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Pregnancy, Parenting, And Substance Use: Stigma, Fear and a Call for Improved Messaging to our Families

Marjorie Meyer MD
Professor
Vice Chair, Obstetrics
University of Vermont, Larner College of Medicine
Burlington, Vermont

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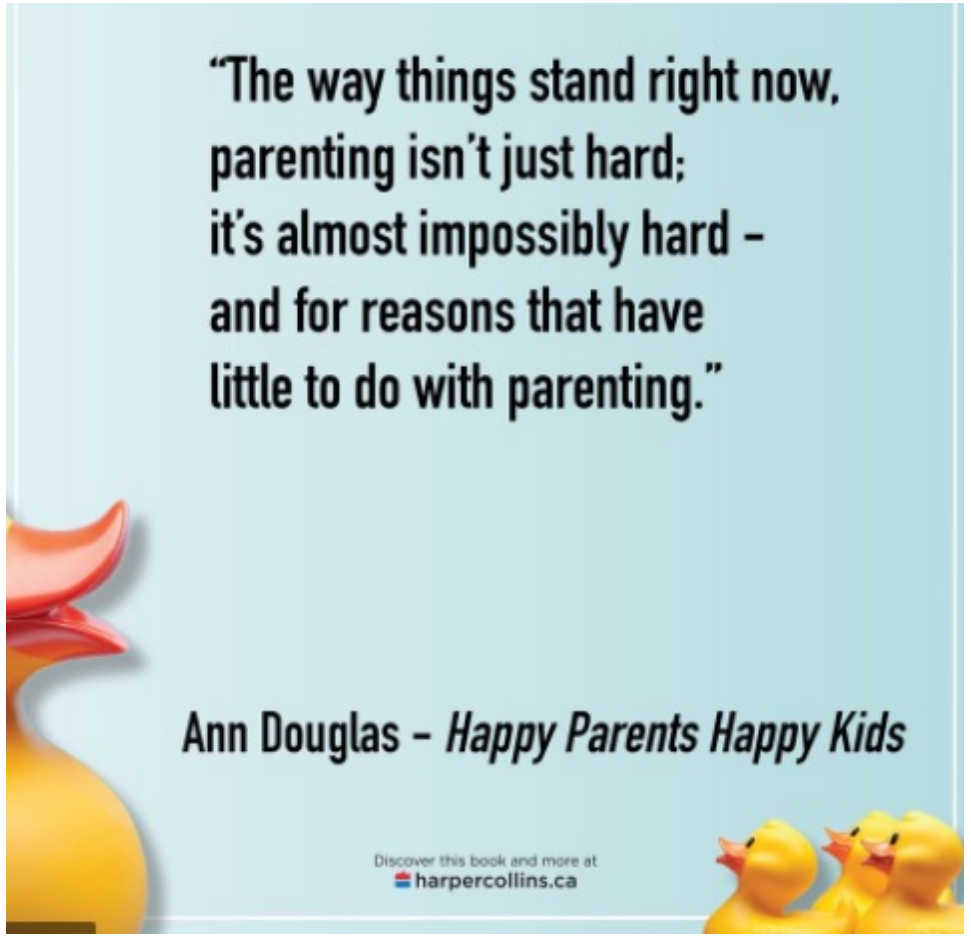
Parenting is hard

YOU'RE FINDING IT HARD BECAUSE IT IS HARD, NOT BECAUSE YOU'RE A BAD PARENT.



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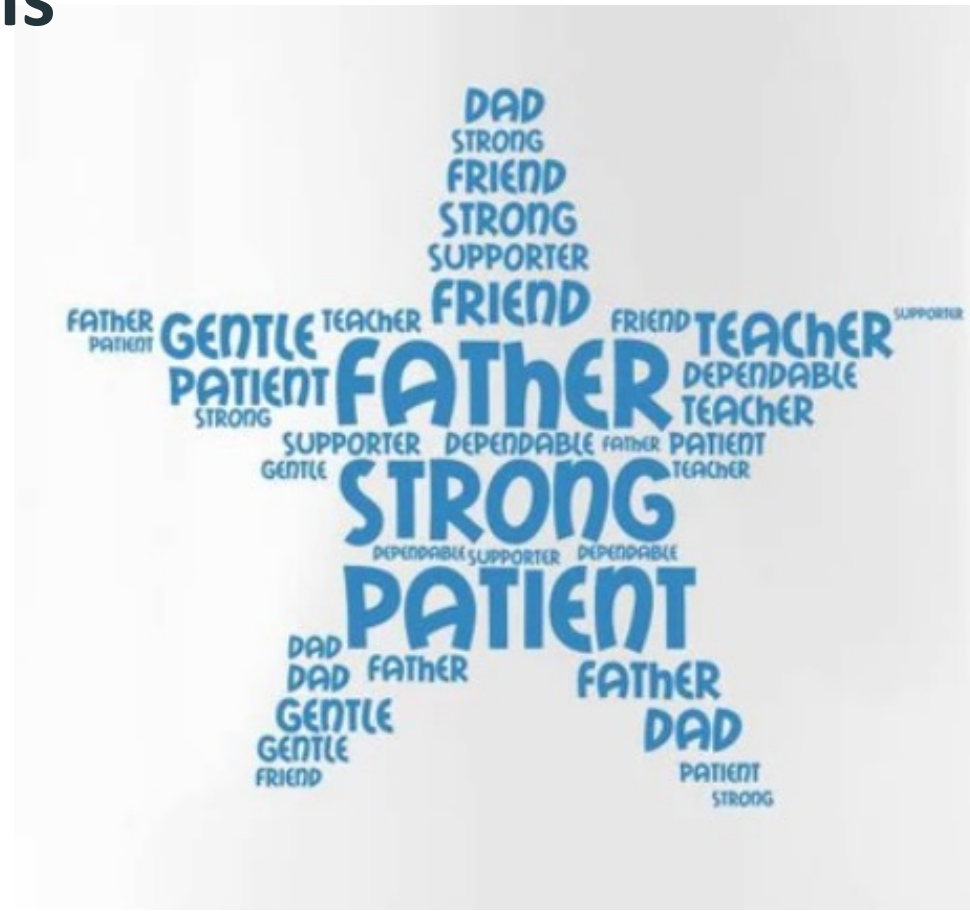
Different words are used to describe Mothers and Fathers: there are pervasive social norms



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Motherhood identity has a lifetime impact

Contents lists available at ScienceDirect

Journal of Substance Abuse Treatment

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"A good mother": Impact of motherhood identity on women's substance use and engagement in treatment across the lifespan

Zoe M. Adams [a], Callie M. Ginapp [a], Carolina R. Price [b], Yilu Qin [c], Lynn M. Madden [b,d], Kimberly Yonkers [e,g], Jaimie P. Meyer [b,f,*]

Most FG participants also expressed **feelings of shame, regret, and guilt** when they could not meet socially constructed expectations of motherhood:

"I missed out on a lot and I have a lot of regrets you know…Because I wasn't a good mother I don't think. I mean, ***they ate, they were clothed, they had shelter****, but still they didn't have time that I should've spent with them, they didn't have my time and they should've. They had seen me sick from the drugs you know. They shouldn't have had to go through that." (FG 1 Participant)*

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Women that lose custody have regrets **even years later**

Separation can result in intergenerational trauma:

The traumatic impact of separation from family persisted into adulthood and was seen as intergenerational.

"So they [my children] can come back to me 18–20 years later looking at me like why did you leave me, why did you give up on me, why didn't you fight for me? Because I have the same question for my mother. Why didn't you come back for me, you were supposed to come back for me after you got out of rehab. What happened? She never came back." (FG 2 Participant)

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Women identified **their children and responsibilities as mothers** as **important motivators** in accessing SUD treatment and in contributing to despair after loss of custody with return to use

"They're both the reason why you cry real hard and the reason why you're struggling. It makes me depressed I don't have my kids but at the same time they're the main reason I go seek treatment. Like I don't want to give up 'cause of them but at the same time I'm devastated that I don't have them. (FG 2 Participant)"

"After I lost my son, and after reality hit that the police weren't gonna give him back—I didn't even know where he was. Once I knew for a fact that I wasn't gonna just be able to pick him up and take him home, that's when I hit rock bottom and, yeah, went to the heroin. (Interview participant)"

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Identity as a mother has a profound impact on how patients view themselves and their recovery from SUD

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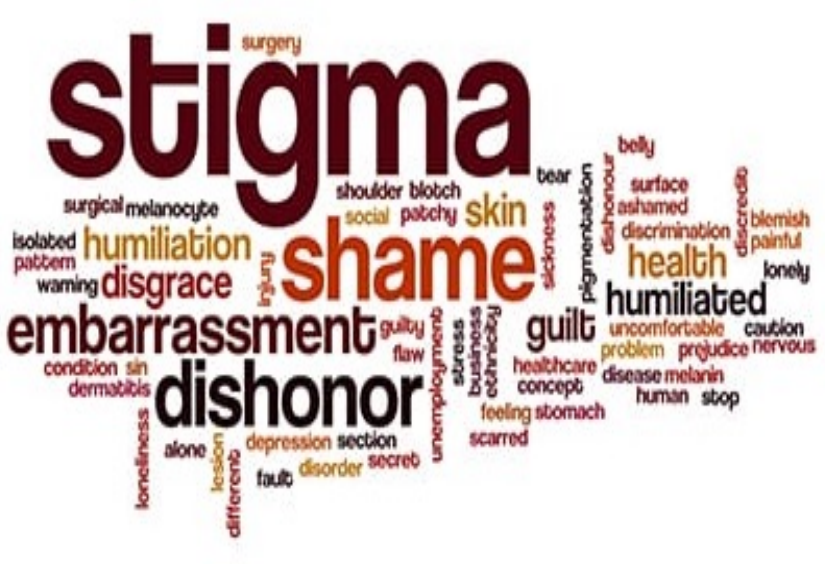
Stigma and Social Acceptance



Goffman: 1963:
Defines stigma as an "attribute that is deeply discrediting" resulting in a ***lack of full social acceptance.***

Attributes could include real or perceived medical conditions, socioeconomic status, and sexual identity; and demographic characteristics such as age, race, and sex

People are socially rewarded when adhering to social norms, and punished when deviating from them.

Using Substance Use Disorder Instead of Substance Abuse (tpoftampa.com)

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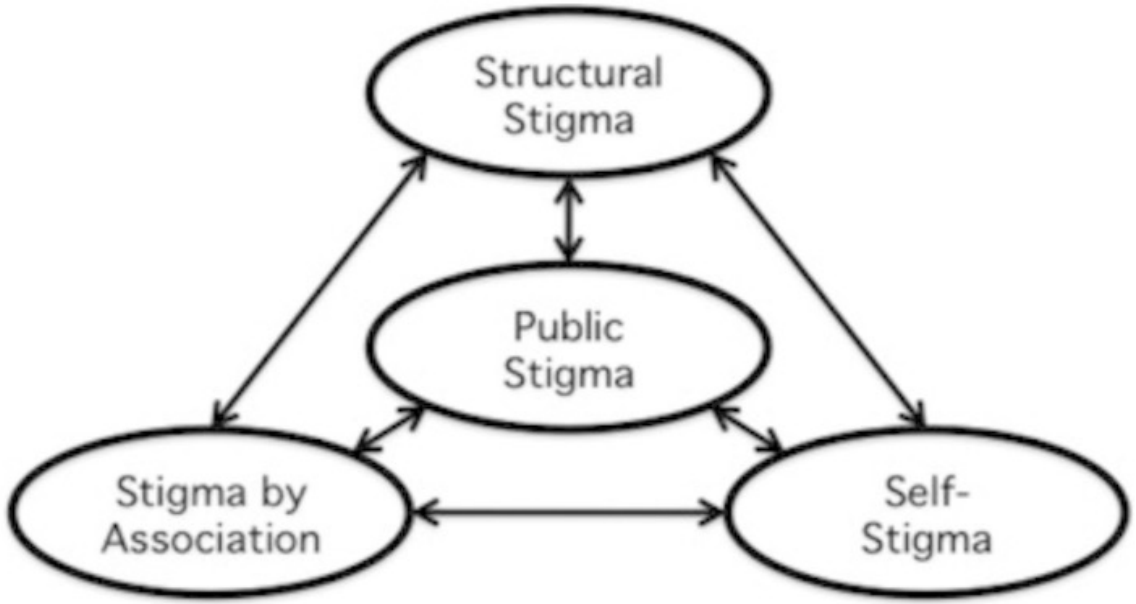

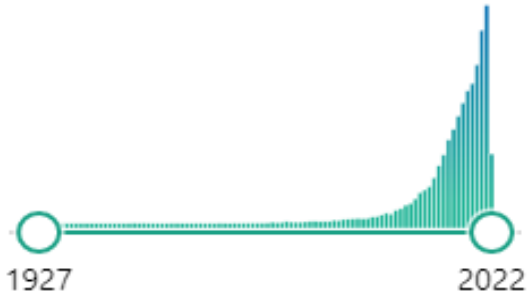

PubMed: Number of articles published by date

Stigma:

Pryor and Reeder's theory (2011): all interrelated:

(1) Public (social) stigma:

- people's social and psychological reactions to someone they perceive to have a stigmatized condition

(2) Self-stigma:

- the social and psychological impact on a person of having a stigmatized condition

(3) Stigma by association:

- social and psychological reactions to people associated with a stigmatized person

(4) Structural stigma:

- the perpetuation and legitimization of stigma by institutions and ideological systems

Present since societies were born (500 BC (1500 BC-500 AD)) (Nature, 2019)

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Society uses stigma to conform the population to social norms *(like motherhood)* and discourage undesired behaviors *(like substance use)*

- Tobacco is an example of denormalization policy that was successful in preventing and reducing tobacco use (and stigmatizing smokers)
- "War on Drugs" an example of denormalization policy that contributed to mass incarceration and bias


Opinions

OPINION: The war on drugs has been a colossal waste

By Pat Dougherty
Updated: February 19, 2022
Published: February 19, 2022

Stigma and substance use disorders: A clinical, research, and advocacy agenda

Valerie A. Earnshaw, Ph.D.
University of Delaware

Am Psychol. Author manuscript; available in PMC 2021 December 01.

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2 major flaws with stigma to enforce a "social norm" re: substances:

- Overemphasizes the role of person control in the initiation of substance use
- Stigma can not prevent people from engaging in behavior they can not control
- Sacrifices the wellbeing of people with SUDs, given that stigma is a barrier to their recovery efforts

Stigma and substance use disorders: A clinical, research, and advocacy agenda

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Where do people with OUD feel stigmatized?

Locations of stigma related to OUD:

- *Hospitals*
- Government Agencies were second

Table 1
Locations where stigma was experienced.

Location	# of focus groups with at least one mention (N = 10)	# of mentions	% of all mentions
Hospital[a]	8	26	29%
Government agency	7	17	19%
Pharmacy	4	14	15%
Workplace	8	12	13%
Doctor's office	5	9	10%
Other[b]	5	6	7%
Recovery program	3	4	4%
Correctional facility	1	3	3%

From *Experiences of stigma among individuals in recovery from opioid use disorder in rural setting: A qualitative analysis*

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Who do people with OUD feel stigmatized by?

Perpetrators of stigma:

- *Pharmacists*
- Family and friends
- Health care professionals

"Pharmacists are nice when you go in to get thyroid meds, but they're not the same when you go in to get your Suboxone. They change and they're not even nice."

Table 2
Perceived perpetrators of stigma.

Perceived perpetrator type	# of focus groups with at least one mention (N = 10)	# of mentions	% of all mentions
Pharmacists or pharmacy techs	4	10	18%
Other	5	9	16%
Family and friends	4	9	16%
Doctors	6	7	13%
Law enforcement	6	7	13%
Medical support staff	4	7	13%
Nurses	3	6	11%

From *Experiences of stigma among individuals in recovery from opioid use disorder in rural setting: A qualitative analysis*

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The Language of Stigma: Words Matter

US studies: Disorder first language linked with more willful misconduct, greater social threat, more deserving of punishment compared to Person First language.

Disorder First Language

Betty is a 38-year-old alcoholic. She is married but sometimes has issues with her partner. She experiences a lot of responsibilities at home. It is not the first the that Betty is an alcoholic, she has had treatment before. Now, she drinks, at least half but usually a whole, bottle of wine daily. The general practioner has referred her to addiction treatment again.

Person First Language

Betty is 38 years old and has an alcohol addiction. She is married but sometimes has issues with her partner. She experiences a lot of responsibilities at home. It is not the first time that Betty has an alcohol addiction, she has had treatment before. Now, she drinks, at least half but usually a whole, bottle of wine daily. The general practioner has referred her to addiction treatment again.

(Netherlands: no differences in health care workers with any of these examples)

Kelly, 2010

Health Soc Care Community. 2020;28:1504–1513.

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The Language of Stigma: Words Matter

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Victim Language

Betty is 38 years old and suffers from an alcohol addiction. He is married but sometimes has issues with her partner. She experiences a lot of responsibilities at home. It is not the first time that Betty suffers from an alcohol addiction, she has had treatment before. Now, she drinks, at least half but usually a whole, bottle of wine daily. The general practitioner has referred her to addiction treatment again.

Recovery Language

Betty is 38 years old and is in recovery from an alcohol addiction. She is married but sometimes has issues with her partner. She experiences a lot of responsibilities at home. It is not the first time that Betty is in recovery from an alcohol addiction, she has had treatment before. Now, she drinks, at least half but usually a whole, bottle of wine daily. The general practioner has referred her to addiction treatment again.

(Netherlands: no differences in health care workers with any of these examples)

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Stigma as a Barrier to Treatment

- Do women feel stigma is a barrier to treatment more than men?
- Do parents (regardless of gender) feel that stigma is a barrier to treatment?

From *Stigma as a Barrier to Substance Abuse Treatment Among Those With Unmet Need: An Analysis of Parenthood and Marital Status*

Stigma is a barrier to SUD treatment in women more so than men:

Hypothesis 1:

- Among those with unmet need for SU treatment, we find that **women are more likely than men to report stigma as a barrier to treatment** (26.3% of women and 20.2% of men, $p < .01$).
- Women are more likely to be parents compared with men (44.9% of women are parents compared with 36.9% of men $p < .01$)

Hypothesis 2, 3, 4:

- No significant differences in stigma by parenthood status
- No significant between mothers and nonmothers, between fathers and nonfathers
- No significant differences in stigma by marital status

J Fam Issues. 2018 January ; 39(1): 3–27. doi:10.1177/0192513X15581659.

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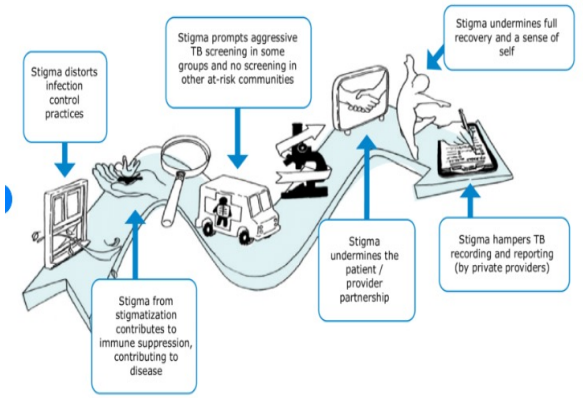
Types of stigma and how different types of stigma are barriers to care for pregnant and parenting women

Individual level of stigma



Institutional level of stigma

Interpersonal level of stigma

Population level of stigma

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Stigma creates barriers to harm reduction and child welfare services

Individual level of stigma

Person who experiences individual stigma

- Unfair treatment
- Internalized stigma
- Anticipated stigma that inhibits accessing support

Barriers to harm reduction:

- Fear or mistrust of the child welfare system
- Internalized stigma (limiting self-esteem/ capacity to seek support, feel like they should not parent)
- Fear of failing to reduce substance use
- Trauma history
- Previous substance use treatment attempts
- Fear of prenatal care
- Fear of prosecution due to substance use

Health Soc Care Community. 2021;29:589–601.

REVIEW ARTICLE

Social Care in the community

Examining barriers to harm reduction and child welfar
services for pregnant women and mothers who use su

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Stigma creates barriers to harm reduction and child welfare services

Interpersonal level of stigma

From friends, family, service providers, social/work networks

- derogatory language
- intrusive questions
- hate crimes

Barriers to harm reduction:

- Partner's/family influence on treatment access
- Stigma (substance use, mothering, pregnancy)
- Having to restore trust and rebuilding relationships with children
- Belief from providers that substance use results in an inability to parent
- Lack of trusting and respectful relationships with service providers
- External expressions of trauma

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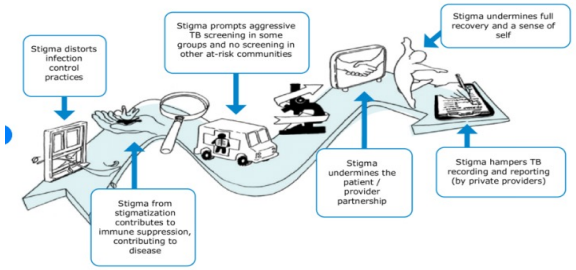
Stigma creates barriers to harm reduction and child welfare services

Institutional level of stigma

Organizational

- Being made to feel less than
- Longer wait times
- Non-inclusive
- Physical environment institutional policies that cause harm)



Barriers to harm reduction include:

- Lack of coordination across service High expectations placed on women who use substances to meet an unrealistic number of tasks (including administrative tasks)
- Institutional stigma due to pregnancy or mothering status
- Impact of child welfare system (e.g. distracting mothers from reducing their substance use or increased substance use after apprehension)
- Reunification timelines (mothers' readiness for reunification in relation to how long a child can be in foster care before parental rates are terminated)
- Lack of family-centered programming

Health Soc Care Community. 2021;29:589–601.

REVIEW ARTICLE

Examining barriers to harm reductio
services for pregnant women and m

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Stigma creates barriers to harm reduction and child welfare services

Population level of stigma

Mass media, policies, law

- Stereotypes
- Negative portrayals in media
- Discriminatory policies and laws
- Inadequate legal protections

Barriers to harm reduction:

- Discrimination due to mental health status
- Discrimination due to substance use
- Punitive approaches, including prenatal child welfare laws and apprehensions at birth
- Discrimination due to intergenerational involvement with child welfare
- Historical trauma

Health Soc Care Community. 2021;29:589–601.

REVIEW ARTICLE

Examining barriers to harr
services for pregnant won

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What stigma, pregnancy, and parenting look like through the rural lens

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Research: Association of Pregnancy and Insurance Status With Treatment Access for Opioid Use Disorder

- "Secret Shopper": people called clinics with a script about needing OUD treatment: all women, half said they were pregnant
- Called outpatient clinics that provide buprenorphine and methadone (randomly selected from publicly available treatment lists in 10 US states, many rural)
- Pregnant vs non-pregnant woman and private vs public insurance assigned randomly to callers to create unique patient profiles.
- Asked to get an initial appointment

Overall: Fewer pregnant women could get an appointment (61%) compared to not pregnant (74%)

JAMA Network Open. 2020;3(8):e2013456. doi:10.1001/jamanetworkopen.2020.13456

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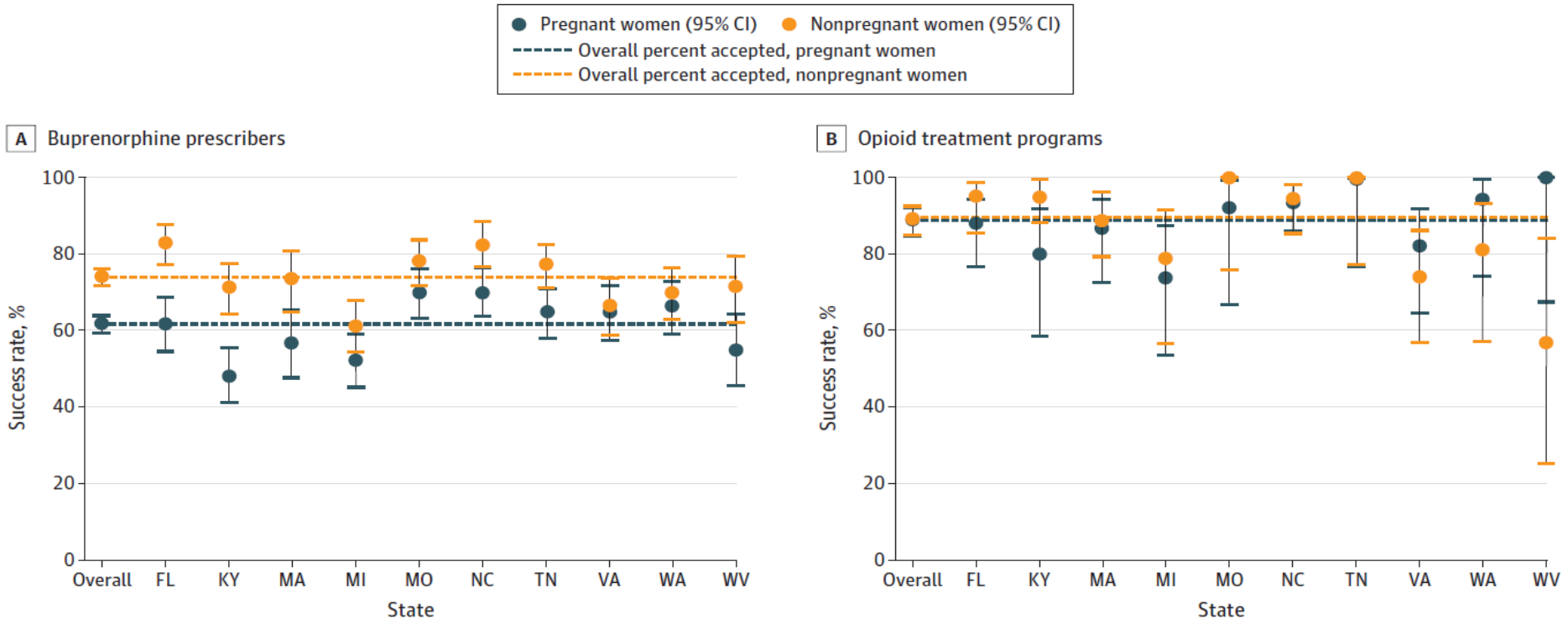
Research: Association of Pregnancy and Insurance Status With Treatment Access for Opioid Use Disorder

Figure 1. Ability of Pregnant and Nonpregnant Callers to Obtain an Appointment for Treatment Among Buprenorphine-Waivered Prescribers and Opioid Treatment Programs



Ability to obtain an appointment with insurance or cash payment.

- Office based buprenorphine access was more limited than opioid treatment programs
- Women that stated they were pregnant had less access to buprenorphine compared to women that did not state they were pregnant

JAMA Network Open. 2020;3(8):e2013456. doi:10.1001/jamanetworkopen.2020.13456

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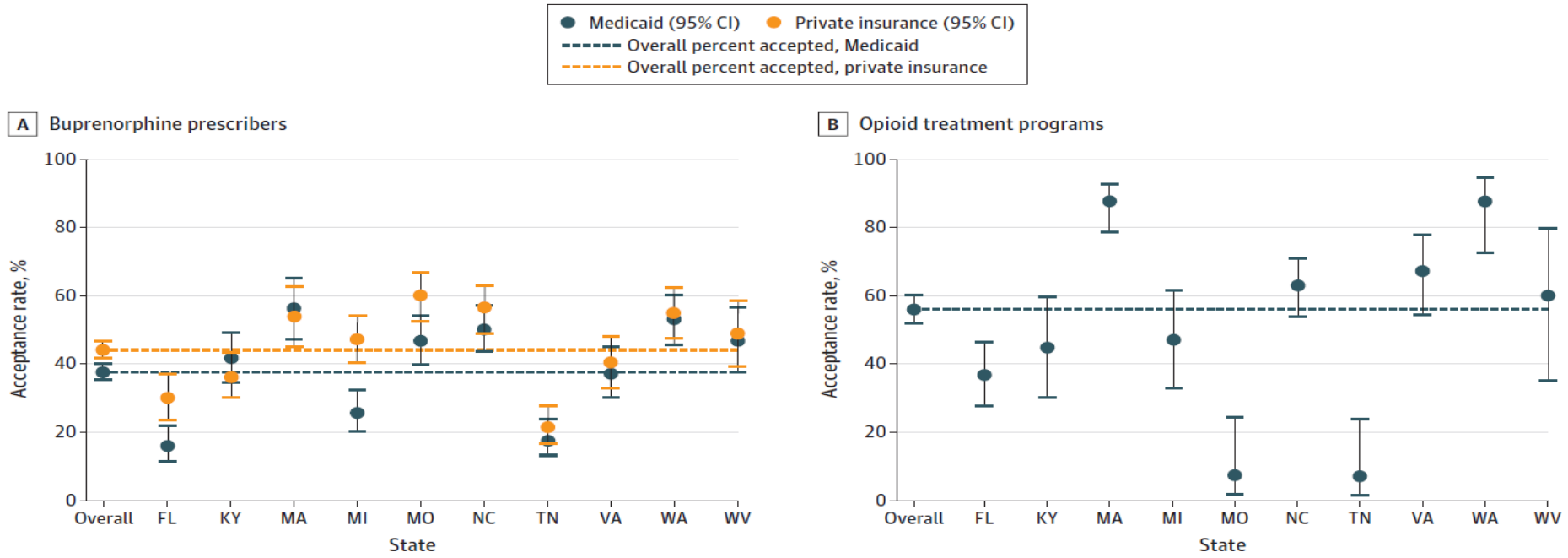
Research: Association of Pregnancy and Insurance Status With Treatment Access for Opioid Use Disorder

Figure 2. Acceptance of Medicaid or Private Insurance for Treatment Among Buprenorphine-Waivered Prescribers and Acceptance of Medicaid for Treatment Among Opioid Treatment Programs



JAMA Network Open. 2020;3(8):e2013456. doi:10.1001/jamanetworkopen.2020.13456 August 14, 2020 7/12

Insurance/Cost is a barrier:

26.1% of buprenorphine clinics and 32.5% of OTP granted only cash only appointments

Cash cost:

$250 buprenorphine $34 methadone

JAMA Network Open. 2020;3(8):e2013456. doi:10.1001/jamanetworkopen.2020.13456

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Research: Barriers to accessing treatment for pregnant women with opioid use disorder in Appalachian states

Survey of OTPs and buprenorphine providers (n=113)

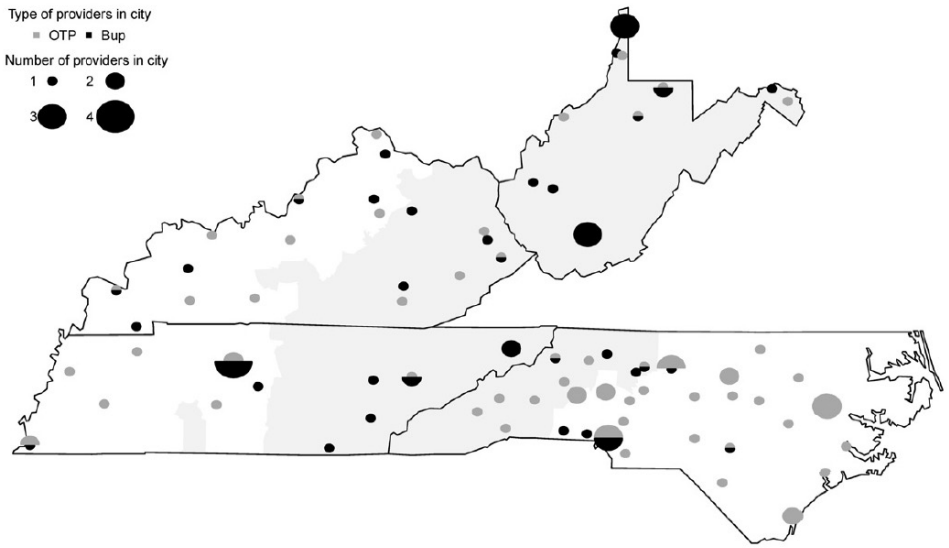

Figure 1. Geographic distribution of surveyed providers. Appalachian counties shaded in gray. OTP: opioid treatment program; Bup: outpatient buprenorphine provider.

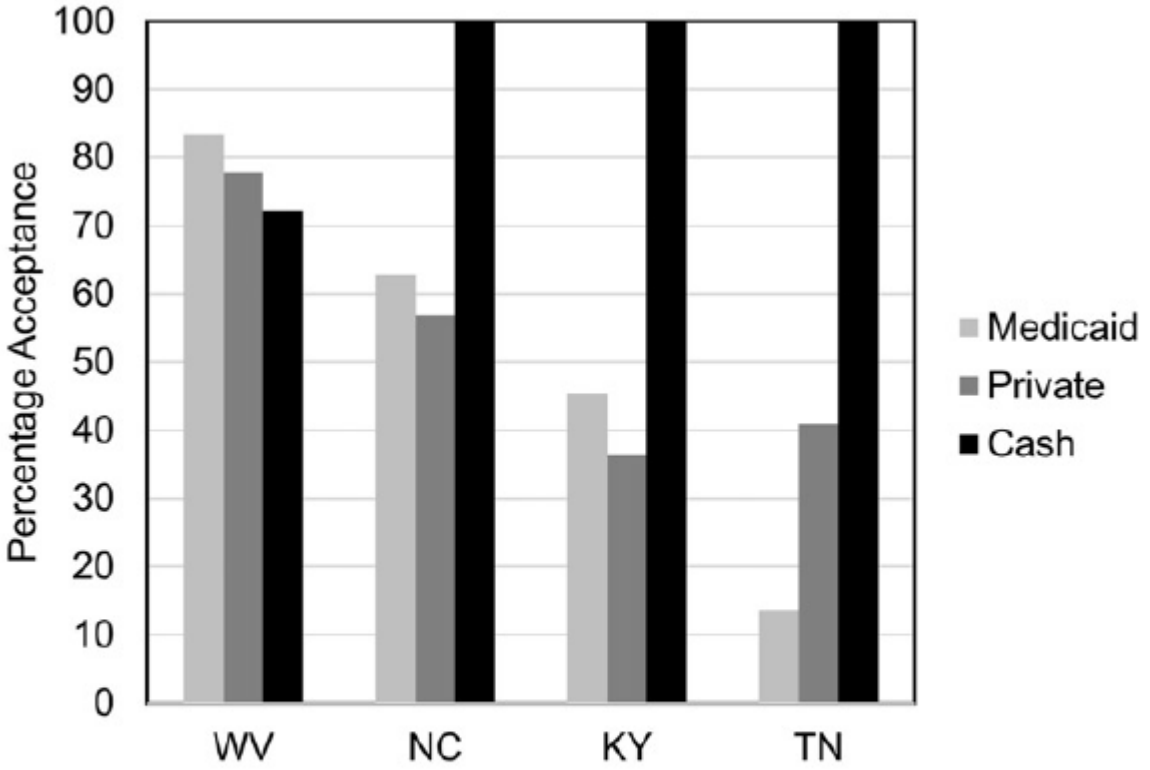

Figure 2. Surveyed providers accepting Medicaid, private insurance, or cash payments for treatment of opioid use disorder: Kentucky, North Carolina, Tennessee and West Virginia. Medicaid: $p < .01$; private insurance: $p = .04$; cash payments: $p < .01$.

SUBSTANCE ABUSE
2019, VOL. 40, NO. 3, 356–362
https://doi.org/10.1080/08897077.2018.1488336

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Survey of OTPs and buprenorphine providers (n=113)

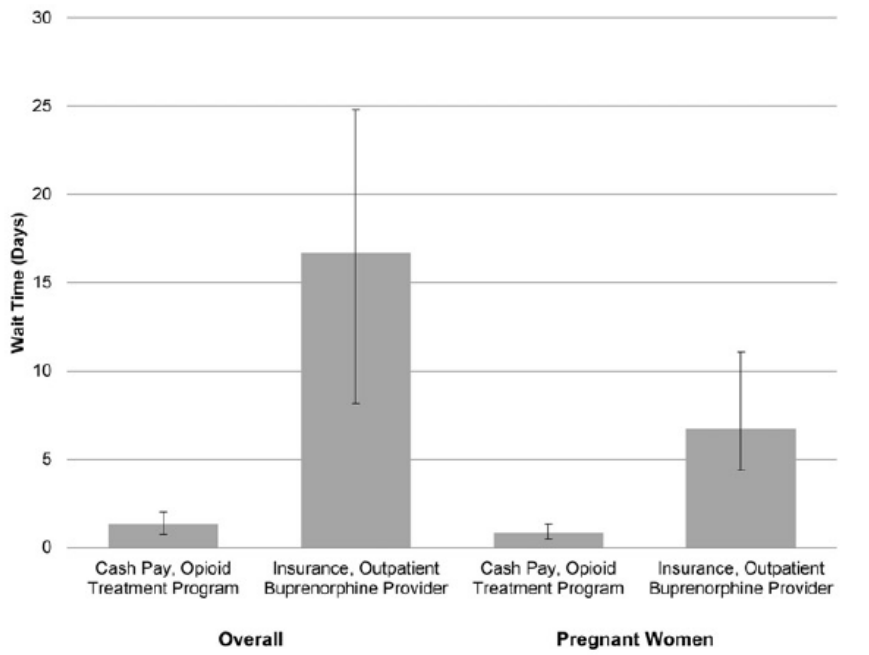

Figure 3. Predicted wait time in days by insurance and provider type. Applying models, accounting for insurance, provider type and state.

	OTP	Buprenorphine
Accept any patient	97%	83%
Accept pregnant patient	91%	53%
Wait time (all), days	1 (0-3)	7 (2-14)
Wait time (pregnant), days	0 (0-1)	3.5 (1-7)
Cash pay, weekly	$49-160	$35-245

- **A large number of MOUD services do not take pregnant patients**
- **A large number do not take insurance**
- **For pregnancy, having insurance was a barrier to getting into buprenorphine treatment (Medicaid not accepted)**

SUBSTANCE ABUSE
2019, VOL. 40, NO. 3, 356–362
https://doi.org/10.1080/08897077.2018.1488336

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Research: Treatment access for opioid use disorder in pregnancy among rural and American Indian communities

Unannounced standardized patient, pregnant (secret shopper): rural Utah

- Only 27% of clinics on the SAMHSA site had buprenorphine treatment available (n=9)
- Low level of comfort providing OUD treatment to pregnant individuals (*n* = 5, 17.9%)
- Although referrals offered, travel distances were long for rural patients

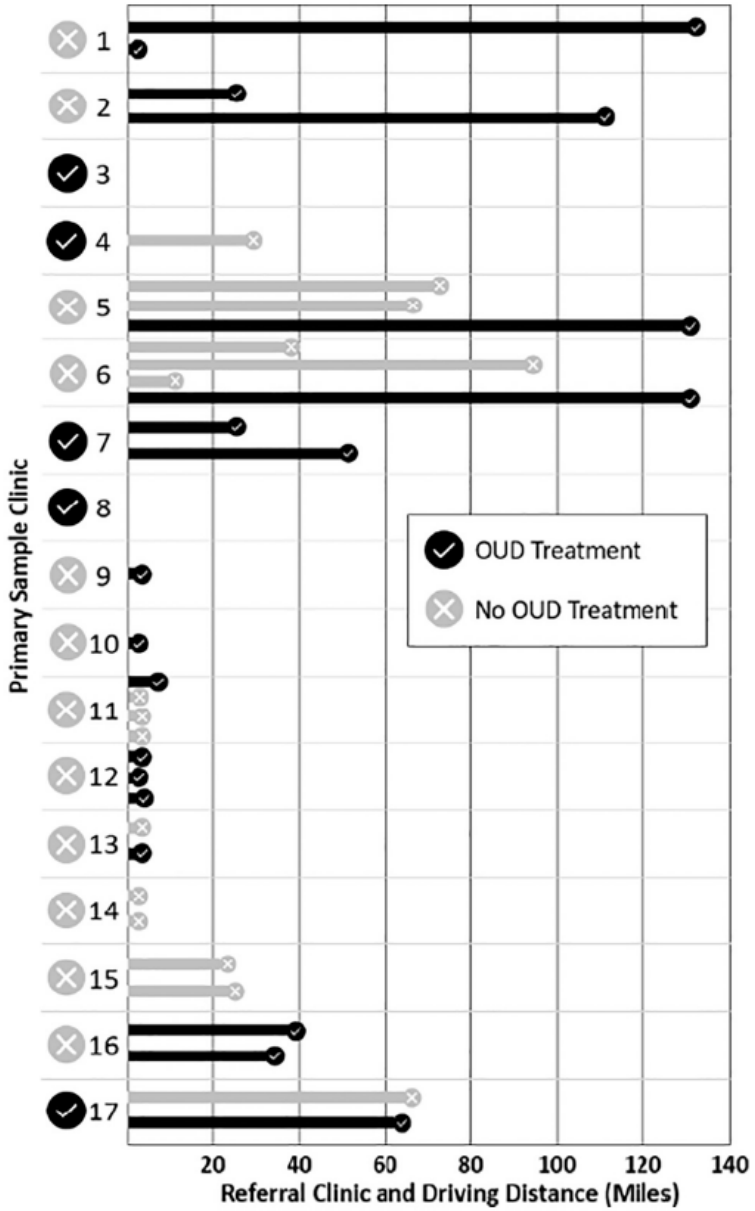

Fig. 1. Referral relationships between primary sites and referral sites.
Notes: Primary site referral data for both white and AI profiles are included. A clinic was marked as offering treatment if treatment was offered for either profile.

Journal of Substance Abuse Treatment 136 (2022) 108685

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Research: Pregnant women and substance use: fear, stigma, and barriers to care

Interviews were conducted in Missouri investigating barriers to care for pregnant women with opioid use disorder

- **Fear** of Detection
- **Social Isolation** and denial of pregnancy
- **Other Barriers** including treatment ambivalence and insufficient follow up after treatment

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Research: "The elephant in the room;" a qualitative study of perinatal fears in opioid use disorder treatment in Southern Appalachia

Fear of Social Services

- Fear of legal ramifications of substance use treatment, specifically MOUD would result in automatic removal of their child
- Legal issues of OUD treatment in pregnancy poorly understood re: reporting and Social Services involvement
- There was confusion and distrust related to reporting in general

> *"… I was scared coming here, because I thought it's gonna be immediate Social Services [involvement]. I [thought I] was never gonna see my child again… I never heard of this program, until the day I admitted I needed help, and that day was terrifying for me, because I'd had no idea what was gonna happen… people had told me [seeking treatment would mean immediate removal]…"*

> *I can see why a lot of people are nervous about Social Services. I've had a lot of people say like, 'well since you're you know—in the [buprenorphine] clinic, they're going to automatically –Social Services is automatically going to come to see you.'*

Prenatal interviews n=18
Post-partum interviews n=11

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Research: "The elephant in the room;" a qualitative study of perinatal fears in opioid use disorder treatment in Southern Appalachia

Introduced a *Perinatal Substance Exposure Educator* to prepare for delivery and reduce fear of Social Services:

- Reviews prenatally what to expect at delivery and afterward
- Explains the way reporting laws work
- Explains NAS/NOWS

> *"My plan is set up for Social Services prevention. I don't currently have Social Services involved in my life, but considering my [substance use] history and the fact that I'm on [MAT],[I know] Social Services is gonna come visit me at the hospital. So, it's taking steps to prevent that and to help me with legal things that I have going on right now."*

> *"… the [Perinatal Substance Educator] walked me through, 'this is how [it's gonna happen]…how the steps would play out…" it went exactly how she said it would."*

Prenatal interviews n=18
Post-partum interviews n=11

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Research: In their own words: a qualitative study of factors promoting resilience and recovery among postpartum women with opioid use disorders

- Themes for resilience and recovery:
  - Individual: motivation, self-efficacy
  - Family/Household: relationships
  - Social Community level: Peer support
  - Social policy level: transportation, insurance

Interviews n=10

Goodman *et al. BMC Pregnancy and Childbirth* (2020) 20:178
https://doi.org/10.1186/s12884-020-02872-5

It is not a coincidence that the themes of resilience and recovery promotion match those of stigma

Stigma

Individual level of stigma:
How people experience stigma in everyday life

Interpersonal level of stigma:
How relationships and interactions with family, friends, and providers can be stigmatizing-includes communication and language

Institutional level of stigma:
Social services, hospitals, and community organizations can have policies that create harm and barriers (do not treat pregnancy, no child accommodation, transportation)

Population level of stigma:
Punitive laws (incarceration for SUD in pregnancy)
Child Welfare reporting

Resilience and Recovery

Themes for resilience and recovery:

- Individual: motivation, self-efficacy
- Family/Household: relationships
- Social Community level: Peer support
- Social policy level: transportation, insurance

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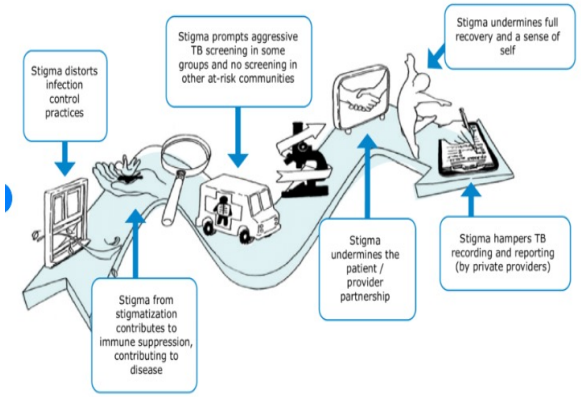
Individual level of stigma:
How people experience stigma in everyday life



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Social services, hospitals, and community organizations can have policies that create harm and barriers (do not treat pregnancy, no child accommodation, transportation)

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How relationships and interactions with family, friends, and providers can be stigmatizing-includes communication and language

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Major stigma and barrier to treatment that we can address: Fear

Our patients with substance use disorder are **afraid of us** (the health care system and supports such as child welfare), **do not know what to expect**, and as with almost all mothers, are **afraid of separation** from their newborn or other children. Our child protection system is both motivator and can cause sufficient stress to return to use.

Involvement of CPS as both a barrier to substance use treatment access and a reason for relapse:

"I was more or less scared of going [to treatment] because I didn't want [CPS] to find out right then and there" (FG 2 Participant).

When you're trying to hide your use from [CPS]…Like I didn't want anybody to know I relapsed this time, I probably would have gotten help ya know sooner. (FG 2 Participant)

Working with CPS to regain custody of children also proved to be stressful for some participants. The stress from CPS's added demands compounded the trauma from family separation:

"[Drugs] basically ruined my life…Because I don't have what I want the most…what I want the most is my kids but I can't get it, and it's like [CPS] is just dangling my kids in my face and [CPS] is like pushing me to relapse and I realize they're pushing me to do a lot of things but I can't do it." (FG 2 Participant)

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Institutional level of stigma:

Barriers to harm reduction:

- **Lack of coordination across service High expectations placed on women who use substances to meet an unrealistic number of tasks (including administrative tasks)**
- Institutional stigma due to low socioeconomic status or interpersonal resources (i.e., housing and food)
- **Institutional stigma due to pregnancy or mothering status**
- Lack of outreach/ability to access harm reduction and treatment programs
- Lack of gender-and trauma-informed programming
- Geographic and transportation barriers to visitation (particularly in relation to substance use treatment programs)
- **Impact of child welfare system (e.g. distracting mothers from reducing their substance use or increased substance use after apprehension)**
- Proof of treatment completion and abstinence from substances
- Reunification timelines (mothers' readiness for reunification in relation to how long a child can be in foster care before parental rates are terminated)
- Lack of financial support for programs (including allied services)
- Wait times to access substance use services
- Lack of family-centered programming
- Lack of information sharing (with women and across staff)
- Staff turnover
- Insurance acceptability
- Different perceptions of the impact of substance use across fields
- Institutional barriers due to use of methadone maintenance

Of all the levels of control, we collectively can have the most impact on institutional stigma:

- How our practices work
- How our hospitals work
- How our health systems work (soft of)
- How our social supports work (sort of)

Example:

Preparation for delivery and reduction fear of Social Services using a Perinatal Substance Exposure Educator:

- Reviews prenatally what to expect at delivery and afterward
- Explains the way reporting laws work
- Explains NAS/NOWS

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Research: Effect of Exposure to Visual Campaigns and Narrative Vignettes on Addiction Stigma Among Health Care Professionals: A Randomized Clinical Trial

- *Words Matter* emphasized the harm of stigmatizing language
- *Medication Treatment Works* focused on the effectiveness of medications approved by FDA for the treatment of OUD.
- Message frames were communicated through either a visual campaign alone or:
  - a visual campaign in combination with a written narrative ***vignette*** from the perspective of a simulated patient with OUD, a clinician, or a health care system administrator

Words Matter and Medication Treatment Works alone:
No difference

Words Matter and Medication Treatment Works with patient vignette:
When patient vignette was included results were improved with less stigma

Medication Treatment Works and patient vignette:
Improved marry, neighbor, warmth

Any paired with clinician vignette:
no difference

SAY THIS	NOT THAT
Person with a substance use disorder	Addict, junkie, druggie
Person living in recovery	Ex-addict
Person living with an addiction	Battling/suffering from an addiction
Person arrested for drug violation	Drug offender
Chooses not to at this point	Non-compliant/bombed out
Medication is a treatment tool	Medication is a crutch
Had a setback	Relapsed
Maintained recovery	Stayed clean
Positive drug screen	Dirty drug screen

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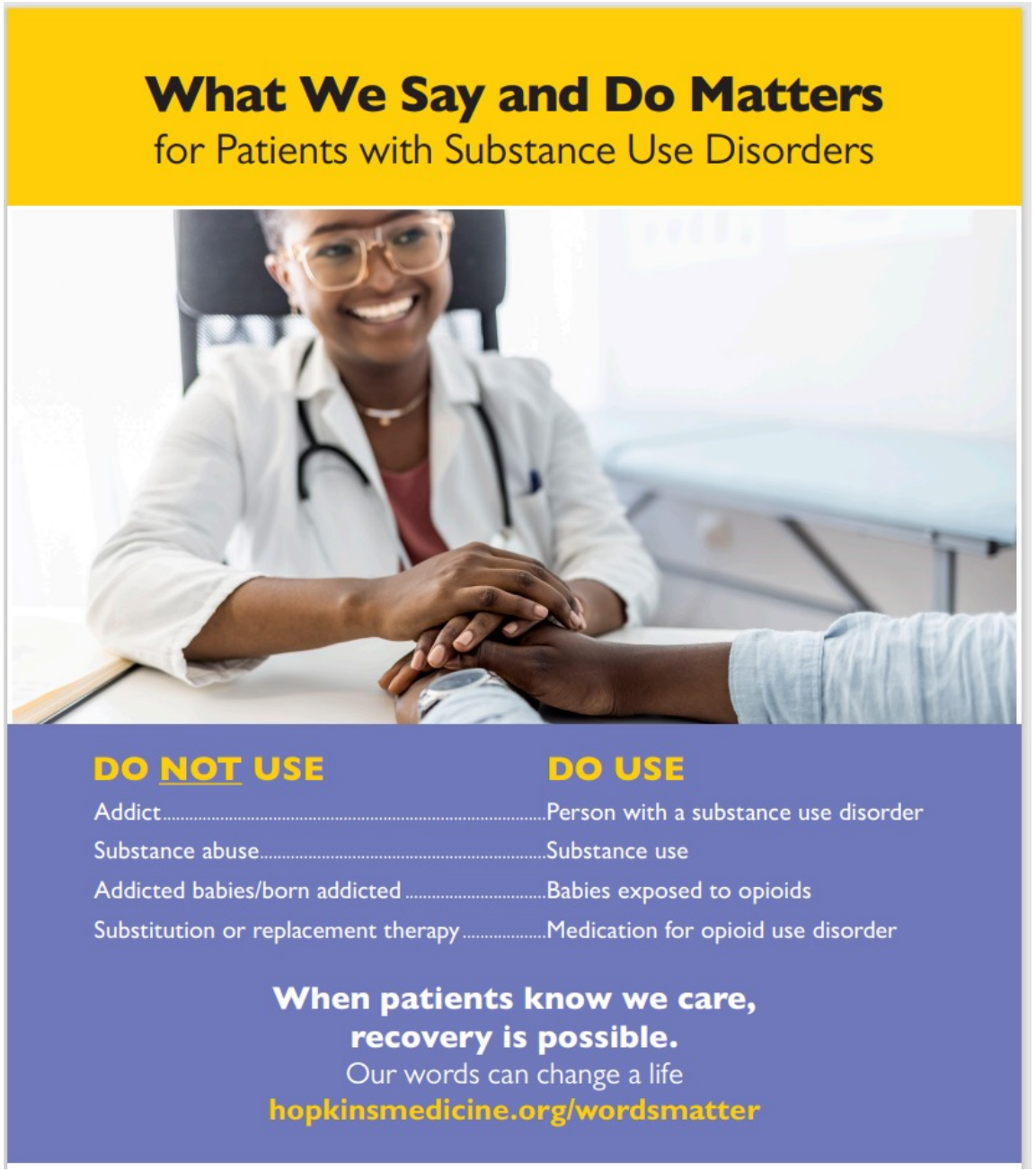
One participant described how Neonatal Abstinence Syndrome scoring negatively affected how clinicians perceived them during their first birth at a hospital:

"[The] first time was hell. […] I felt so judged and cried every day. [The] second time I was here my child did not get scored and my stay was a pleasure."



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Participants described unwelcome interactions with pharmacists when picking up prescriptions for MAT:

"Sometimes I feel like I get a weird look picking up prescriptions for Suboxone."

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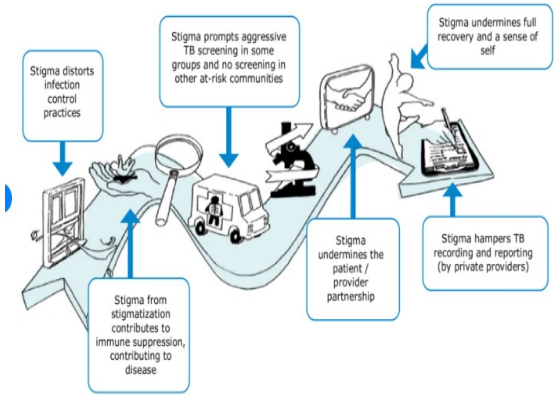
Individual level of stigma:
Use language with care

Institutional level of stigma:

- Stigma training and education for all providers
- Prepare patients for admission or health care interactions (to make sure they know what to expect)
- Make sure patients know what to expect with Child Protection and build community trust between services and patients



Interpersonal level of stigma:
Educate families and support people

Population level of stigma:

- Advocate to repeal laws that punish patients for treatment in pregnancy
- Encourage legal approaches that foster trust

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If you or anyone you know has concerns treating a pregnant person, please email:
marjorie.meyer@uvm.edu

Learn more: UVMCORA.ORG | Contact us: CORA@uvm.edu

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SOC 331: Foundations of Sociological Theory on WordPress.com