Bixby Center for Global Reproductive Health

UCSF University of California San Francisco

How can we eliminate congenital syphilis in the context of a broken reproductive healthcare system?

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Disclosures

None

Outline

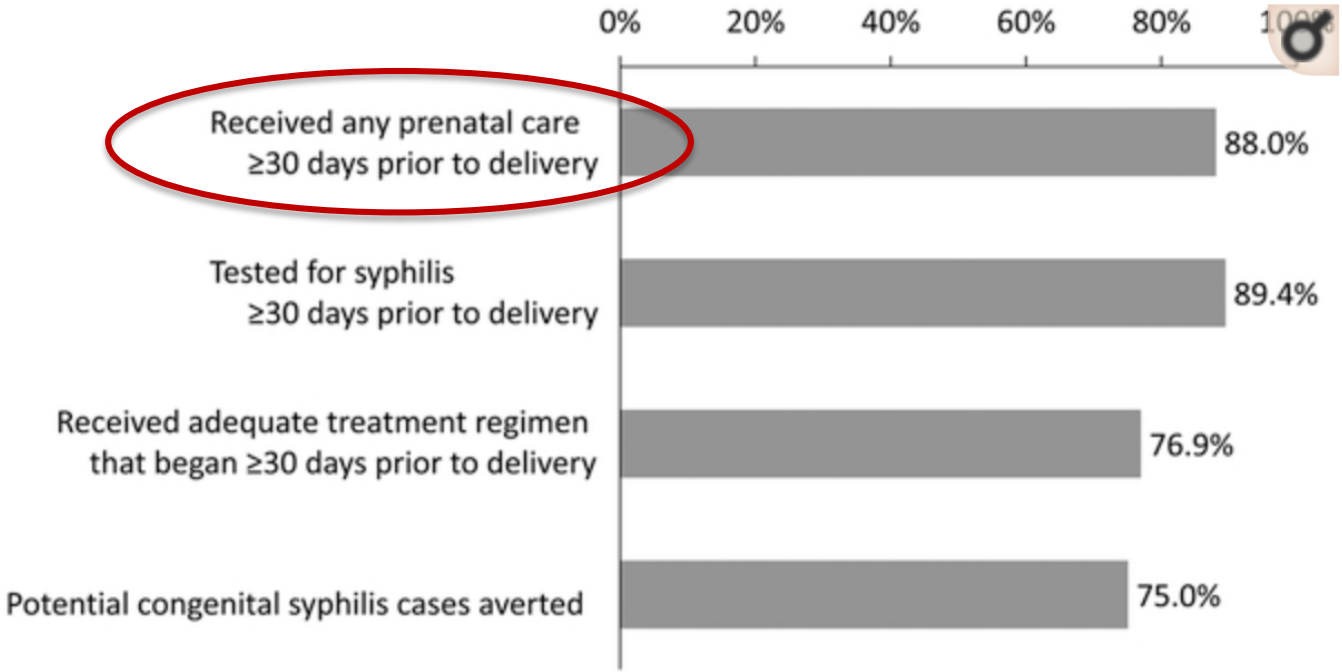
Congenital syphilis cases demonstrate we have a broken reproductive healthcare system

What is known (and unknown) about the care experiences of people facing significant barriers to pregnancy care

How does syphilis screening/treatment fit into this context?

Providing healthcare services, including syphilis screening/treatment, to women facing significant barriers to care

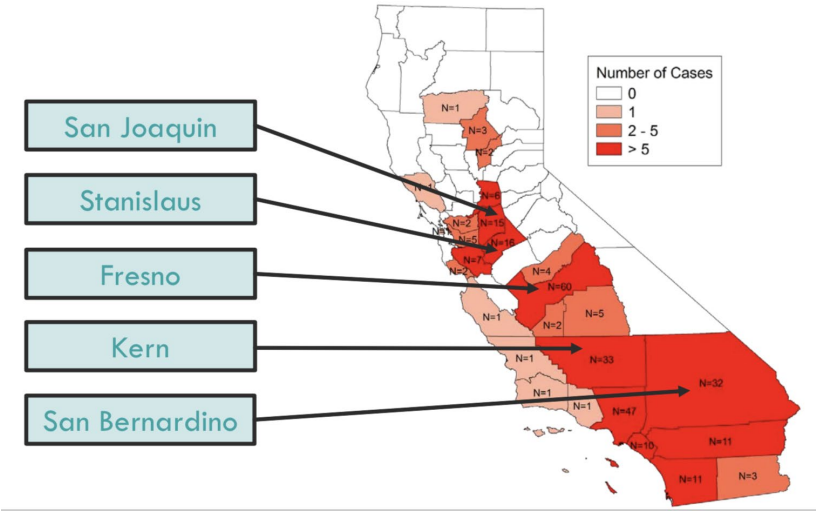
Congenital syphilis prevention cascade

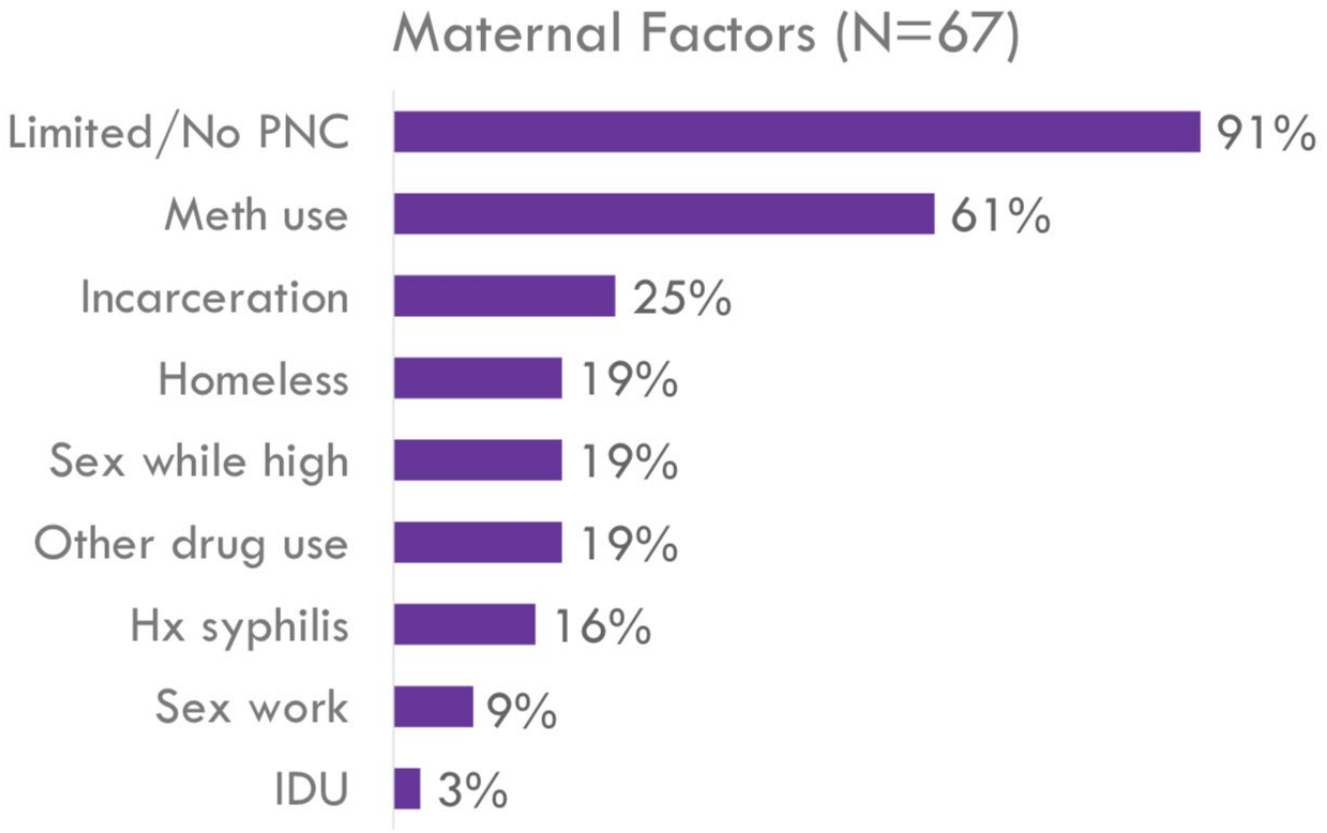


Estimated proportion of pregnant women with syphilis (n = 2508) who received congenital syphilis prevention services and estimated proportion of potential congenital syphilis cases prevented, United States, 2016.

Kidd et al. STD 2018.

Characteristics of mothers with congenital syphilis (CS) cases (N=67) in 5 counties, 2017





Slide courtesy of Ashley Dockter, CA DPH

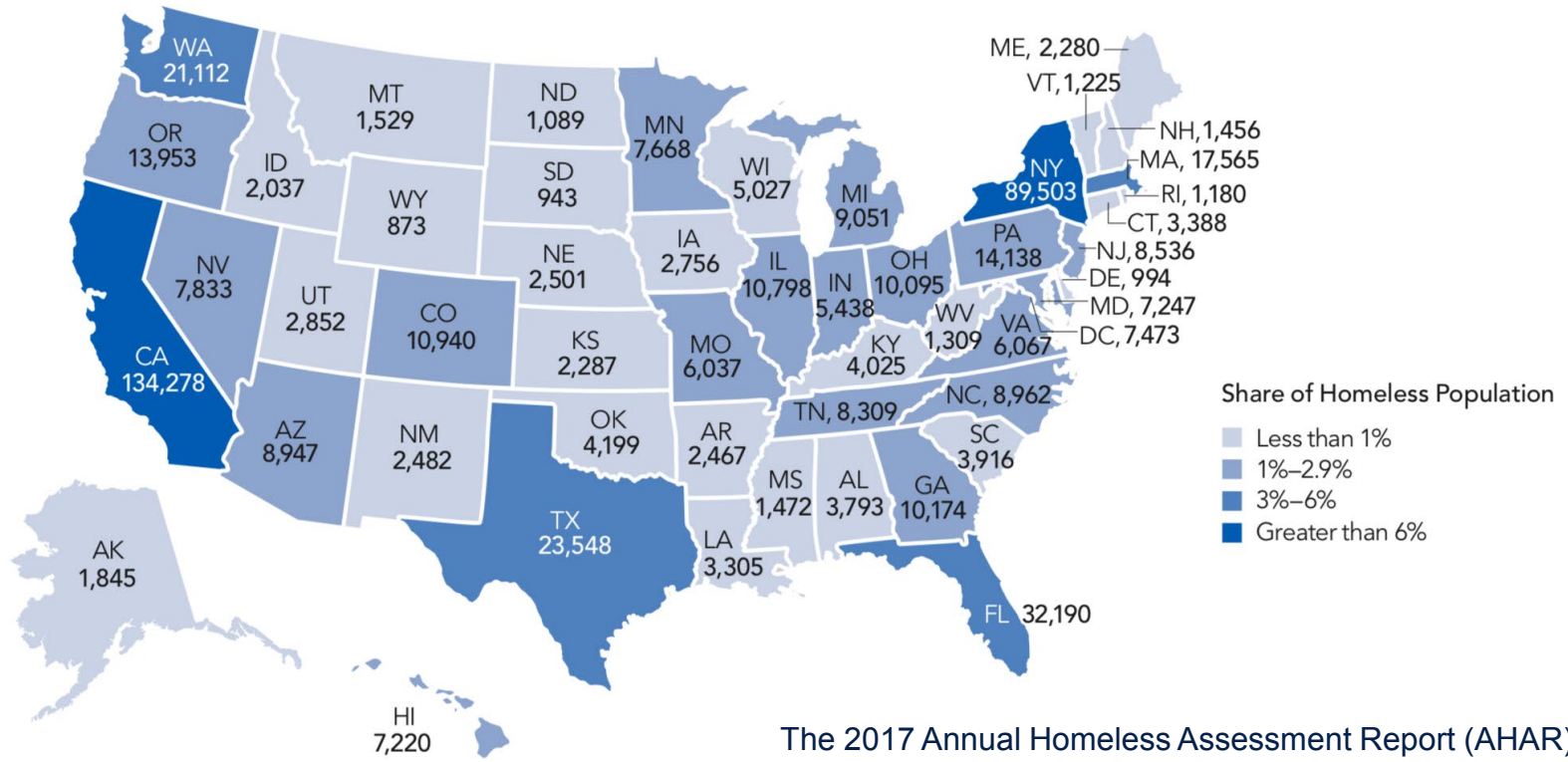
Homelessness in mothers of babies with congenital syphilis (CS), CA (except SF & LA)

- In-depth review of CS cases; data collected outside routine surveillance
- Reviewers document homelessness if any mention in investigation notes, interview, or medical record
- 2017: among mothers of CS cases, **23% had homelessness noted**

Data courtesy of Nicole Olson Burghardt, Epidemiologist, STDCB, CDPH

25% of all people in the US experiencing homelessness live in CA.

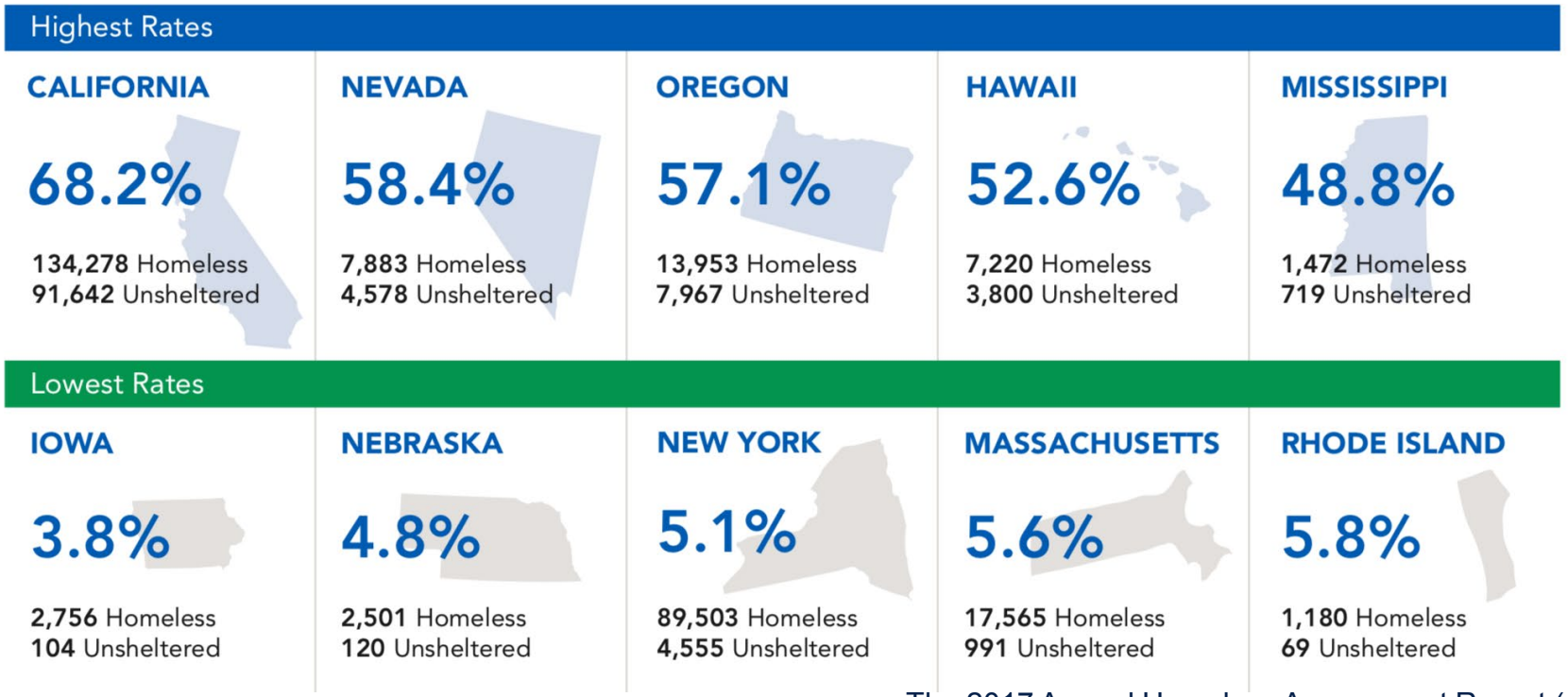
EXHIBIT 1.6: **Estimates of Homeless People**
By State, 2017



The 2017 Annual Homeless Assessment Report (AHAR) to Congress, Dec. 2017.
https://www.hudexchange.info/resources/documents/2017-AHAR-Part-1.pdf

CA has the highest proportion of unsheltered individuals nationwide--~50% of all unsheltered people in the country.

EXHIBIT 1.7: **States with the Highest and Lowest Rates of Unsheltered People Experiencing Homelessness**
2017



The 2017 Annual Homeless Assessment Report (AHAR) to Congress, Dec. 2017.
https://www.hudexchange.info/resources/documents/2017-AHAR-Part-1.pdf

Women experiencing homelessness: violence, trauma & PTSD

- Violence is the leading cause of homelessness for women and families
  - 20–50% of homeless women and children are homeless due to violence
- Homeless women are far more likely to experience violence compared with women who are not homeless
- Domestic violence shelters are prohibited from reporting client information→estimates undercount number of homeless women/families
- PTSD among women experiencing homelessness: ~40%

ACOG committee opinion; Whitbeck, J Traumatic Stress, 2015.

Homelessness and pregnancies

- Historical data
  - Twice the prevalence of pregnancy compared to women who are stably housed
  - ~75% of pregnancies are “unplanned” in women experiencing homelessness

Saver, Women’s Health, 2012.

Sidebar: what does a “planned pregnancy” really mean?

- Not all women are “planners”

- Pregnancy “intendedness” in stigmatized groups may be harder to assess / more likely to be underestimated

Dehlendorf, Contraception 2018; Aiken, Persp Repro Health 2016

Reproductive justice

The human right to have children, not have children, and parent in safe communities - *SisterSong*

Image credit: Repeal Hyde Art Project

Homelessness and pregnancy intentions, San Francisco

	N=32
Age (mean)	31 years
Homeless >1 year	78%
Unsheltered	69%
Desire pregnancy in the next year*	(n=30)
Yes	30%
Don't know	17%
How would you feel if you found out you were pregnant today?	
Somewhat or very happy	63%
Unsure	14%
Somewhat or very unhappy	27%
*** Two women were pregnant at the time of interview**	

Seidman, Newmann, unpublished data 2018.

Homelessness and contraception, San Francisco

	N=30
Pregnancy prevention at last intercourse	
Nothing	47%
Withdrawal	25%
Condoms	14%
Anal or oral sex instead of vaginal	3%
Using a clinician-prescribed contraceptive method	14%
Birth control method you would start tomorrow if available**	
Male condoms	17%
Female condoms	7%
Emergency contraceptive pill	0%
Pill/patch/ring	33%
Depo	13%
IUD	10%
Nexplanon	7%
Sterilization	3%
Fertility Awareness Method	14%
None of the above	36%

** Respondents could choose more than one method

Seidman, Newmann, unpublished data 2018.

Pause.

Applying the concepts of reproductive justice to our w
is challenging.

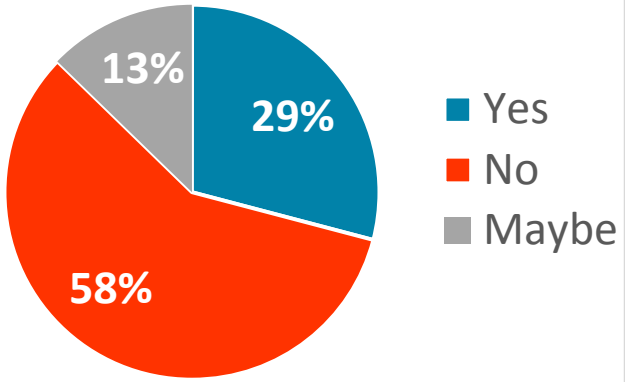
How do you feel about an unsheltered woman who injects drugs wanting to get pregnant and start a family?

How do you feel about an unsheltered woman stating that no contraception works for her, and if she gets pregnant, so be it?

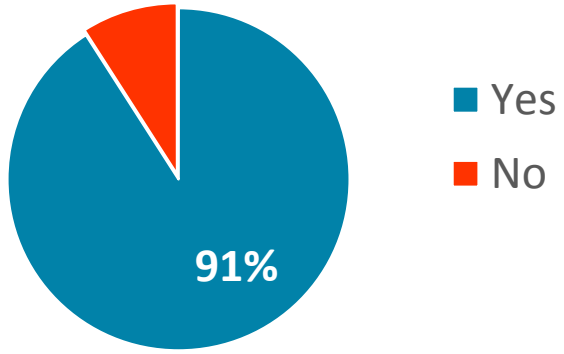
How do you feel about a woman who presents to the emergency room at 34 weeks with no prenatal care, who is focused on treating scabies and refuses prenatal labs?

Homeless women's reproductive & parenting histories, San Francisco (n=55)

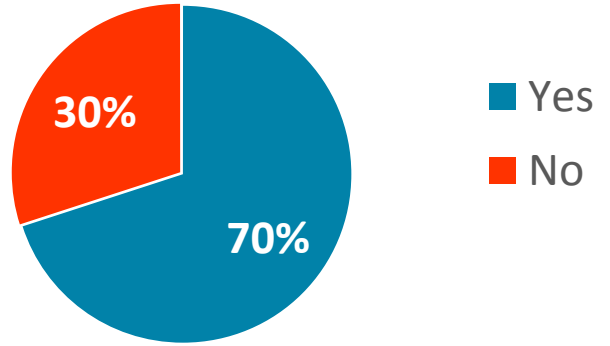
Q2. Do you want to be pregnant in the next 12 months? (n=55)



Q3. Have you ever been pregnant?



Q4. Have you ever given birth?



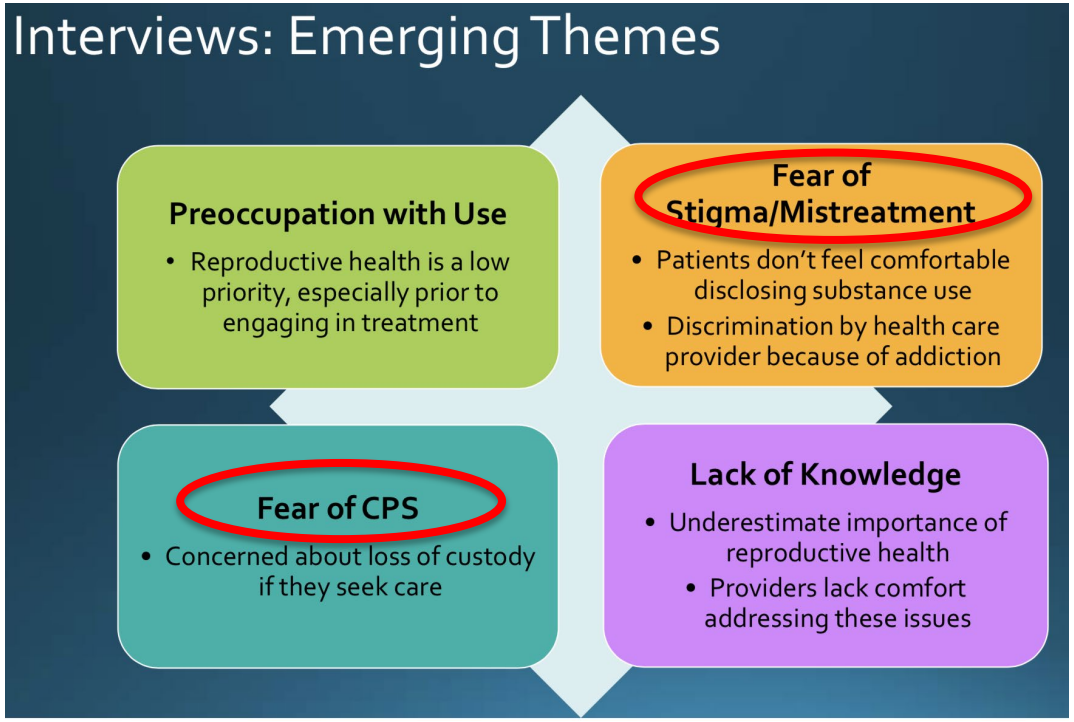
Of 35 women who have given birth, only 1 had a child in her custody

Unpublished data, HHOME program. Slide courtesy of Dr. Deb Borne.

Women accessing care at substance use treatment programs, MI (N=271; facilities=30)

Reproductive Health History	Percent
Sex for money/drugs	55
Pelvic Inflammatory Disease	16
Hepatitis C	24
HIV/AIDS	1

Barriers to Reproductive Health	Percent
Cost	43
Stigma/fear of mistreatment	36
Fear of results	23
Fear of child protective services (CPS)	27
Lack of transport	22
Don't know where to go	23



Slide courtesy of Lauren MacAfee, unpublished data

A real-life example: pregnant woman, homeless, uses meth, 23 weeks pregnant, presents to ER after assault

Substance Use: Pt erports smoking cigarettes and marijuana, admits to meth use when prompted but gets upset talking about it. EDSW offered Harbor Lights, pt not ready at this time but encouraged to return if interested.

Pregnancy: Pt reports she is having a baby boy and is due in December. Pt is excited about pregnancy, has not accessed prenatal care and does not know where she will deliver. EDS discussed homeless prenatal program in SF, pt accepted info.

CPS: EDSW called [redacted] and filed CPS report on behalf of unborn child, intake worker: [redacted]

Plan:

-EDSW filed a CPS report with [redacted] County CPS.
-Pt provided with resources on Homeless Prenatal Program, shelters and substance abuse tx.

What message would you like to pass on to health providers about working with women experiencing homelessness?

"Even if they come here stinking, don't turn them away. Just help them."

"Housing is real and it's hard … that is the biggest thing for everybody out here -- to be homeless."

"Don't try and push anything …if someone doesn't agree (and you push it), they will completely shut down about anything you have to say afterwards."

"Just treat us like people. Educate yourself."

Seidman, Anderson, Borne, Shapro, Newmann, unpublished data 2018.

Syphilis prevention and treatment for pregnant women with histories of trauma and other significant barriers to care

- Contextualize the encounters in which pregnant women with histories of trauma contact the healthcare system
- Discuss best practices to care for people with significant trauma histories
- Apply a reproductive justice lens

Trauma-informed care

Trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful…that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being.

- Perceptions and experiences of trauma vary dramatically
- Trauma overwhelms our coping capacities

SAMSHA, National Center for Trauma Informed Care

Trauma & Triggers

Trigger – a stimulus that sets off a memory of a trauma

- some can be identified & anticipated; others are subtle and unexpected

Dysregulation – stress response in addition to physical changes in the brain

Slide courtesy of Lauren MacAfee

Medical settings can be a trigger

Physical triggers

- Touch
- Removal of clothing
- Invasive procedures/tests/exams
- Vulnerable positions

Emotional triggers

- Personal, invasive questions
- Power dynamics/loss of power
- Loss of privacy
- Coercive or or stigmatizing language
- Lack of choice

Slide courtesy of Lauren MacAfee

How can we respond?

- Use universal precautions, trauma-informed care
  - Reproductive healthcare may be particularly triggering
- Reframe: welcome people into care
- *Where have you been? → Welcome back. We are glad you are here.*
- Use language carefully
- Provide patient-centered care, recognizing the effects of homelessness (and other determinants) on pregnancy

Trauma-informed encounters

- Establish rapport in a safe and respectful setting
- Give patient power and control wherever possible
    - Meet patient with clothes on
    - Knock on the door, WAIT for response
    - Start when she is ready, take a break if needed
- Collaborate: acknowledge that she is the expert on her body, her past experience, her current situation
- Ask: *What can we do to make this experience better for you?*

Slide courtesy of Lauren MacAfee

Trauma-informed communication

- Listen, don't interrupt, be fully present
- Slow down speech, be patient
- Ask questions rather than commands
  - *When you're ready, would you please show me where you'd like this shot?*
- Avoid invasive questions. Only ask questions that serve a purpose.
- Acknowledge and validate concerns
- Non-verbal cues

Grounding / Responding to triggers

- Reassure and normalize the response – acknowledge she is responding appropriately to an anxiety-producing event
- Use a calm, matter-of-fact voice
- Avoid sudden movements
- Explain what you are doing and why; stop, wait
- Bring her back to the moment: water, blanket, a hand to hold

Slide courtesy of Lauren MacAfee

The power of words

Stigmatizing words	Alternatives
Homeless people	People experiencing homelessness
Non-compliant	Has significant barriers to care / taking medicines
Unfit to parent	Unable to parent at this time
Addict, abuser, junkie, user	Person with addiction, person with a substance use disorder
Clean	Substance-free, in recovery
Drug habit	Substance use disorder, addiction
Drug of choice	Drug of use
Replacement or substitution therapy	Treatment, medication, medication-assisted therapy
Refusing care	Declining care, unable to receive services at this time

Mary Howe, Homeless Youth Alliance; Laren MacAfee

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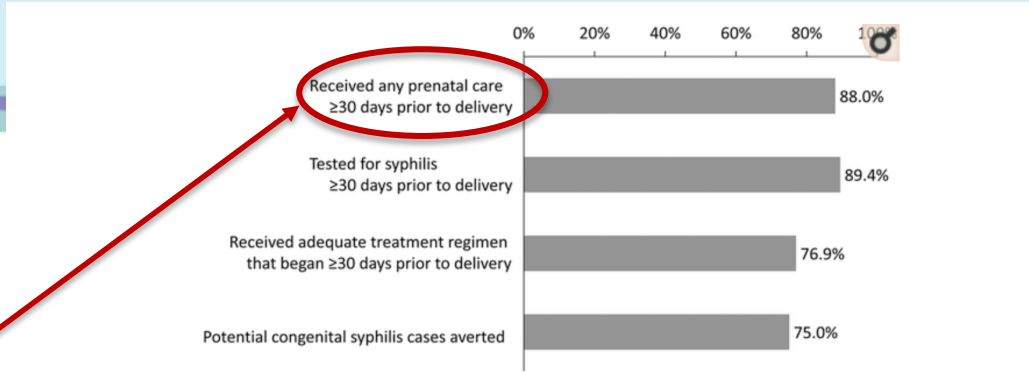
Every visit is a prenatal visit



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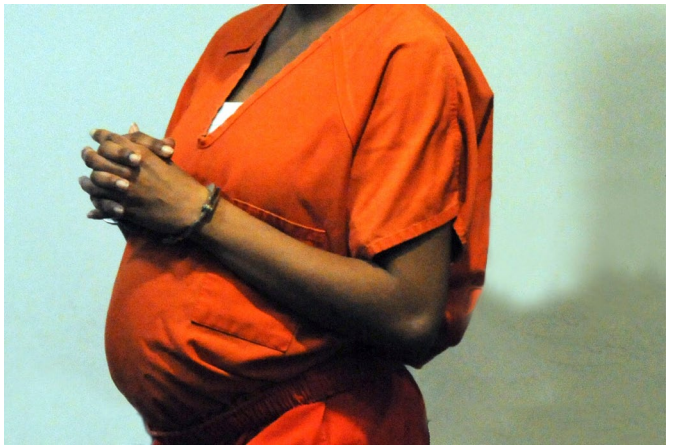

Every visit is a prenatal visit

- ✓ What does SHE want / need?

- ✓ What can YOU offer?
  1. Prenatal labs
  2. Vaccines
     1. Prenatal (TDAP, flu) and Hepatitis A, B
  3. Anatomy scan
  4. Prevention options
     1. HIV (PrEP, PEP, TasP, condoms), other STIs
     2. Needle exchange, safer injection practices, Narcan
  5. Substance use counseling / treatment
  6. IPV resources
  7. Housing resources
  8. Mental health resources
  9. Stabilization / admission
  10. Outreach/follow-up with a warm handoff
  11. Knowledge of services/orgs that will meet her needs – drop-in hours, welcoming staff, etc.

Every visit can be a preconception visit

1. ASK about pregnancy intentions; offer preconception, contraception, pregnancy or abortion services as appropriate

2. OFFER:

- Labs (RPR, HIV, Hepatitis serologies, Rubella, VZV, GC/CT)
- Vaccines
- Prevention options (HIV, STIs, needle exchange, safer injection practices, Narcan)
- Substance use counseling / treatment
- IPV resources
- Housing resources
- Mental health resources
- Outreach/follow-up with a warm handoff

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Prevention counseling

Prenatal labs

Vaccines

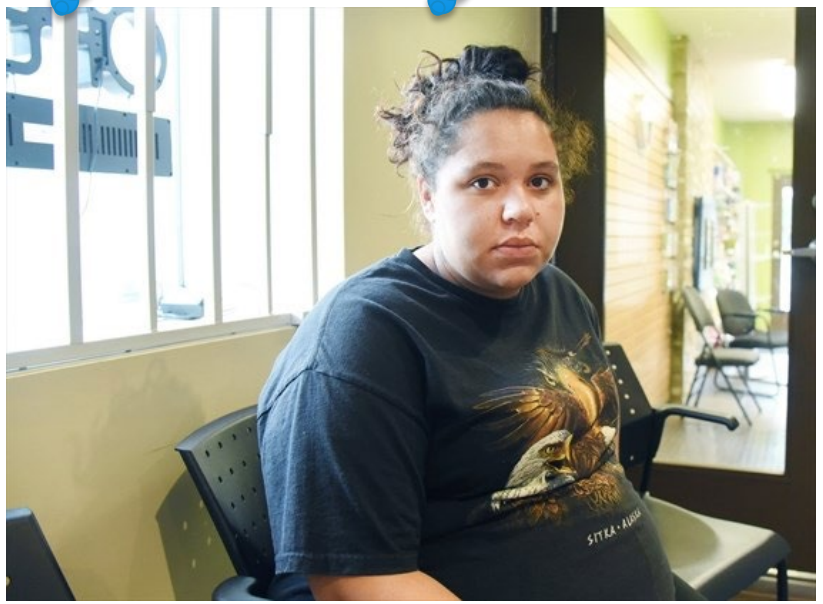
ultrasound

I really need to charge my phone

Where am I going to sleep tonight

I have a court date tmrw …and it's going to be horrible

I hope my stuff is still there when I get back



Accepting our roles

While we would all love to receive instant respect and gratitude we aren't going to get it and the sooner we accept that, the easier and more fulfilling our work will be. The youth we encounter don't owe us anything for working with them. While they appreciate our presence and willingness they are here because they need something. These youth are incredibly tough, resilient and more often than not, resistant to traditional forms of care; they are seeing us as a last resort because they can't fix this problem themselves. You will need to be accepting, humble, consistent and patient to earn their trust...

Nobody saves anybody else. People save themselves. Dignity and self-worth are not things we are going to give them. Self esteem is a result of their own skills, and resilience. By treating them with respect and dignity it helps create opportunities for those qualities to grow.

Mary Howe, HYA

Ask for permission to collect multiple forms of contact info and to do outreach.

Facilitate warm hand-offs that day (when possible); know and use your partners.

HOMELESS PRENATAL PROGRAM

Team LILY

What we do: Team LILY is a ZSFG-based roving care team providing wraparound services to pregnant people experiencing significant barriers to engagement in clinic-based prenatal care. We primarily serve pregnant people with housing insecurity, active substance use, and/or mental health diagnoses.

Who we are: Team LILY is a collaboration between HIVE, ObGyn, OB-Psychiatry, and Solid Start.

Approaching (pregnant) women diagnosed with syphilis

- What are the woman's priorities?
- Assess pregnancy intentions
- Provide wrap-around services
  - **Who knows her best? Who does she trust?**
  - Bring services to her
- Offer an integrated prevention approach: HIV, other STIs, contraception if desired, preconception care if applicable, prenatal or abortion care, housing, substance use treatment, IPV resources
- Invite her to L&D for treatment and stabilization
  - Provide a warm handoff
  - Educate L&D providers
  - Develop a plan with her for next steps

Our most challenging (& rewarding) story to date - PCN desensitization for a woman who HATES hospitals.

Prior child removal

Sleeping in a tent

Using meth & heroin

Complex PTSD with regular outbursts

Extensive street family who also do not trust the healthcare system

…

Requires PCN desensitization for syphilis treatment

Our approach

- What are her priorities?
- Assess pregnancy intentions
- Provide wrap-around services
  - **Who knows her best? Who does she trust?**
  - Bring services to her
- Offer an integrated prevention approach: HIV, other STIs, contraception if desired, preconception care if applicable, prenatal or abortion care, housing, substance use treatment, IPV resources
- Invite her to L&D for treatment and stabilization
  - Provide a warm handoff
  - Educate L&D providers
  - Develop a plan with her for next steps
- Don’t give up if it doesn’t work the first time!
- Ask questions / push limits when care systems don’t meet patients’ needs

Take-aways

We have a broken reproductive healthcare system that does not meet the needs of people affected by trauma.

Trauma is pervasive.

We have an opportunity to

- provide trauma-informed care, and develop trauma-informed clinics/orgs and systems
- use and reflect on principles of reproductive justice in our work
- develop partnerships to facilitate warm hand-offs within our current system
- rethink care systems to minimize barriers to entry
- rebuild trust with individuals who have experienced trauma from the healthcare system

Questions? Comments?

I'd appreciate learning about your experience.

Thanks!

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