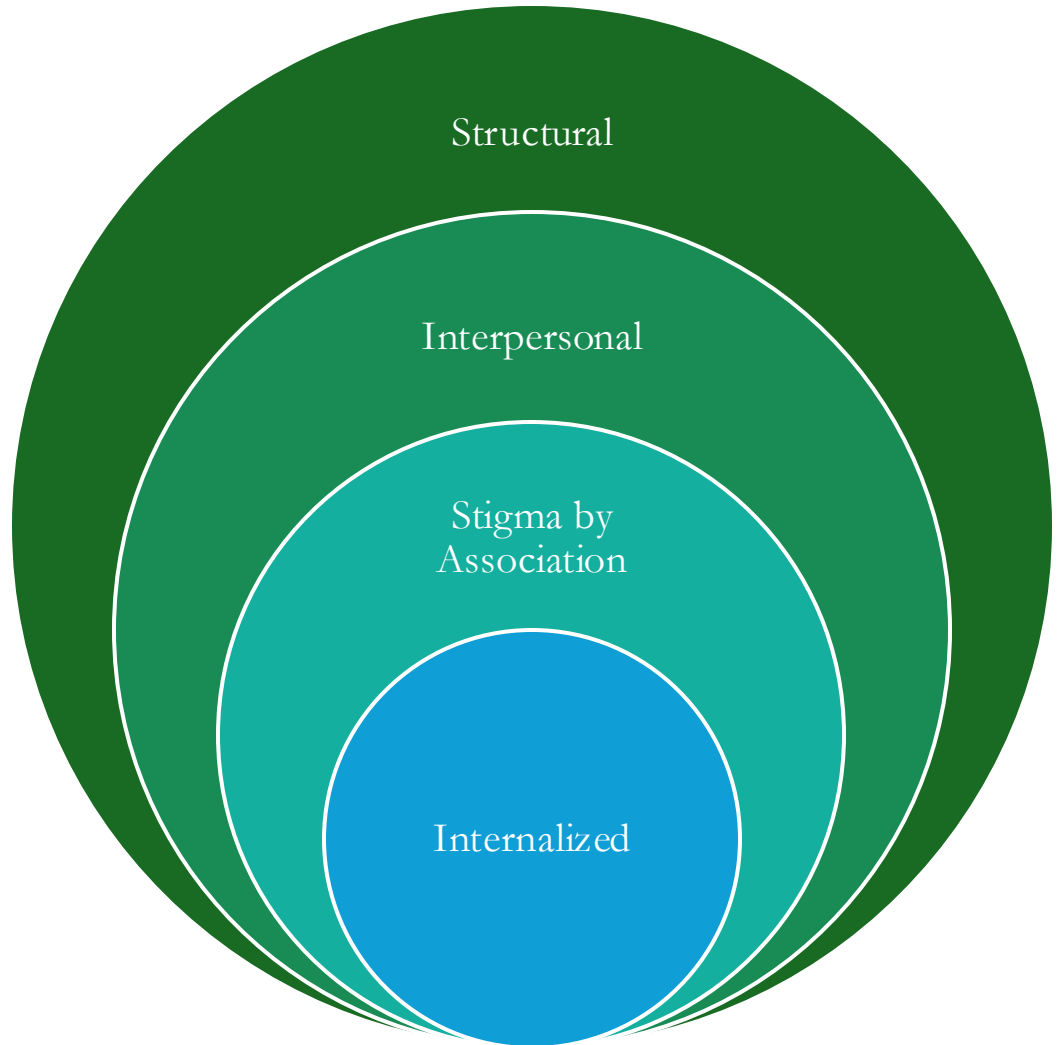
# Defining Stigma



## **Self-Stigma**

- Assigning negative labels to self
- Expecting judgement
- Withdrawing from support systems

# Defining Stigma



**These levels feed into each other**

Structural policies → shape provider behavior

Interpersonal stigma → reinforces internalized stigma

# A Look At The Literature

## Often unidimensional:

- Single type of substance exposure
- Single perspective
- Single setting

## Limited integration of:

- Polysubstance exposure experiences
- Living experience perspectives

# Our Aim



**Synthesize 20 years of literature**

Center perspectives of those with living experience



**Identify:**

Common stigma themes

Gaps in research

Future directions

# Methods

## Focus on:

- Individuals with prenatal exposure/s
- Birth parents
- Caregivers, family members

## Databases searched:

- APA PsycInfo, CINAHL, Embase, Ovid MEDLINE, PubMed, Web of Science

## Search terms included:

- **Prenatal substance/alcohol exposure**
- **Stigma, bias, stereotypes, discrimination**

## Included studies:

- Empirical, peer-reviewed
- Directly included experiences of stigma
- **Perspectives of individuals/families**

## Process:

- Double-coded by  $\geq 2$  reviewers
- Title/abstract review
- Full-text review
- Data extraction

## Identification

Studies from databases/registers (n = 13629)

References from other sources (n = )  
Citation searching (n = )  
Grey literature (n = )

References removed (n = 6987)

Duplicates identified manually (n = 229)  
Duplicates identified by Covidence (n = 6758)  
Marked as ineligible by automation tools (n = 0)  
Other reasons (n = )

## Screening

Studies screened (n = 6642)

Studies excluded (n = 6299)

Studies sought for retrieval (n = 342)

Studies not retrieved (n = 0)

Studies assessed for eligibility (n = 342)

Studies excluded (n = 263)

Other (n = 2)  
Review (n = 21)  
Wrong setting (n = 1)  
Wrong outcomes (n = 43)  
Wrong comparator (n = 1)  
Wrong population (n = 84)  
Wrong study design (n = 19)  
Wrong Population, women and X Use Disorder. (n = )

## Included

Studies included in review (n = 79)

# Methods

## Focus on:

- Individuals with prenatal exposure/s
- Birth parents
- Caregivers, family members

## Databases searched:

- APA PsycInfo, CINAHL, Embase, Ovid MEDLINE, PubMed, Web of Science

## Search terms included:

- **Prenatal substance/alcohol exposure**
- **Stigma, bias, stereotypes, discrimination**

## Included studies:

- Empirical, peer-reviewed
- Directly included experiences of stigma
- **Perspectives of individuals/families**

## Process:

- Double-coded by  $\geq 2$  reviewers
- Title/abstract review
- Full-text review
- Data extraction

## Identification

Studies from databases/registers (n = 13629)

References from other sources (n = )  
Citation searching (n = )  
Grey literature (n = )

References removed (n = 6987)

Duplicates identified manually (n = 229)  
Duplicates identified by Covidence (n = 6758)  
Marked as ineligible by automation tools (n = 0)  
Other reasons (n = )

## Screening

Studies screened (n = 6642)

Studies excluded (n = 6299)

Studies sought for retrieval (n = 342)

Studies not retrieved (n = 0)

Studies assessed for eligibility (n = 342)

Studies excluded (n = 263)

Other (n = 2)  
Review (n = 21)  
Wrong setting (n = 1)  
Wrong outcomes (n = 43)  
Wrong comparator (n = 1)  
Wrong population (n = 84)  
Wrong study design (n = 19)  
Wrong Population, women and X Use Disorder. (n = )

## Included

Studies included in review (n = 79)

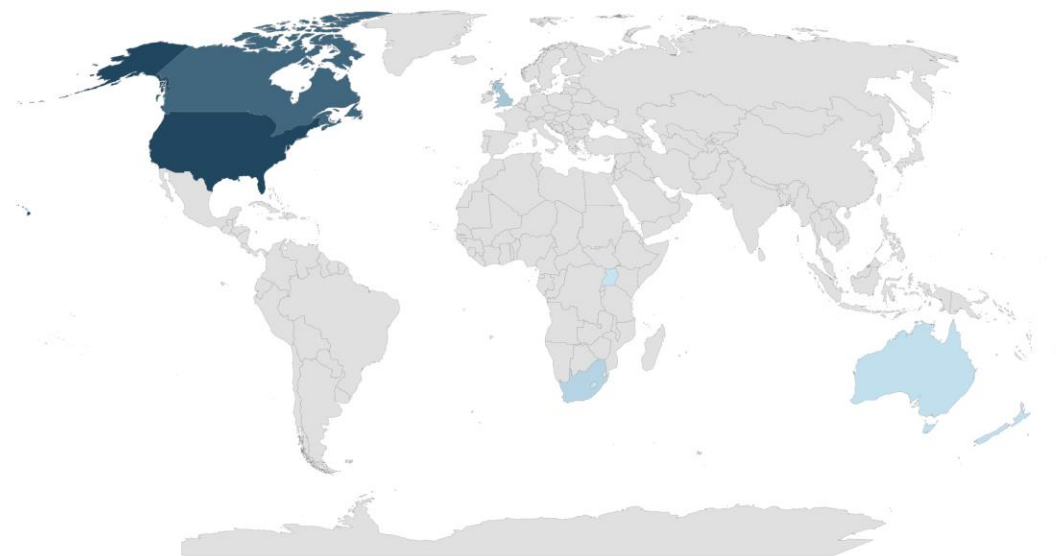
**23%**

1999

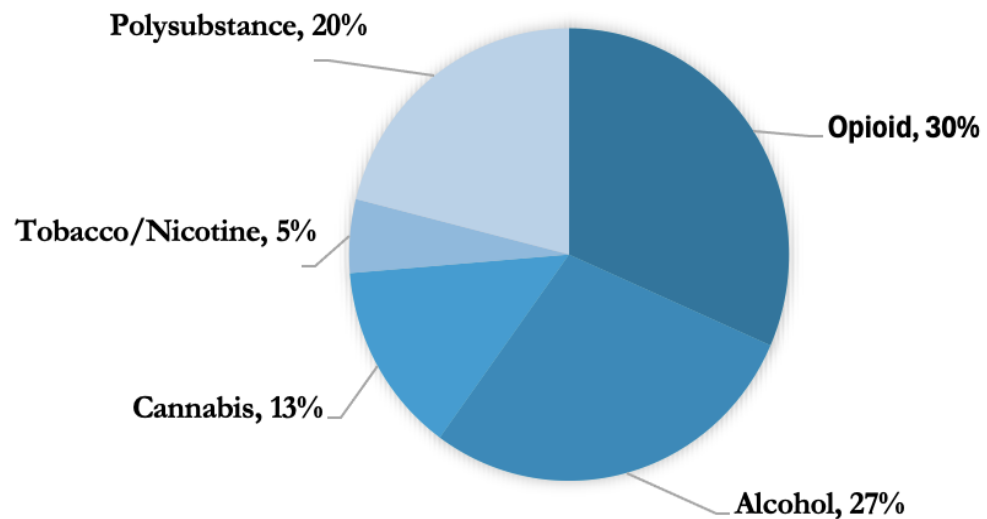
# Timeline



2023



## EXPOSURES



Countries	Percent
United States	42.5%
Canada	34.2%
UK	9.6%
Australia	2.7%
New Zealand	2.7%
South Africa	5.5%
Lesotho	1.4%
Uganda	1.4%

“Sometimes, I feel as though that, when I’m [at the substance use treatment program]...**I have been labeled as a bully...** And I feel as though...**everybody who was called [a bully] was Black. I felt that was discrimination.** Because I don’t feel as though only Black people are bullies”

-Birth Mother

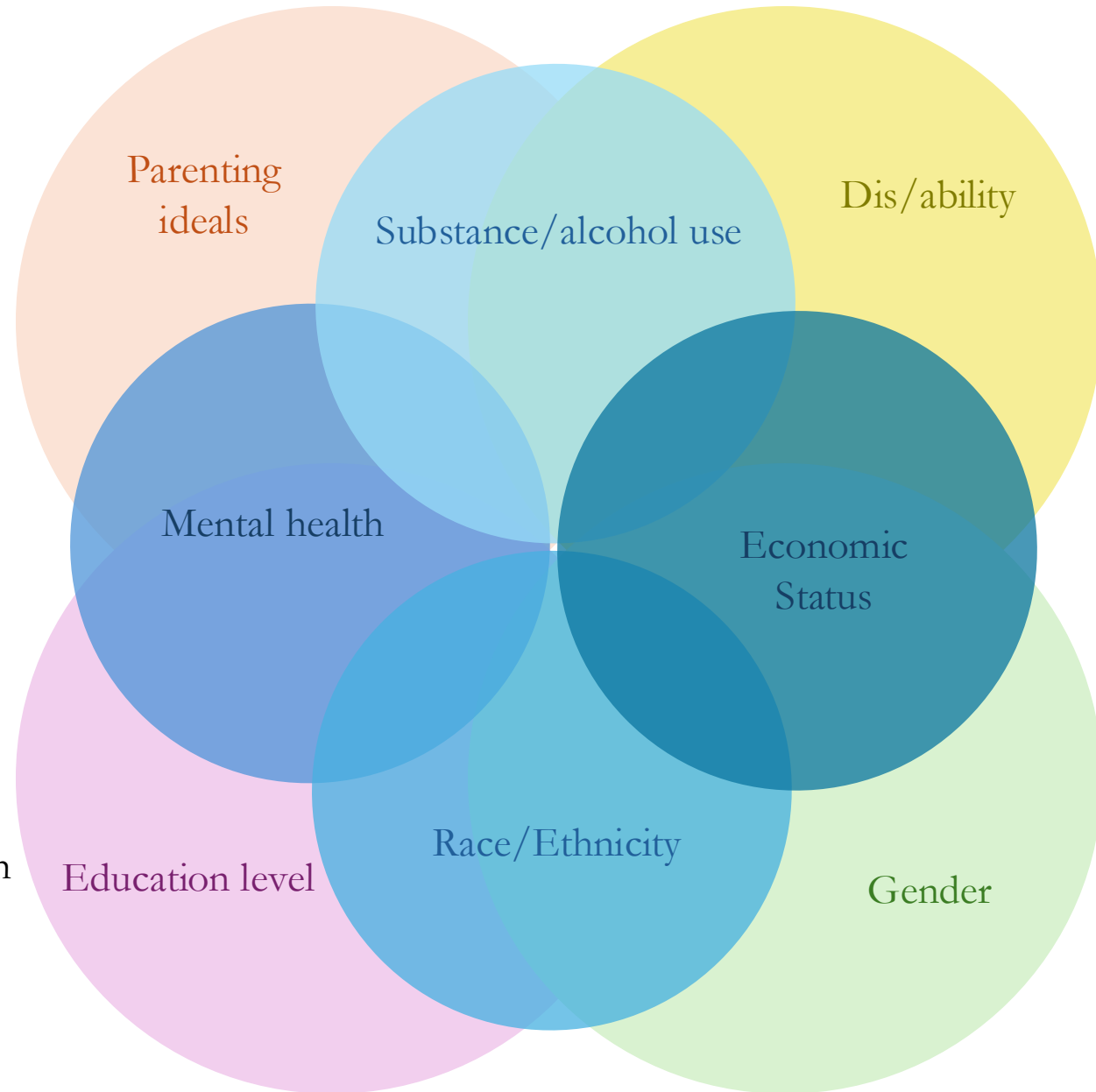
---

## Intersectional Nature of Stigma

---

“**Pregnant mothers don’t have food to eat, and there is no money to buy needs as told by health workers.** For instance, I don’t have maternity wear and yet it's needed... Without it, the health workers quarrel with us, which makes us feel bad. We work very hard to get money. Given our condition, getting firewood is a problem for us here and you can’t eat what you feel like eating. **I have to drink to forget the rude remarks from health workers**”

-Birth Mother

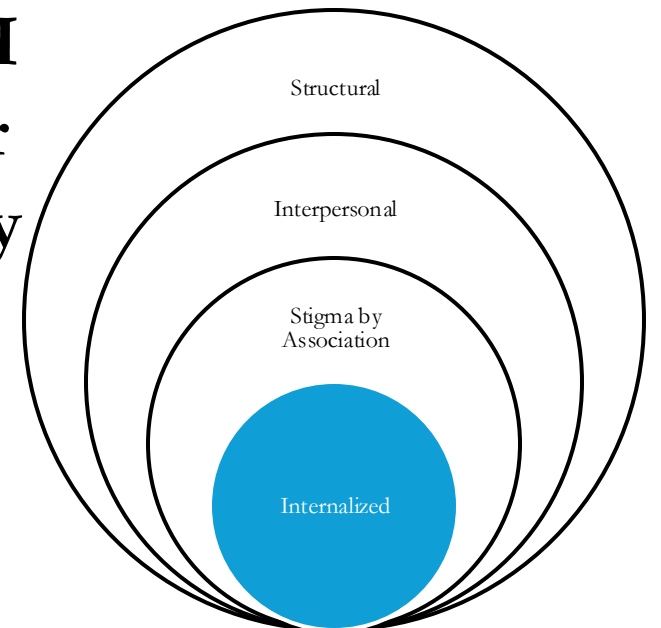


# Internalized

- Feelings of shame, guilt, embarrassment, moral failure
- Conflict between internalized societal expectations and lived experience
- Negative Labels

“...saying...anybody with FAS or FASD is going to be a criminal. They’re going to, you know, go rob a bank...steal a car or something...yes, some of us will get into that ... [but] **I find that stereotyping stuff like that ... that gets into our heads, and then we start feeling, well, because people say that, well, now we have to be like that”**

-Person with FASD

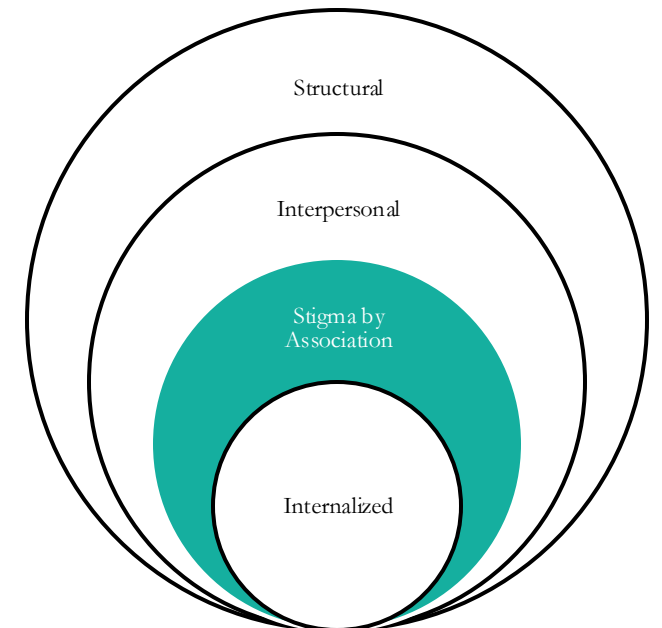


# Stigma by Association

- Scrutiny and Judgment
- Lack of knowledge/ability/skills
- Social Isolation

“It’s ignorant stereotypes: ‘You’re a bad parent. That kid’s spoiled rotten that’s having a tantrum in the middle of the store’. [My child] cleared a [local store] when she was [very young]. They had to close the store. **‘You’re a bad parent, and she’s a bad child, she’s a spoiled child’.** So, **it’s more ignorant stereotypes.’**”

-Caregiver

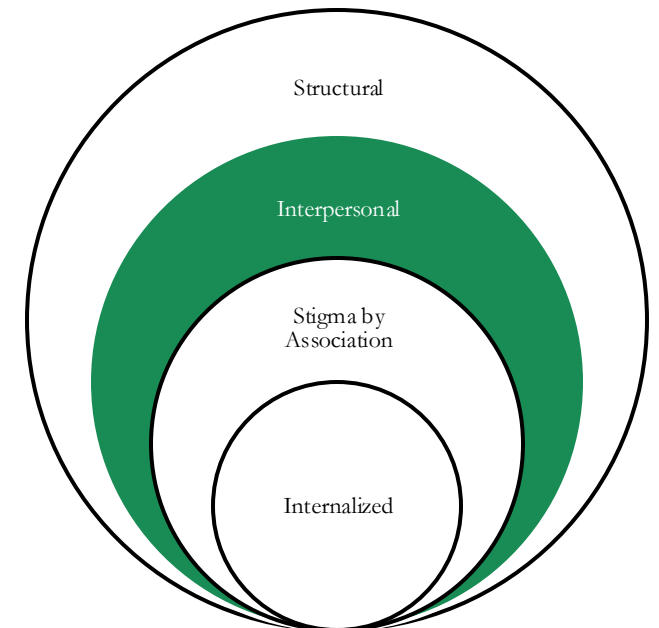


# Interpersonal

- **Feeling judged, shamed, blamed, or moralized (as well as a reduction in empathy)**
- **Discrimination**

“...it’s really misunderstood ... it’s just so generalized ... you look completely normal on the outside, but there’s like a million things on the inside that just don’t align, **don’t add up, don’t make sense to the normal general population. And it’s really hard when you have to try to jump into normal society...**”

-Person with FASD

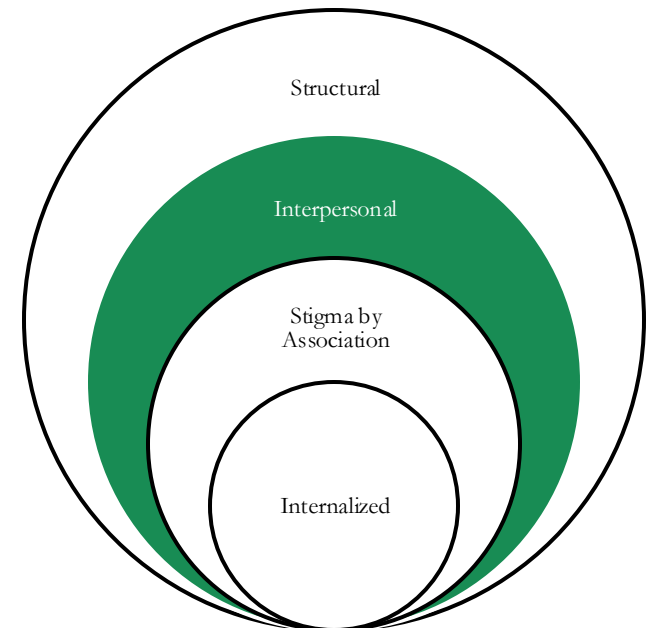


# Interpersonal

- **Feeling judged, shamed, blamed, or moralized (as well as a reduction in empathy)**
- **Discrimination**

“... I was dreading it you know and she was like, “Honey,” ... “I don’t see why you’re so shaky for.” I said, “What do you mean?” ... **She said, “Because you stick yourself,” and pointed, and touched my arm like that; she said “You stick yourself.” And I said, “Excuse me?” ... “No I don’t.”** She said, “Well, you do it to yourself so why should it bother us poking you?” And I started crying instantly right there because it made me very angry”

-Birth Mother

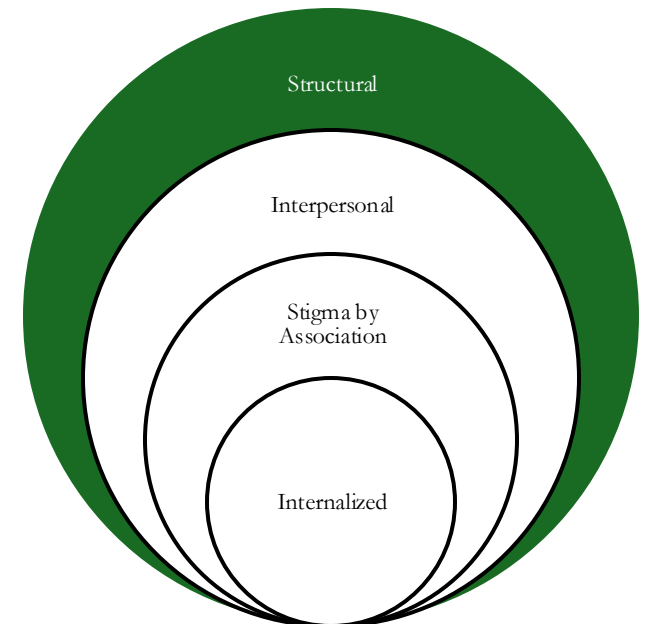


# Structural

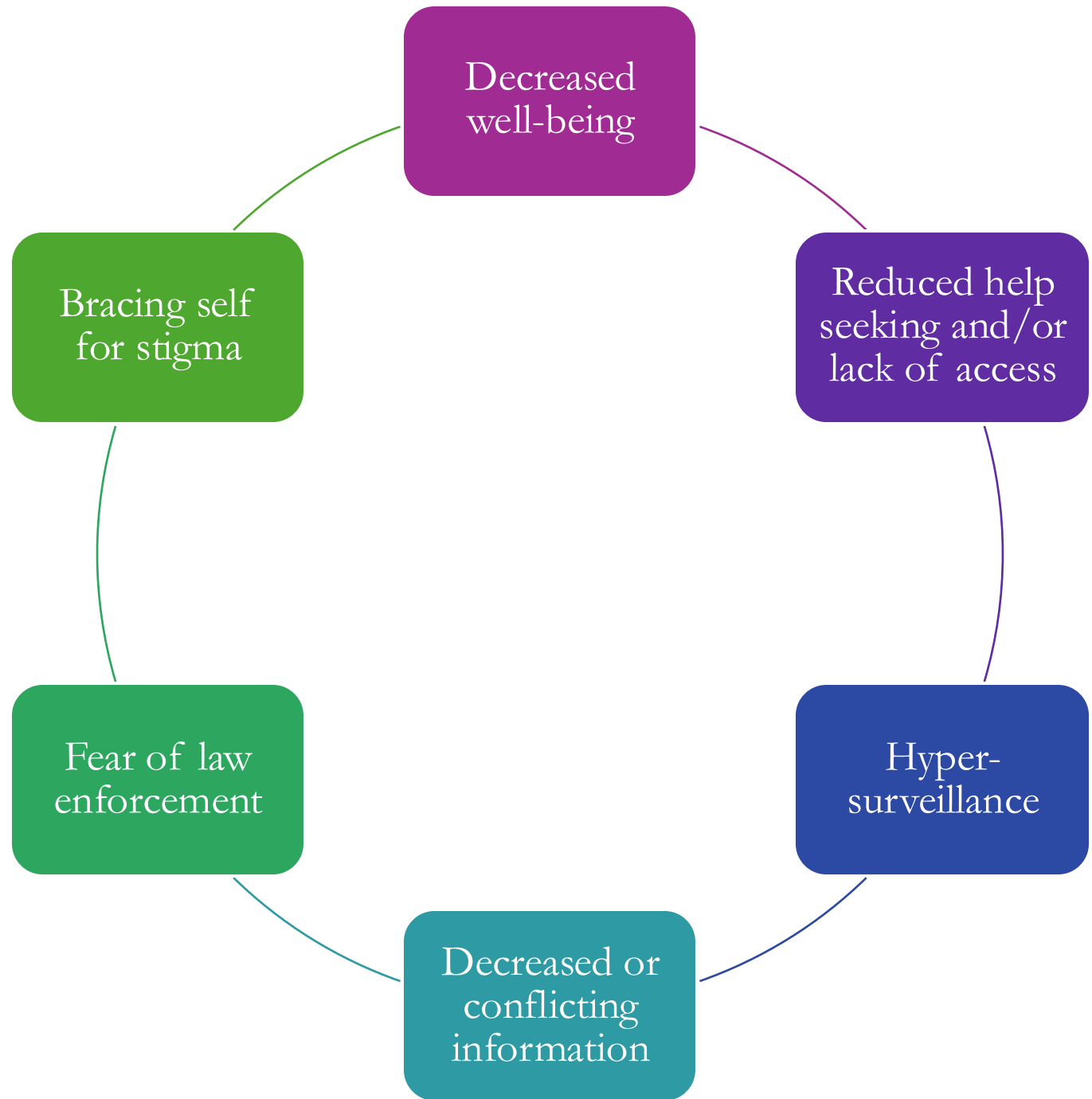
- Punitive policies
- Increased (and disproportionate/selective) surveillance
- Barriers to care

“Alexis communicated that the hospital **did not inform her that they tested her for substances**. She discovered that the hospital notified family policing agents about her substance use from a letter in the mail accusing her of child neglect....her negative experience, like others, deterred her from disclosing her substance use to healthcare professionals in the future.”

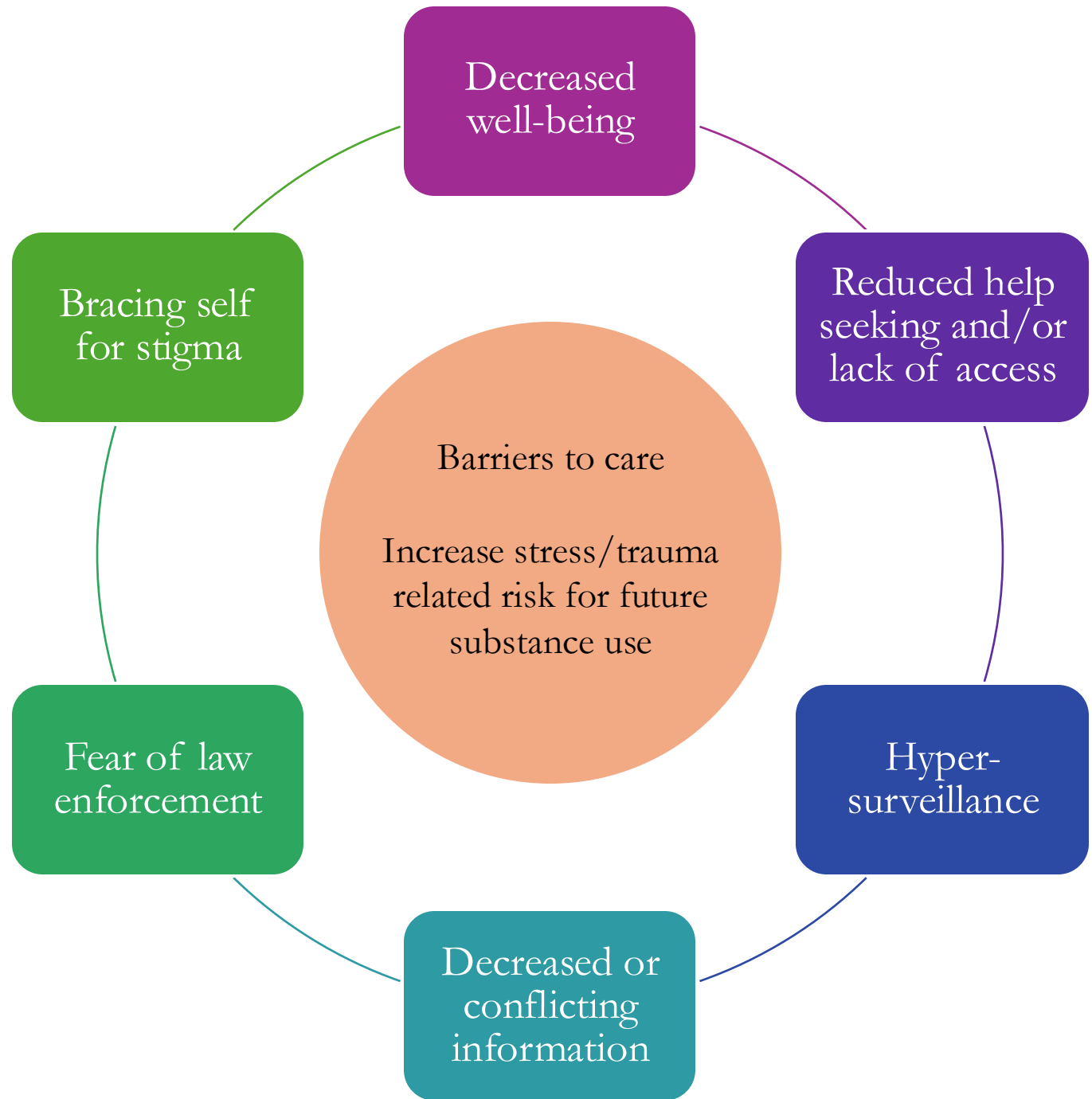
-Birth Mother



# Impacts of Stigma



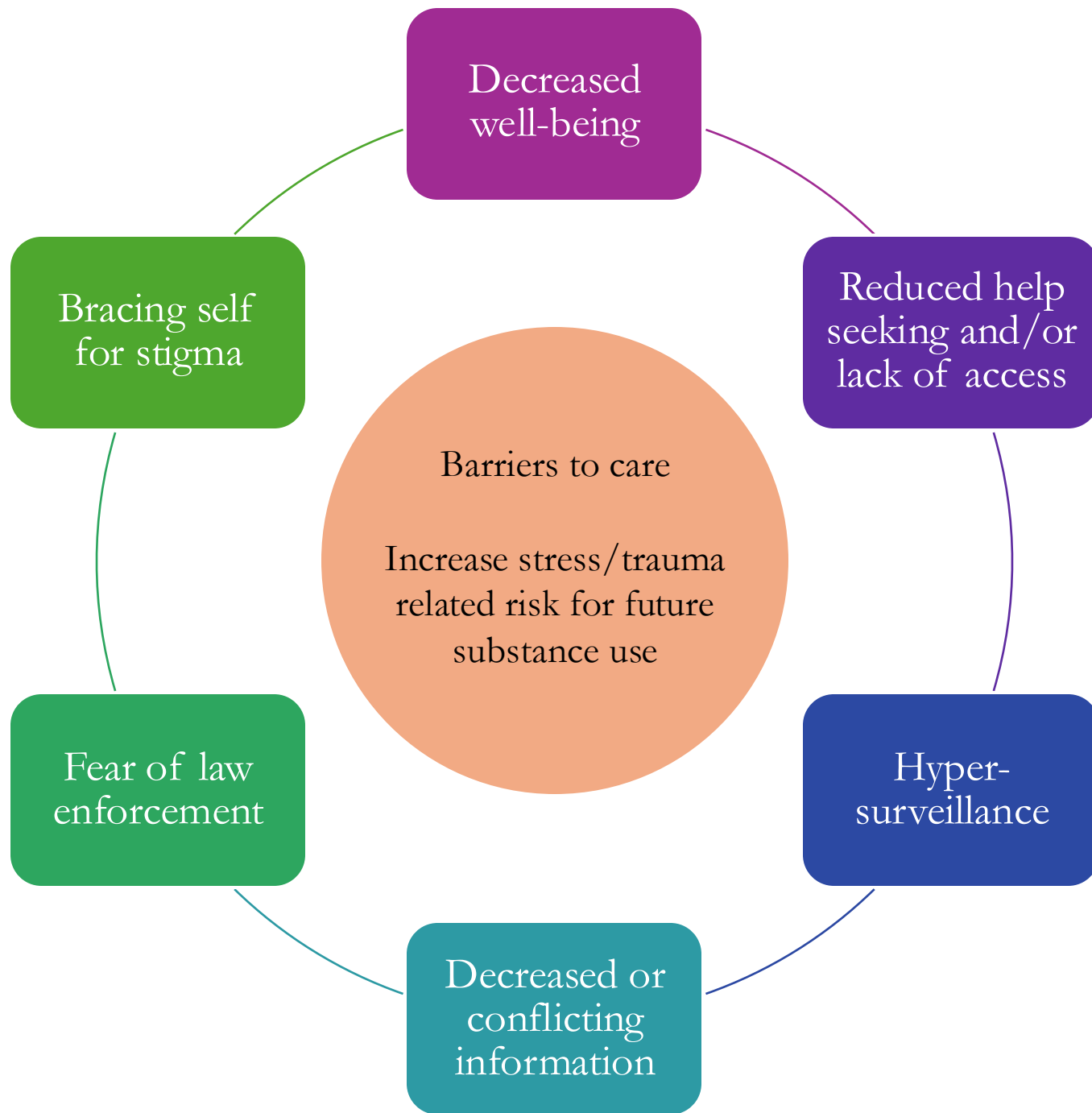
# Impacts of Stigma



## Positive interactions can act as a buffer!

Supportive, nonjudgmental  
relationships can:

- Reduce internalized stigma and shame
- Improve engagement in care and services
- Strengthen resilience and coping skills



# Key Gaps In The Literature

Limited lived-experience-centered research

Lack of interdisciplinary integration

Underrepresentation of:

- Polysubstance exposure
- Incorporating intersectionality and family systems
- Lived experience from
  - Birth fathers
  - Other family members (e.g., siblings, grandparents).
  - Individuals with prenatal substance exposure
  - Longitudinal, long-term impacts

# Summary

Stigma is pervasive and consequential

Shapes experiences across the lifespan

Positive experiences can buffer these effects!

## Practical Applications

- Use non-stigmatizing language
- Lead with empathy and understanding
- Integrate trauma-informed care
- Improve accessibility of services
- Address stigma across systems:
  - Healthcare
  - Education
  - Justice
  - Community



Language  
& Stigma  
Guide

