

# Meeting the Moment: Addressing Structural Barriers to Sexual and Reproductive Health Care Access and Equity



#### **SESSION PRESENTERS:**

**Alejandro McGhee** (presenting in place of Kaytura L. Felix, MD)

Making Planned Community-Based Childbirth a Viable Option to Address Structural Racism

Johns Hopkins Bloomberg School of Public Health

#### Madeline T. Morcelle, J.D., M.P.H.

Fostering Sexual and Reproductive Health Equity Through Federal Nondiscrimination Law and Policy

National Health Law Program

#### Amy Mercieca, PhD(c), MPH, MBA

Building Resilient Coalitions for Public Health Advocacy: Lesson's from Ireland's Abortion Rights Movement

Tulane University Celia Scott Weatherhead School of Public Health and Tropical Medicine





# Making Planned Community-Based Childbirth a Viable Option to Address Structural Racism

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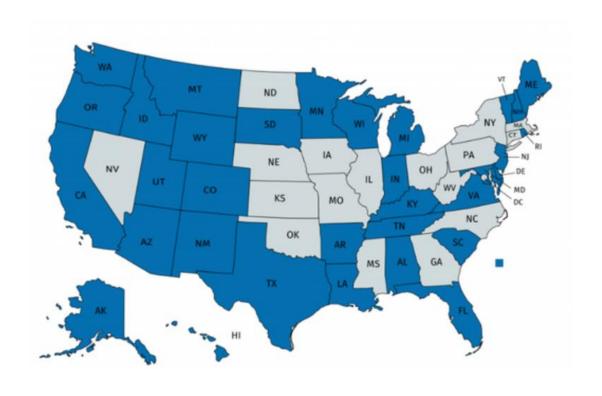
#### **Presentation Goals**

- Introduce the current state of midwifery in the United States
- Describe the common barriers that Black birthing clients face accessing community midwifery across different regulatory environments
- Describe the common barriers that Black community midwives face delivering care
- Describe the experiences of Black midwives and their clients during client transfer from community to hospital care
- Share Black midwives and birthing clients' recommendation for increasing access to community childbirth



#### Introduction

- Black birthing people in the U.S., over the past three decades, are increasingly choosing community-based childbirth to avoid the effects of structural racism in hospitals.
- Direct entry midwives or certified professional midwives (CPMs) are trained to provide that care, recognized or licensed in only three out of four states, and reimbursed by Medicaid in 18 states + D.C.
- Policy and legal barriers undermine efforts to expand access to this important care option.

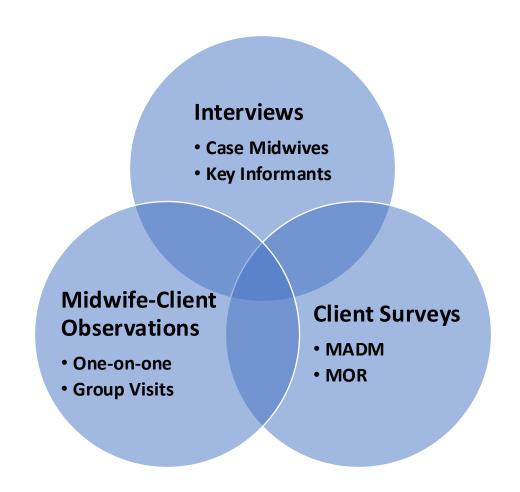




#### Methodology

We conducted in-depth interviews with eleven Black direct entry midwives and their Black clients who experienced out-of-hospital childbirth in five states with varying state-level regulatory environments to identify key supports and barriers.

A total of 57 participants were interviewed.







#### Diverse Regulatory Conditions

State Characteristics	PA	FL	МО	CA	HI
Are CPMs recognized/licensed to practice?	No/No	Yes	Yes/No	Yes/Yes	Yes/Yes
Are CPMs eligible to receive Medicaid reimbursement?	N/A	Yes	No	Yes	Yes
Is there Medicaid reimbursement equity with nurse midwives?	N/A	Yes	N/A	No	N/A
Are private insurances state mandated to reimburse CPMs?	N/A	Yes	No	No	No
What is the level of integration between community midwifery and hospital care?	Very Low	Moderate	Low	Moderate	Low
Is the apprenticeship pathway recognized for state licensure?	N/A	No	N/A	Yes w/ Challenge Mechanism	No

#### Study Findings: Participant Barriers

#### **Client Barriers**

 Clients' barriers included high out of pocket costs, lack of available information on community midwifery, misinformation regarding clients' eligibility, and mistreatment upon transfer to hospital care.

#### **Example Quotes**

- "...although we file for reimbursement from insurance, they don't really give us that much of it back. So it is a financial, I guess you could say sacrifice to do a home birth..."
  - Midwifery Client
- "The only thing that was challenging was the fact that insurance companies do not cover home births...They're willing to pay that amount of money to a hospital but not like 5, 6 thousand dollars to a home birth." -Midwifery Client



#### Study Findings: Participant Barriers

#### **Midwife Barriers**

 Midwives' barriers included high cost and inadequate institutional support for training, maintaining a financially viable practice, and hospital staff's disrespect and lack of regard for their knowledge and expertise.

#### **Example Quote**

"So I definitely, even with myself, have a lot of outstanding balances when it comes to previous clients that had not paid their bill...And with that number, that's possibly upwards of 50K. So this is something that all midwives deal with but don't really talk about because we wear so many hats in our practices.

We're our billers. We're our receptionists. We're our administrative assistants. We're our phlebotomists. We're our lab pickup and drop-off person. We're our scheduler. We're our medical assistant. We're our physician's assistant. We're all the hats. And it isn't always easy making sure that you have consistent income as a midwife."

- Case Midwife





#### Study Findings: Client Transfer Experiences

Black clients and direct entry midwives expressed facing derision from traditional medical providers upon transferring into hospital systems.

Both clients and midwives described instances where they were ridiculed for their choice to have or facilitate out-of-hospital births.

- "In short, what I'll say is [the midwife] and I were mocked. We encountered staff laughing at us as I entered into the surgical ward to receive care...We expected the staff to be urgent and running into action and they were waiting for us. And what the conversation was is, "Oh, that's the girl who decided to have a baby at home." - Midwifery Client
- "I remember a time when the nurses were trying to figure out, was I a real midwife?...So it was more gossipy than it was trying to assist a patient. Or a lot of times, I would take the grunt of the heat when it comes to the patient so they don't have an experience, because sometimes you have staff who feel some type of way that you even attempted a home birth. So I don't want my families to feel less than because of the decision that they made." Case Midwife





#### **Overall Recommendations**

Midwives and clients recommended policy reforms and public education to increase access to direct entry midwives and improve their integration into the health care system.

- "We need expanded access to insurance...[O]ne of the inhibitions from people being able to access this model of care is that they can't afford it. And so we need to start with licensure. License [directentry] midwives so that we can negotiate with the insurance commission so that we can get insurance coverage." - Case Midwife
- "[Midwifery] needs to be funded. It needs to be broadcasted. It needs to be-- there needs to be informational settings. There need to be panels about experiences...Just overall conversation about what it is to be a Black midwife and Black midwifery experiences, in general"
  - Midwifery Client





#### Conclusion

Policymakers, direct entry midwives, and diverse stakeholders must collaborate to strengthen community-based efforts, such as out-of-hospital childbirth, that aim to redress structural racism.







# Fostering Sexual and Reproductive Health Equity Through Nondiscrimination Law and Policy

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#### About the National Health Law Program (NHeLP)

- For over 55 years, NHeLP has advocated, educated, and litigated to expand equitable health care access for low-income and underserved people
- Collaboration:
  - o Health Law Partnerships
  - Partner with a wide range of legal services, civil rights, social justice, anti-poverty advocates
    - Sexual and reproductive health, rights, and justice advocates
- About Us & Equity Stance



#### Discrimination as a Structural and Social Driver of Health

**Discrimination**: adverse and unfair treatment of individuals or groups based on prejudicial beliefs, stereotypes, or general antagonism based on perceived membership in a social category

Occurs on interpersonal and institutional levels

#### Discrimination as a social and structural driver of health: pathways

- Discrimination as a psychosocial stressor
- Discriminatory exclusion from or barriers to health and social resources, power
- Discriminatory violence/bodily harm





Denying, delaying, or discouraging care

Discriminatory benefit design (limiting coverage, copays, adverse tiering, etc.)

Dismissal and/or undertreatment of symptoms

Rough handling, yelling, shouting

Discrimination in Sexual and Reproductive Health Care

Lacking accessible medical equipment

Coercive care

"I'm not taking new patients."

Denying language access

Failing to provide SRH-related (e.g., contraceptive, assisted reproduction) counseling

"I'm not the doctor for you."



# Section 1557 of the ACA (42 U.S.C. § 18116)

- Prohibits discrimination based on race, color, national origin, sex, age,
   disability, or any combination thereof in certain health programs and activities
  - First federal law to prohibit intersectional discrimination + broadly address sex discrimination in health care
- Applies to all health programs and activities that receive federal financial assistance (FFA), are administered by entities created under ACA Title I (the marketplaces), and/or are administered by HHS
- 2024 Final Rule (FR): restored and expanded implementing regulations



# 2024 § 1557 FR: Regulatory Text

- **Definition of sex discrimination**: includes pregnancy or related conditions; sex stereotypes; sexual orientation; gender identity; and sex characteristics, including intersex traits
- Provisions against discriminatory benefit design
- Language access provisions



# Preamble Wins: 2024 FR on § 1557

Renewed recognition that protections against sex discrimination re: pregnancy or related conditions include abortion, *e.g.*:

- Denying abortions based on race, disability, etc.
- Discrimination related to pregnancy related decisions, past, present, or future

So many firsts, e.g.:

- Obstetric violence (mistreatment in pregnancy care based on race, other protected characteristics)
- Discriminatory pain dismissal and denial of pain medications based on sex stereotypes about women



# Section 504 of the Rehabilitation Act (29 U.S.C. § 794)

- Signed into law in 1973, § 504 established the first federal civil rights protections for people with disabilities
- Applies to any entity that receives FFA
- Last spring, HHS updated § 504 regulations for the first time since 1977



# 2024 FR on § 504: Regulatory Text

- **Discrimination in medical treatment**: new regulation prohibiting discriminatory treatment denials/limitations, denials of treatment for a separate symptom/condition, or medical treatment provision based on an individual's disability.
- **Family policing**: new child welfare regulation to prohibit discrimination against qualified individuals with disabilities in the child welfare system, including parents, prospective parents, foster parents, caregivers, and children.



# Defending and Enforcing Federal Rights

- Defending federal regulations: need to ensure a robust response to NPRMs
- Barring acts of Congress, § 1557 and § 504 remain the law of the land
  - Can continue to enforce rights in the courts
  - File a complaint with your state insurance commissioner:

https://content.naic.org/consumer



### **Enforcing and Shoring Up State Protections**

- Few states have their own nondiscrimination laws prohibiting sex-based or intersectional discrimination in health care (grounds vary)
- Where feasible, state advocates should consider advocating for robust state nondiscrimination laws
  - NHeLP is here to support advocates in exploring what this could look like, including how to ensure robust protections against discrimination in SRH care.

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#### NHeLP Resources

- Section 1557 landing page
- SRH Equity landing page (includes SRH-specific nondiscrimination resources)
- www.healthlaw.org





# Building Resilient Coalitions for Public Health Advocacy: Lessons from Ireland's Abortion Rights Movement

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\*slides available upon request





#### Learning Objectives

- Identify three effective strategies for building and sustaining coalitions
- Identify specific digital engagement techniques to enhance public support in advocacy campaigns
- Design a plan for establishing shared goals and roles within a coalition
- Analyze the impact of structured working groups on maintaining focus and coordination



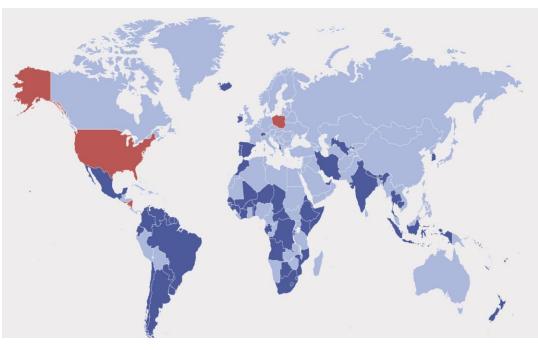
#### Setting the Scene: Global

#### **Abortion**

- Routine medical procedure, highly safe when performed following WHO-recommended methods suitable for the stage of pregnancy and carried out by a trained professional; essential to comprehensive reproductive healthcare
- Justifiable abortion: general attitude toward abortion acceptability across various circumstances, without specifying particular reasons for the procedure.

#### **Global Trends in Access**

- Has ancient origins and been part of human reproductive health for millennia
- Over past 30 years, 4 countries have restricted access to abortion and 60+ have expanded access



- Restricted Access
- Expanded Access
- Made no changes to Access

Global Abortion Laws (CRR, 2024)





#### Setting the Scene: Louisiana Post-Dobbs

- Abortion banned with exception of the life of the mother and vague language around medically futile pregnancies
- Ban includes criminal penalties for providers and vague penalties for patients
- First state to re-classify misoprostol as a dangerous controlled substance (used in medication abortions, but also for postpartum hemorrhage and other obstetric issues); effective 1 October
- Governor, a Catholic, signs law requiring Ten Commandments be hung in every public classroom (June 2024)
- Citizen-led ballot initiatives not allowed
- A proposed constitutional amendment allowing the people to vote on legalizing abortion did not make it out of committee in 2024





#### **Public Health Impact**

#### **Maternal Health**

- States with abortion bans have 62% higher maternal mortality
- Black women: nearly **3× higher mortality** than White women
- Higher rates of low birth weight & preterm births

#### Mental Health & Socioeconomic

- Denial of abortion → anxiety, financial distress, poverty reliance
- Increased risk of remaining in violent relationships
- Harms extend to existing children in household

#### **Healthcare System**

- **11M+** people travel over an hour for nearest clinic
- Maternity care deserts more common in restrictive states (39% vs. 25%)
- OB-GYN shortage worsened by legal fears, vague laws



#### Background & Study Purpose

#### Why Ireland?

- Ireland's Repeal of the 8th Amendment (2018): an example of expanding abortion rights in a conservative, religious context
- Opposite reproductive rights history to U.S., deeply religious culture, conservative politics, historic Church influence, yet rapid social and legal change

#### **Purpose:**

- Understand key strategies, roles, and perspectives and how they influenced the successful Repeal of the 8th with the aim of informing advocacy in restrictive U.S. states
- Advocacy must adapt to shrinking protections and a system that is not working

#### **Guiding Framework:**

 Social Movement Theory: examines how collective action, framing, and coalitionbuilding drive policy change

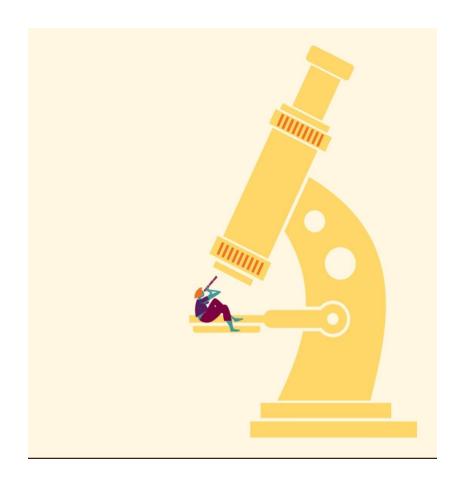
#### **Knowledge Gap**

 Abortion rights movements in religious and conservative contexts remain underresearched, particularly those in occurring in the digital age



#### Methods

- Qualitative Case study design
- In-country contact with the Abortion Rights Campaign
- 19 semi-structured interviews with key stakeholders (virtually and in-person)
  - Advocacy Leaders
  - Politicians (i.e. TD)
  - Institutional voices
  - Academics and legal experts
  - Grassroots activists
- Document analysis (training materials, campaign documents, reports)





## Strategy #1

#### **Context & Shared Objectives**

- Unified around a single, achievable goal: Removing the 8th Amendment
- Built inclusive coalition of 100+ groups with diverse ideologies
- Leadership emphasized compromise and egomanagement

"The first most important thing in any campaign is that you understand thoroughly the context you're dealing with and therefore, allowing the strategy develops out of that. The founding principle and the anchors of the strategy are in the space you're actually in. And that's one of them – sort of desperation actually."

"We had to define what the coalition stood for, come up with a tagline that's broad... so you could agree but didn't have to have a position on abortion itself."



### Strategy #2

#### **Messaging & Narratives**

- Personal Storytelling
  - Sharing real stories humanized the issue and created emotional connections with the public
- Healthcare Framing
  - Positioning abortion access as a healthcare issue rather than a moral or religious concern
- · Consistent but tailored framing
  - Messaging based on outside research kept very tight under Together for Yes but allowed groups to adapt to their context

"It was about women's health, well-being.
Those were the two absolutely key ones. This
was not about morality, this was about health,
and this was absolutely about women. I think
that that was really important."

"Everybody just stuck to the message like glue. It didn't matter if you were Farmers for Yes or Mommies for Yes, everybody had the same messaging, even though it was coming from slightly different perspectives. It was all the same Together for Yes message."



## Strategy #3

#### **Digital Engagement & Visual Branding**

- Highly coordinated social media campaigns amplified voices and helped mobilize younger demographics (hashtag campaigns #HometoVote, #RepealThe8th)
- Combatted stigma through visibility and storytelling (In Her Shoes Facebook page)
- Unique window of opportunity for digital oversight and social media controls post Brexit and 2016 US election (Repeal Shield, citizen-led digital oversight)
- REPEAL jumper, murals

"If you have enough people, you can divvy it out and keep a social media calendar. It was very organized, like a war room."

"ARC engaged in a significant amount of stigma busting. Sticker campaigns in public, lots of stuff in public transport. But all of it was stigma bursting...which is really such an important part of it."

"There were these black jumpers that said 'Repeal'... a powerful tool in talking about abortion without talking about abortion."



### Strategy #4

#### **Working groups and Timelines**

- Volunteers were placed in specialized working groups (e.g. Media, Admin, Partnership & Outreach, Policy & Advocacy, and Actions)
- Matched roles with strengths
- Helped sustain momentum, avoid fragmentation
- Allowed rapid response to opposition narratives
- Timelines helped maintain momentum

"We had retention through clear roles. People stay involved when they have a clear, defined role. If they don't know what to do, they quickly disengage."

"One of the very important principles was that you give people a timeline. I said, 'we've got five years to do this'.

And we did it in just over five years."



#### **Implications**

**Context Matters:** Strategies must be adapted to the political, cultural, and religious environment

**Coalition-building**: Broad, inclusive alliances can be effective, but unity requires good leadership, compromise and clear, shared goals

Messaging: Reframing abortion as health/human rights can bridge divides, but language must resonate locally

**Digital Organizing**: Social media and grassroots oversight were critical in Ireland; harder in the U.S. without platform controls but still important to consider

Sustaining Movements: Consider and mitigate risk of burnout & fragmentation post-policy wins

Equity Focus: Center marginalized communities disproportionately harmed by restrictions





#### Questions?

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Please take this survey to evaluate conference sessions.





# THANK YOU

