



Pregnancy in people with IDD is public health:

Using public health methods to
improve pregnancy experiences and outcomes
in people with IDD

Today's Learning Objectives

1. Describe how pregnant people with IDD receive health care during pregnancy and describe their health outcomes
2. Learn about perspectives of people with IDD about their own health and health care experience during pregnancy
3. Understand how narrative portraiture methods actively engage audiences to listen to participants' voices to interpret and draw conclusions

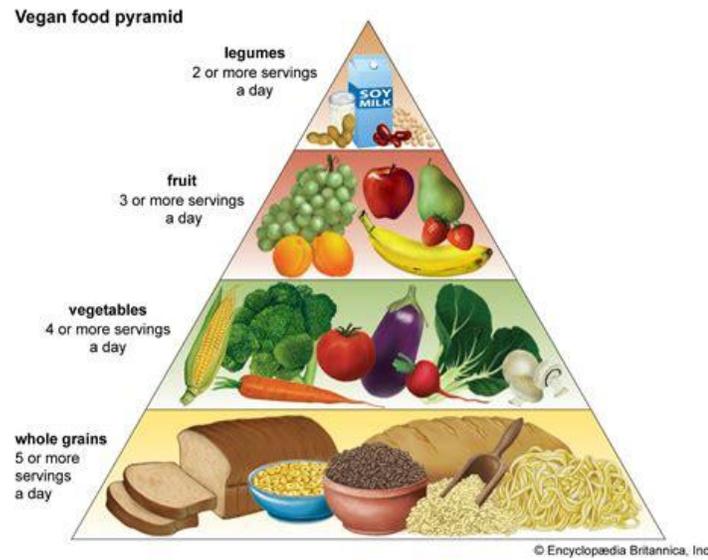
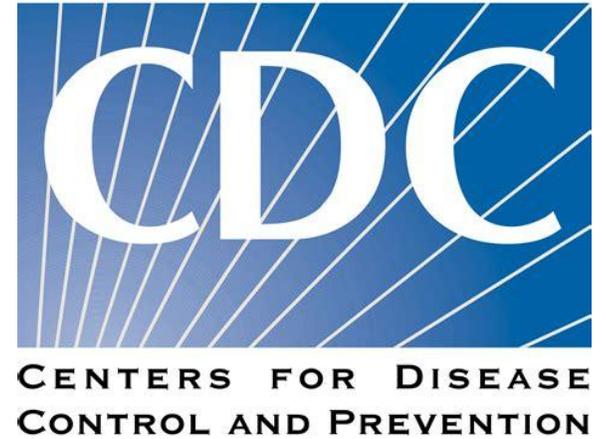
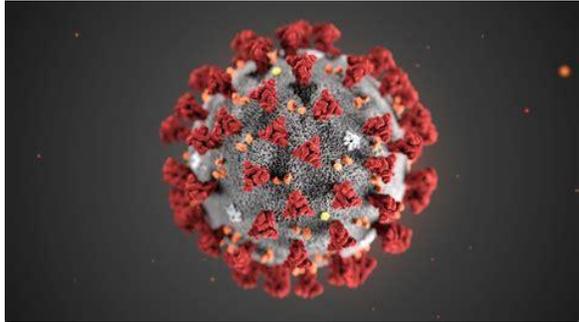
What is public health?



The first thing that comes to mind when you hear public health?



The first thing that comes to mind when you hear public health?



So what is public health?



SHARE

PUBLIC HEALTH CONNECTS US ALL

Public health is the science of protecting and improving the health of people and their communities. This work is achieved by promoting healthy lifestyles, researching disease and injury prevention, and detecting, preventing and responding to infectious diseases. Overall, public health is concerned with protecting the health of entire populations. These populations can be as small as a local neighborhood, or as big as an entire country or region of the world.

Pregnant people with disabilities are a population!



“

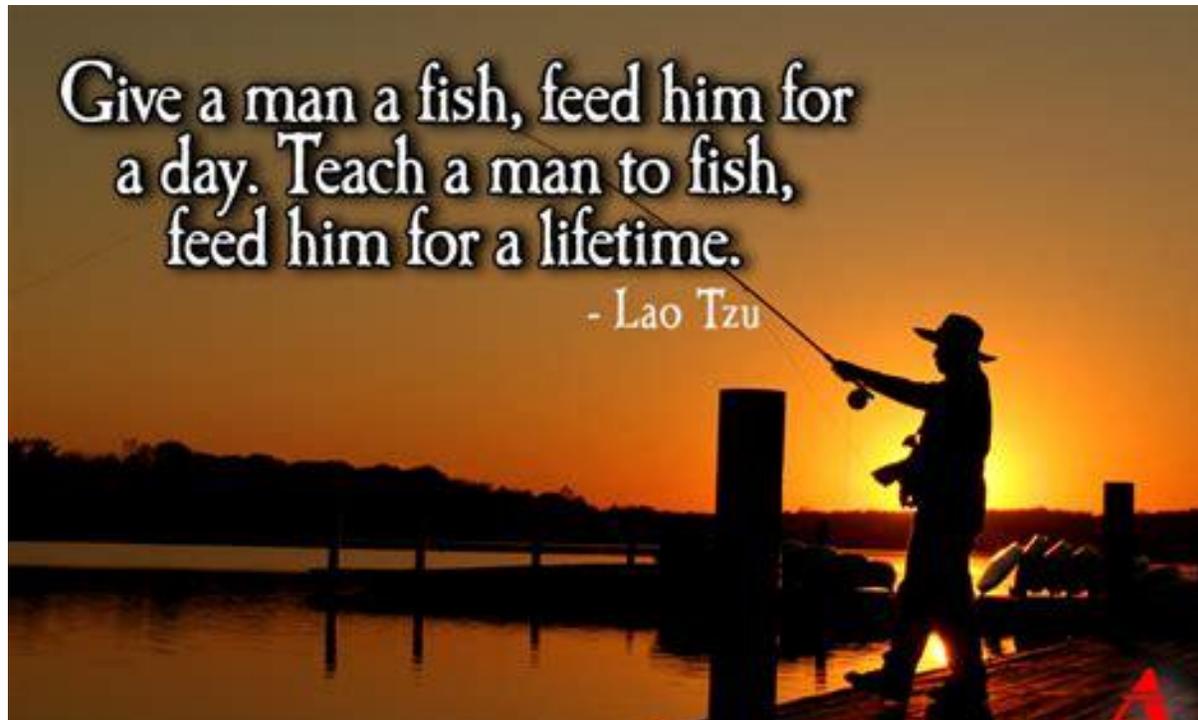
What's good for the goose is good
for the gander.

~ John Ray



Give a man a fish, feed him for
a day. Teach a man to fish,
feed him for a lifetime.

- Lao Tzu



“

What's good for the goose is good
for the gander.

~ John Ray

What's good for one pregnant people with an intellectual disability, who struggled to fight for access, could be good all pregnant people with intellectual disability. Let's try it!



While one story is important, all our stories together are more powerful. Let's not forget that!

**Don't Miss
The Forest
For The
Trees**

Give a man a fish, feed him for
a day. Teach a man to fish,
feed him for a lifetime.

- Lao Tzu

Teach a doctor to be empathetic to people with ID, help a handful of people. Mandate teaching medical students and help a population.



Epidemiology- the science of public health

- Originally mostly the study of *epidemics* (not epidermis)
- Now we study most health conditions
- It's a mix of understanding what makes a population tick and math (I will try to spare you the math)

Epidemiology- the science of public health

How do we do epidemiology in this population?

- Use Big Data
- Most pregnant people interact with doctors
 - Doctors need to make \$, so they charge insurance
 - We can look at those insurance bills to see what happened to the person
 - We can do this with never having to talk to/ bother people
 - We do it safely through removing all identifiable information

What insurance do we use? Medicaid and Medicare

Medicaid

MEDICAID

For individuals, families, and children with limited income & resources

VS

Medicare

MEDICARE

Generally for people who are 65 & older, or who have a qualifying disability

Medicaid

- Public health insurance for low income and disabled adults.
- Can qualify based on income level and/or disability
- Run by the states with money and some rules from the Federal Government.

Medicaid

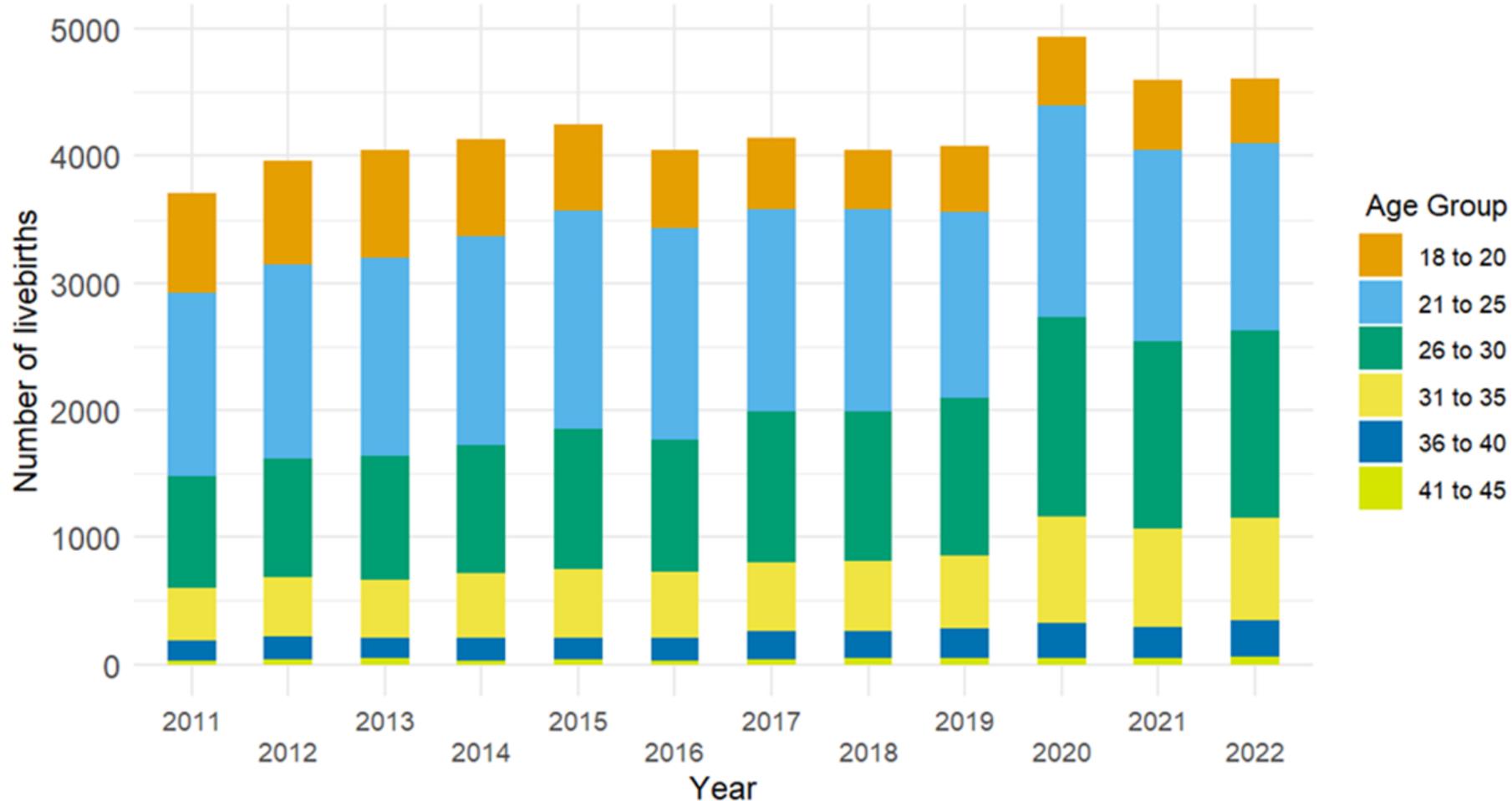
Medicaid State-Specific Alternative Names / Nicknames

State	Alternative Name
Alabama	Alabama Medicaid
Alaska	DenaliCare
Arizona	Arizona Health Care Cost Containment System (AHCCCS)
Arkansas	Health Care
California	Medi-Cal
Colorado	Health First Colorado
Connecticut	Husky Health , Husky C (for aged, blind or disabled persons)
Delaware	Diamond State Health Plan (Plus)

Medicare

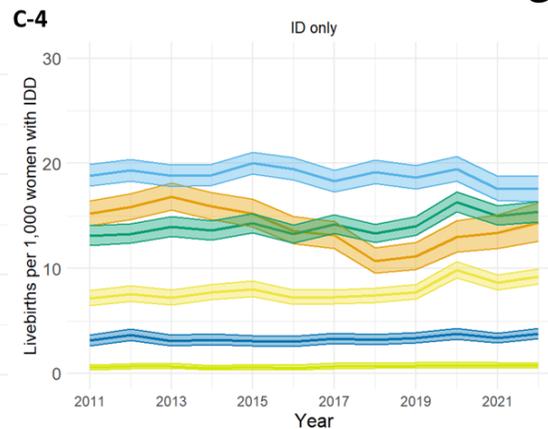
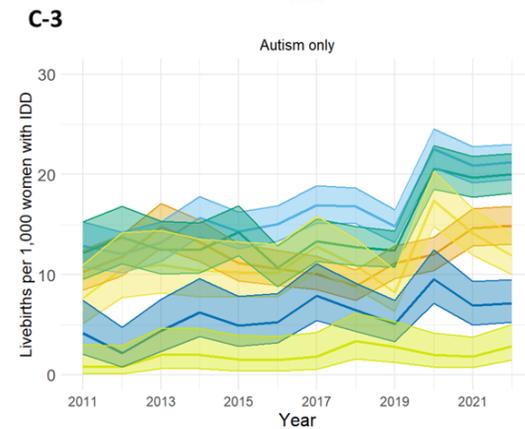
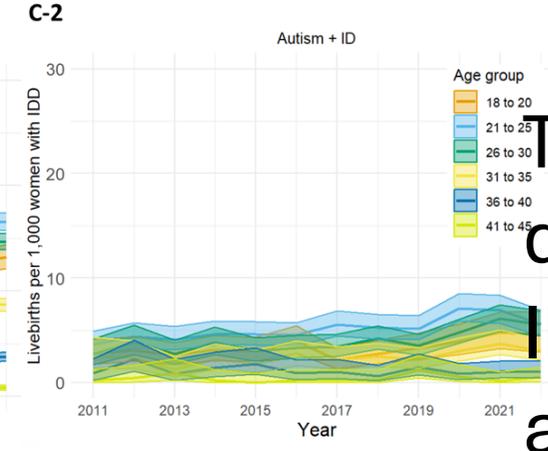
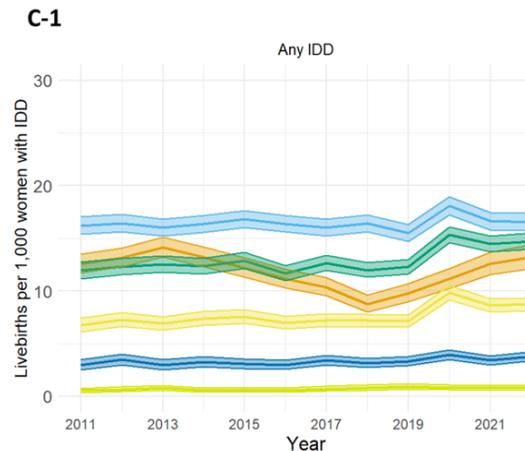
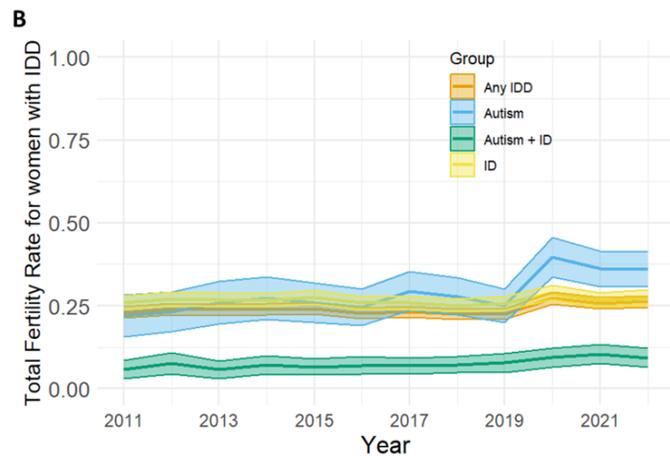
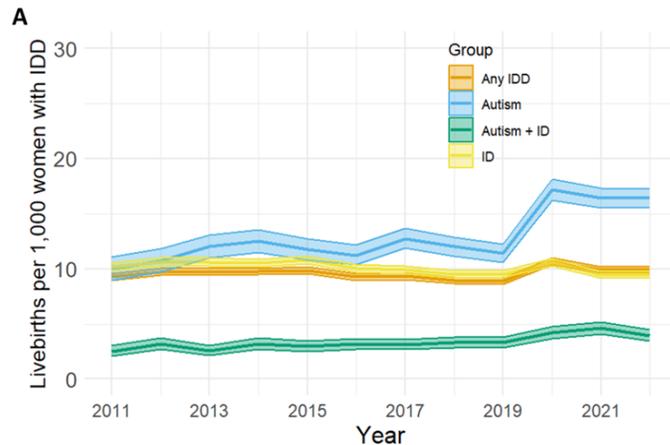
- Insurance for people 65+ with no income requirements
- Some younger people can get it too if they are a dependent of an eligible adult or they have specific disabilities.
- Pregnancy is relatively rare

What do we know about the epidemiology of pregnancy in women with intellectual and developmental disabilities?



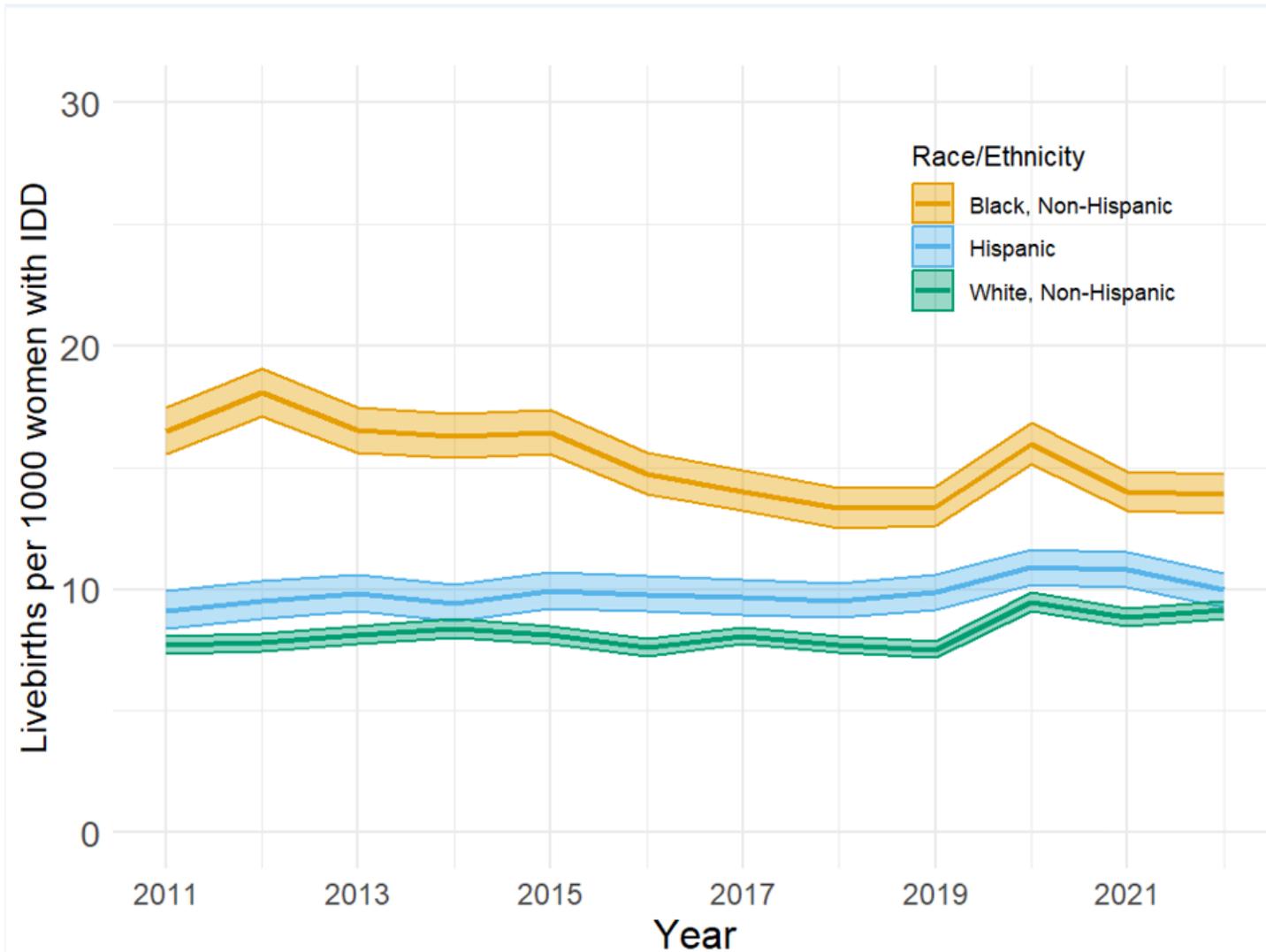
People with
IDD are having
babies (duh)
and the
numbers are
rising (slightly)!

What do we know about the epidemiology of pregnancy in women with intellectual and developmental disabilities?



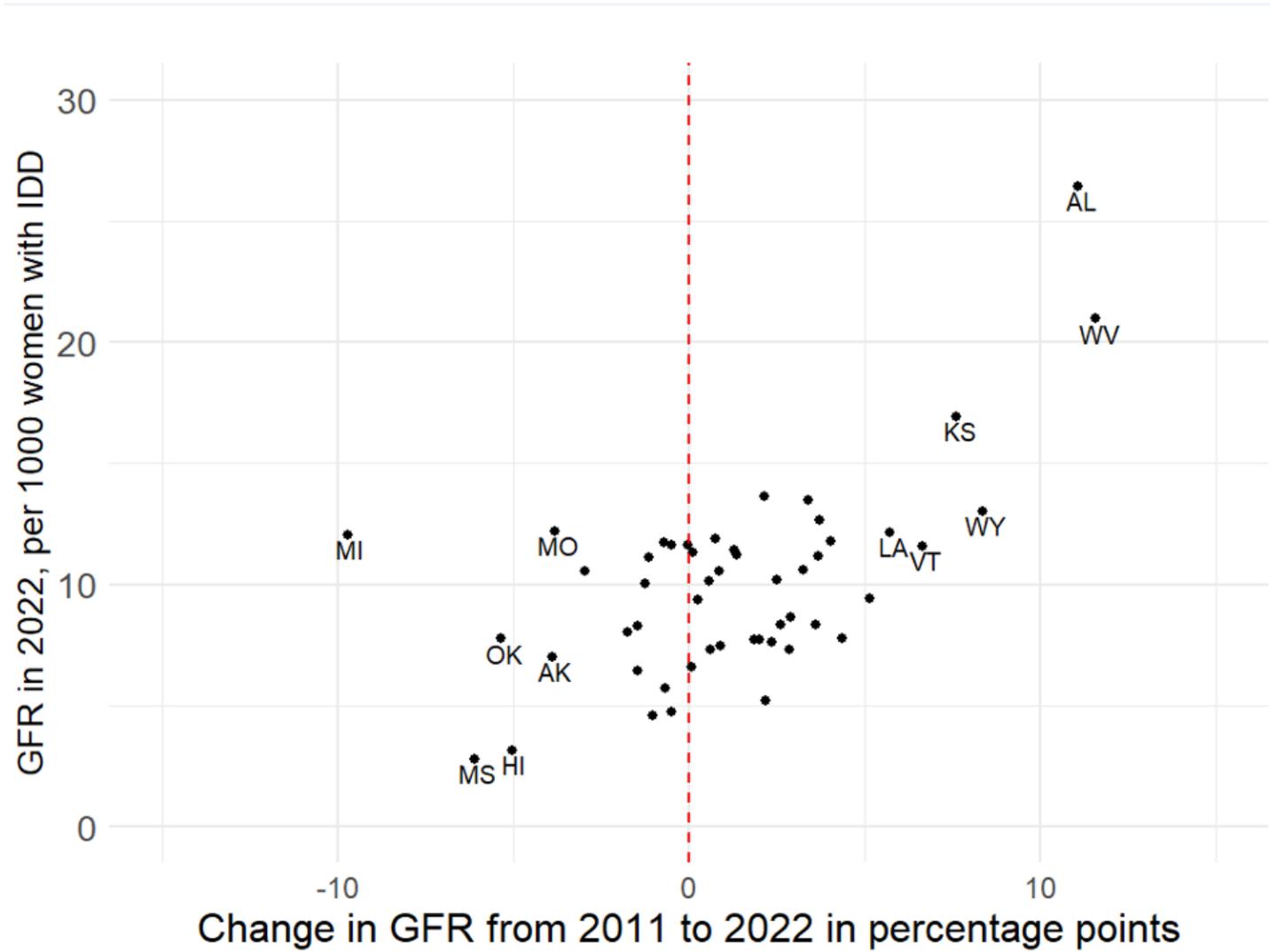
There are big differences by IDD type and age

What do we know about the epidemiology of pregnancy in women with intellectual and developmental disabilities?



Black women with IDD were more likely to have pregnancies but it is getting more even over time.

What do we know about the epidemiology of pregnancy in women with intellectual and developmental disabilities?



State matters!

What we struggle to know

- We can only look at people who were identified by doctors as having an intellectual or developmental disability
 - We miss people who don't go to the doctor a lot
 - We miss people who may identify as disabled but don't get diagnosed

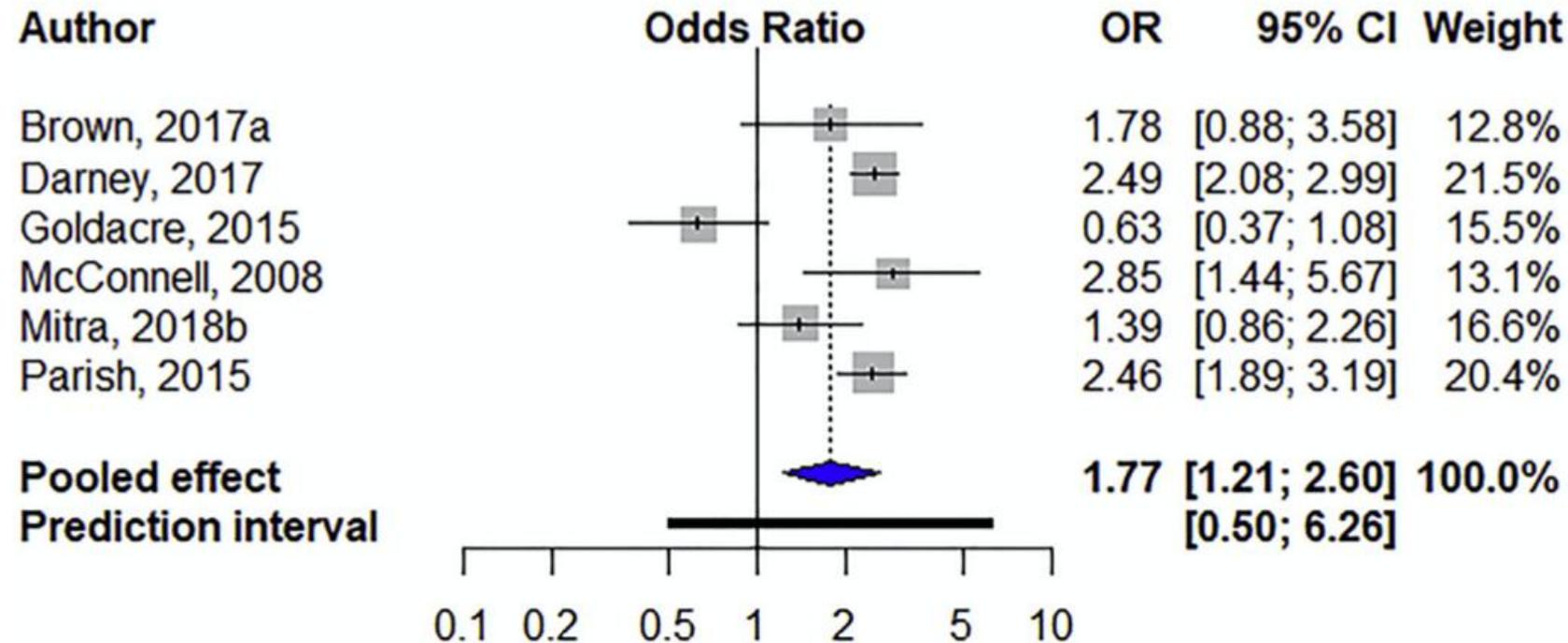
Health outcomes from pregnancy are not great for mom and kid

Lack of care is a likely cause of poor neonatal outcomes

FIGURE 3

Unadjusted association between disability status and hypertensive disorders of pregnancy

C Intellectual and developmental disabilities



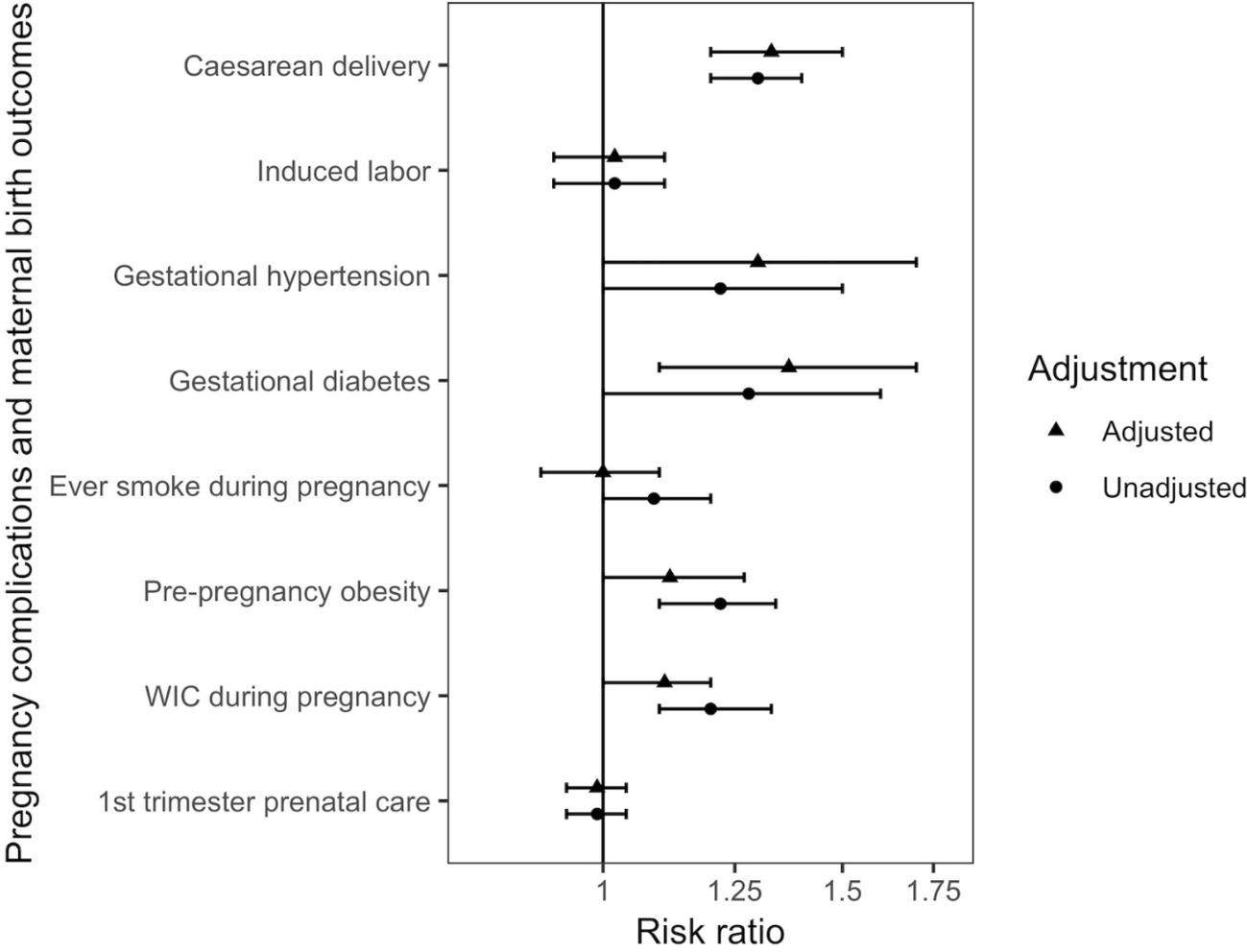


Fig 1. Unadjusted and adjusted risk ratios for prevalent pregnancy complications and maternal birth outcomes for all births comparing women with and without intellectual and developmental disabilities in Wisconsin Medicaid, 2007–2016. Multilevel regression clustered by mother. Adjusted for maternal age, race, ethnicity, foreign born mother, geographic classification of birth county size, parity, marriage, year. Obesity and WIC Data only available for birth years 2011–2016.

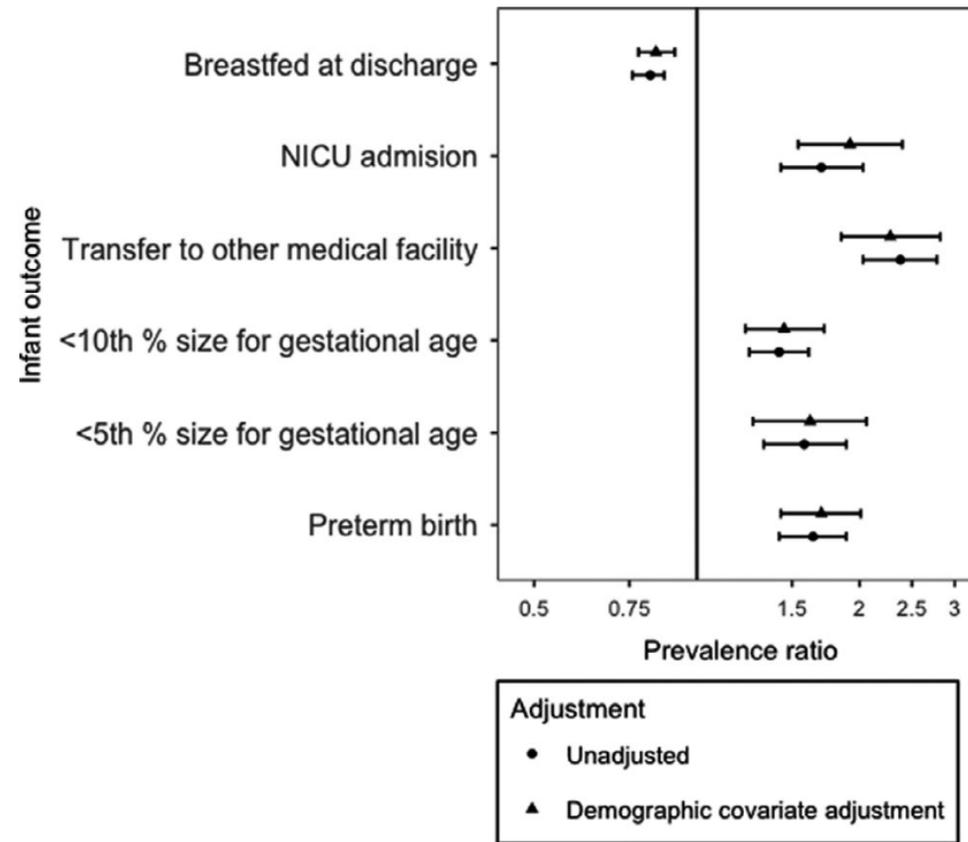


FIGURE 2 Prevalence ratios for prevalent infant birth outcomes comparing singleton infants born to mothers with and without intellectual disabilities in Wisconsin Medicaid, 2007-2016. NICU: Neonatal intensive care unit; Demographics: maternal race, categorised age, Hispanic ethnicity, geographic county size of birth county, father's information on birth record, birth year, parity; NICU admission and breast fed at discharge for 2011-2016 births only. All prevalence ratios are clustered by mother and calculated using log-Poisson regression with robust variance

So, enough misery



Get people health care early in pregnancy



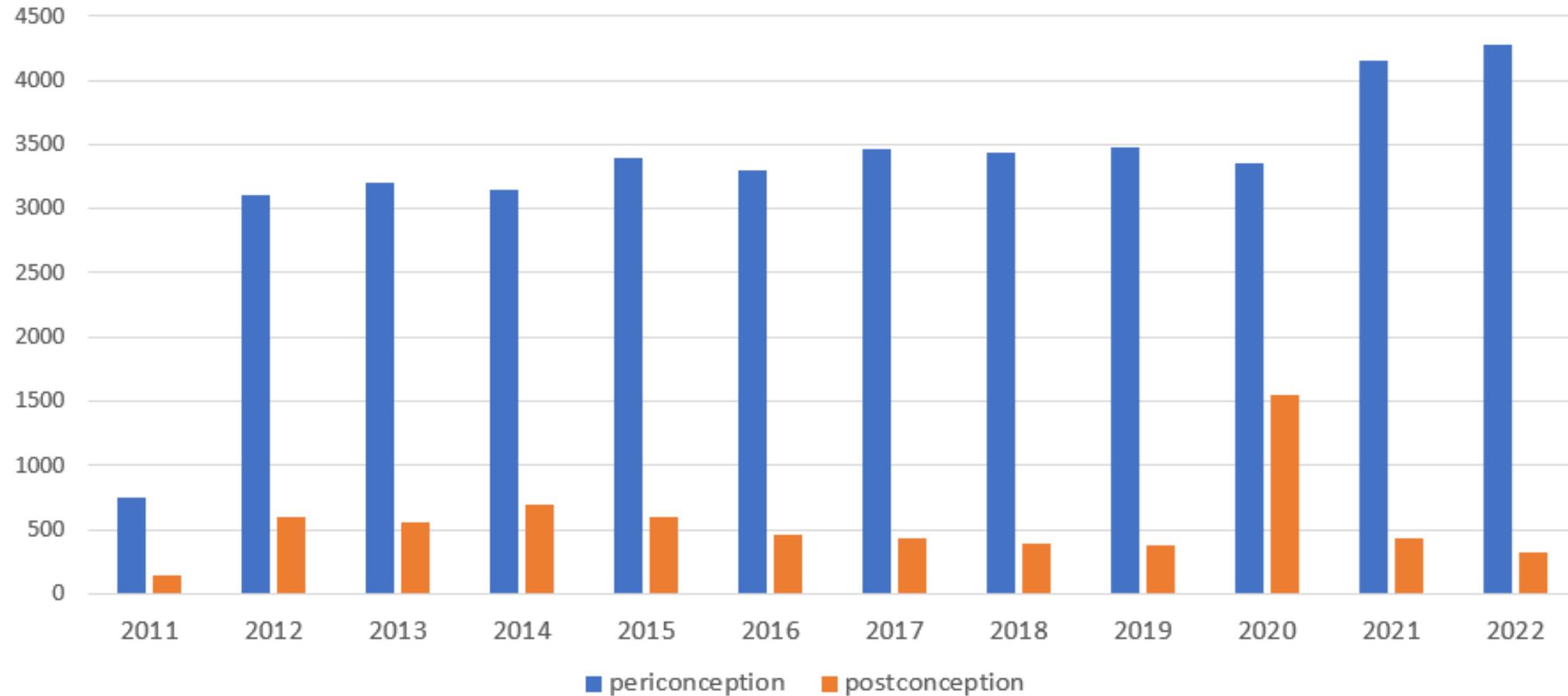
What are the benefits of insurance before you get pregnant

- You had the opportunity to receive some health care for other conditions before your pregnancy
- You can build relationships with your doctors
- You don't have to worry about paper work and signing up while pregnant

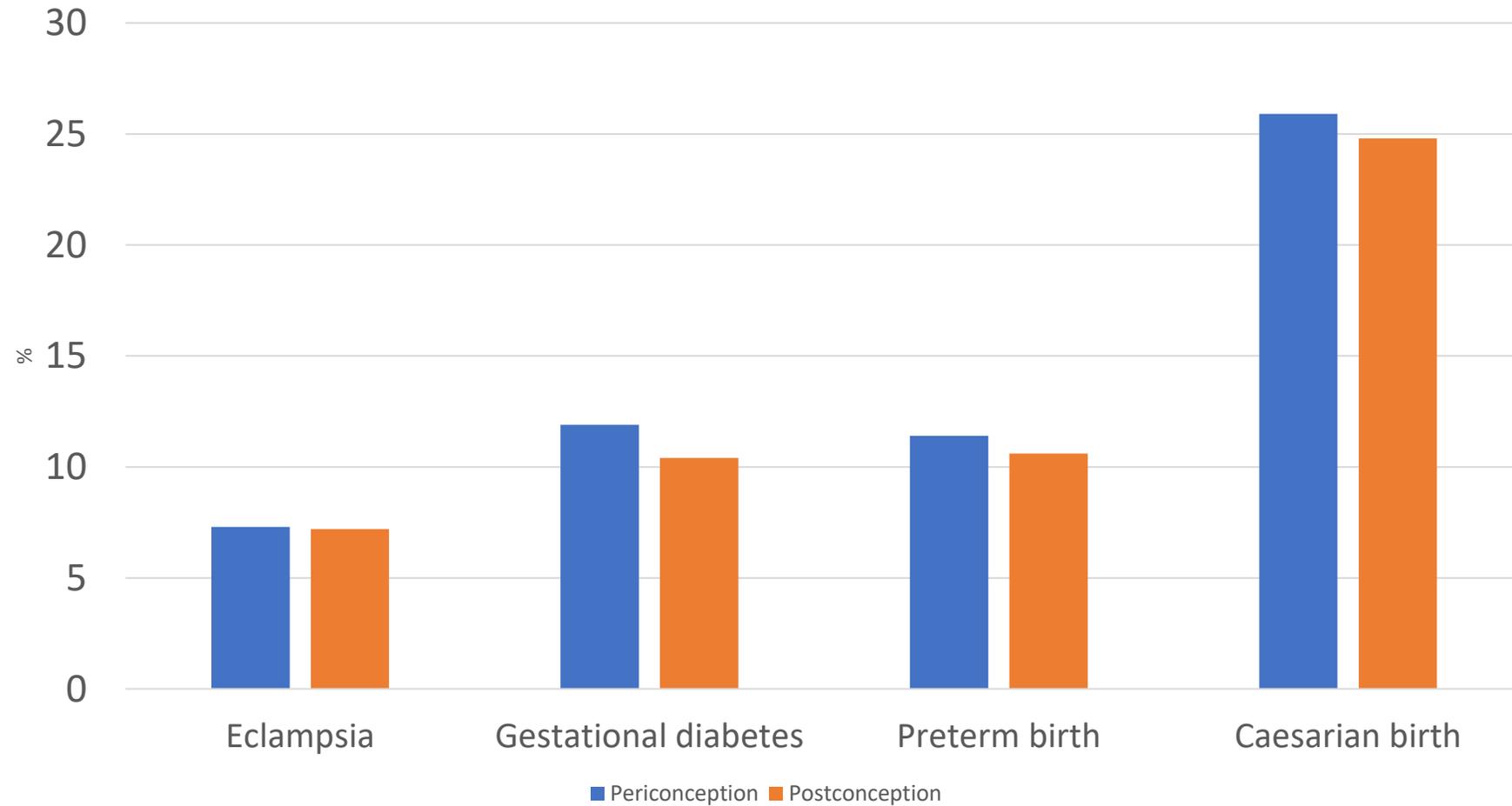
Why are some people not enrolled?

- Too much money
- State opposition
- Administrative barriers

How many are enrolled preconception?



Do outcomes differ?

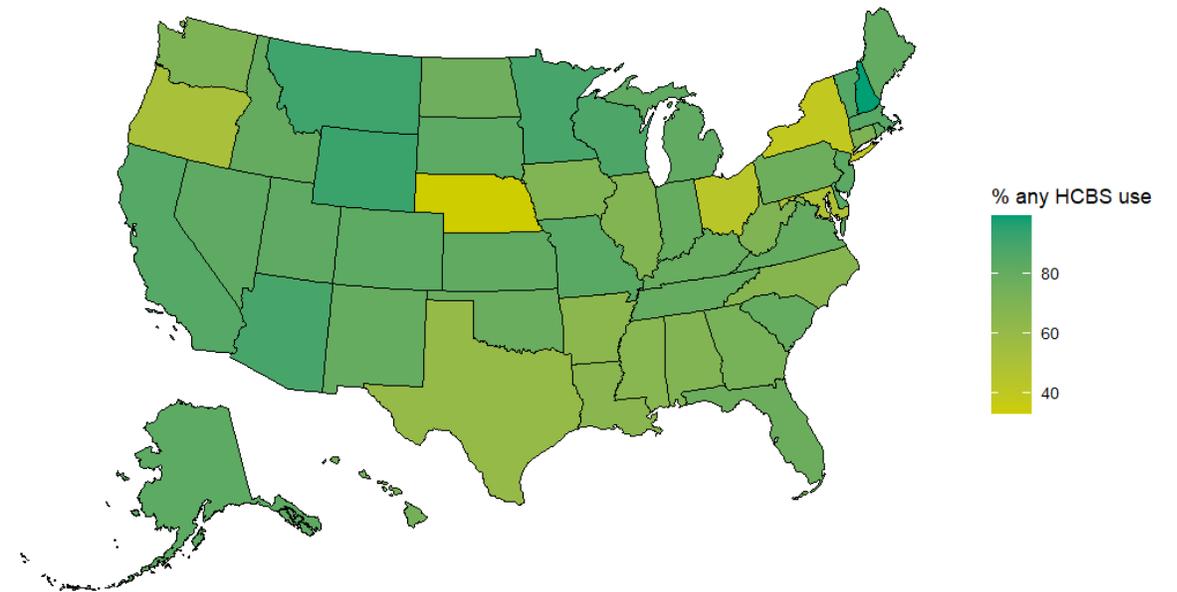


What could be going on

- People enrolling later are healthier
 - People with more impairment already qualified, less likely to be employed
- We are only looking at live births and there is a lot of pregnancy loss

Home and Community Based Services

- Let's make living in the community easier!
- Extra state Medicaid funds for people with IDD for things like transportation, personal care assistants, job coaching
- Cannot be used for child-care
- Varies by state



How HCBS can help pregnancy

- You use HCBS services to pay for job training
 - You get a part time job
 - Now you have more money to take care of yourself and your health
- You use HCBS to hire a personal care assistant
 - You are healthier and happier
 - That helps your pregnancy!

What is our research missing?

- We can only look at people with medical claims for IDD
 - Those self-identified or not diagnosed are not in our data
- We can't examine all pregnancies, just live births
- Many moms are on private insurance

What should we advocate for?

- Everyone should have good health insurance
 - High tides lift all boats
- More HCBS
 - HCBS allowable for child-care?

2. Learn about perspectives of people with IDD about their own health and health care experience during pregnancy



PROMISE-IDD

Exploring Pregnancy Experiences

PROMISE IDD Qualitative Study

Policies for Reproductive Outcomes in Medicaid -
Improving Services for Enrollees with Intellectual and
Developmental Disabilities

PROMISE IDD: Qualitative Study Overview

AIM: to investigate health care and legal barriers, opportunities to improve pregnancy care, and health outcomes through lived experience

Part of a larger national study using large datasets to identify healthcare practices and policies that reduce pregnancy complications in Medicaid-enrolled women with IDD



Community Advisory Board

- 8 members meet 2-3 times a year
 - 6 parents with lived experience
 - 2 work with organizations that support parents with IDD
- Goals
 - Feedback on study design, data collection, dissemination
 - Recruit participants via networks
- Contributions
 - Support with survey and interview accessibility
 - Piloted survey and interview guide
 - Recruitment



Objective

Explore the lived experiences of people with IDD during pregnancy

Focus areas:

- Prenatal care
- Health insurance use (Medicaid)
- Services
- Home and Community Based Service (HCBS) waivers

We will conduct 25-30 interviews with people with IDD to understand their pregnancy stories.

Why this research is important

- People with IDD face stigma and inequity in reproductive and pregnancy care
 - Have a higher risk of gestational diabetes, preterm birth, and being hospitalized after delivery
- More young people are being diagnosed with IDD & need better care as they reach childbearing age
- Little research shows people with IDD's perspectives about their own pregnancy health and healthcare
 - many studies rely on caregiver (proxy) reports instead of self-reports

Methods - interviews

Lived experience matters

- perspectives from women with IDD who were:
 - pregnant in the past 10 years
 - Used Medicaid during pregnancy

Interviews to hear pregnancy stories

- Healthcare: preconception thru postpartum
- Pregnancy planning, health, insurance, care, and support

Timeline mapping of pregnancy experience during interview

Parents with disabilities!
Tell us your pregnancy story

Can I participate?

You may be eligible if:

- You have a thinking, learning, or developmental disability
- You were pregnant in the last 10 years
- You used Medicaid during your pregnancy

What happens if I join?

Two video calls on Zoom:

- **Call 1:** 30 to 45 minutes
We'll talk to see if the study is right for you
- **Call 2:** ~90 minutes
Share your pregnancy story with us

Take breaks when you need them, and ask questions anytime. **We'll go at your pace!**

Receive a \$50 Visa gift card

Interested?

[Click here](#), scan the QR code, or email promidd@bu.edu to get started.

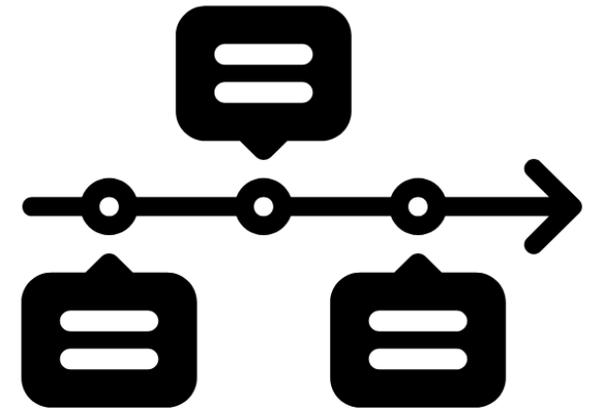
Learn more at:
<https://sites.bu.edu/tubenstein/promise-idd/>

BMC and BU Medical Campus IRB
IRB NUMBER: H-44008
IRB APPROVAL DATE: 11/19/2025

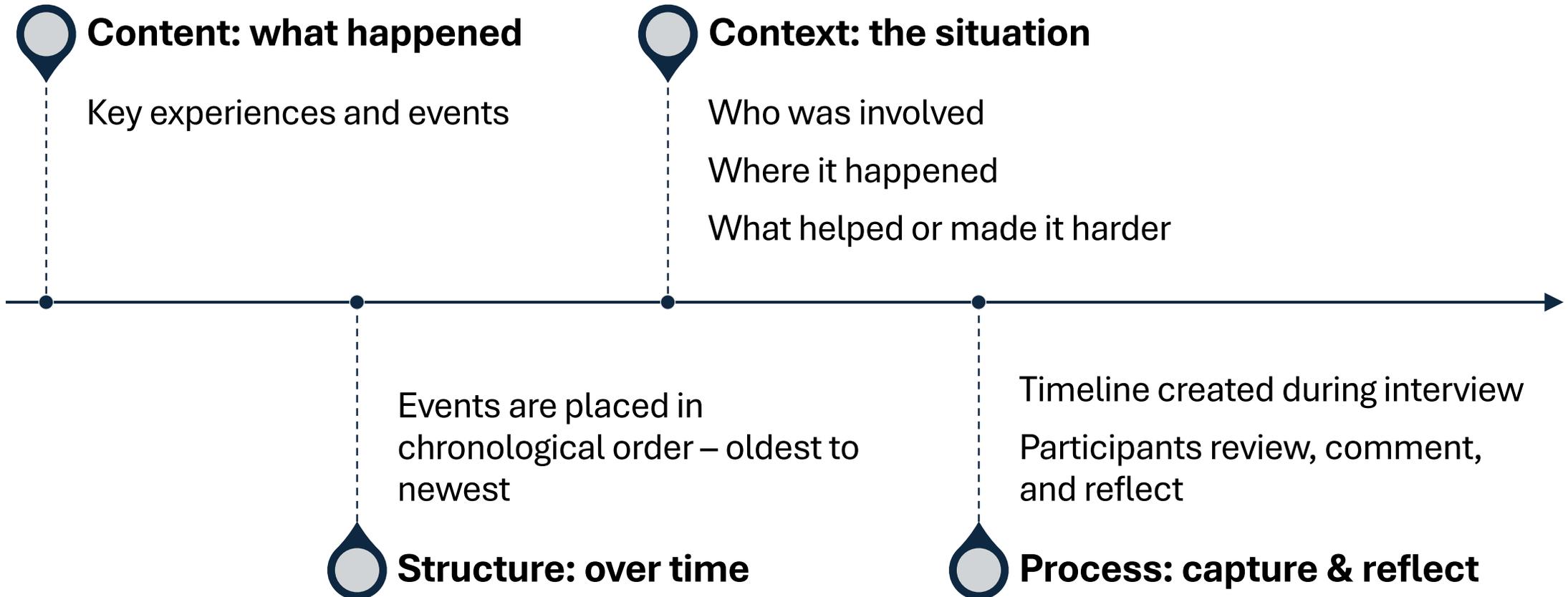
Bottom photo by [Jonathan Baiba](#) on [Unsplash](#)

Methods - pregnancy timeline

- Interview questions encourage storytelling
- Timeline created during interviews
- Built in feedback and reflection with participants
- Participant reflections about:
 - Key events or moments
 - Healthcare decisions



What is timeline mapping?



Timeline Methods – finding meaning together

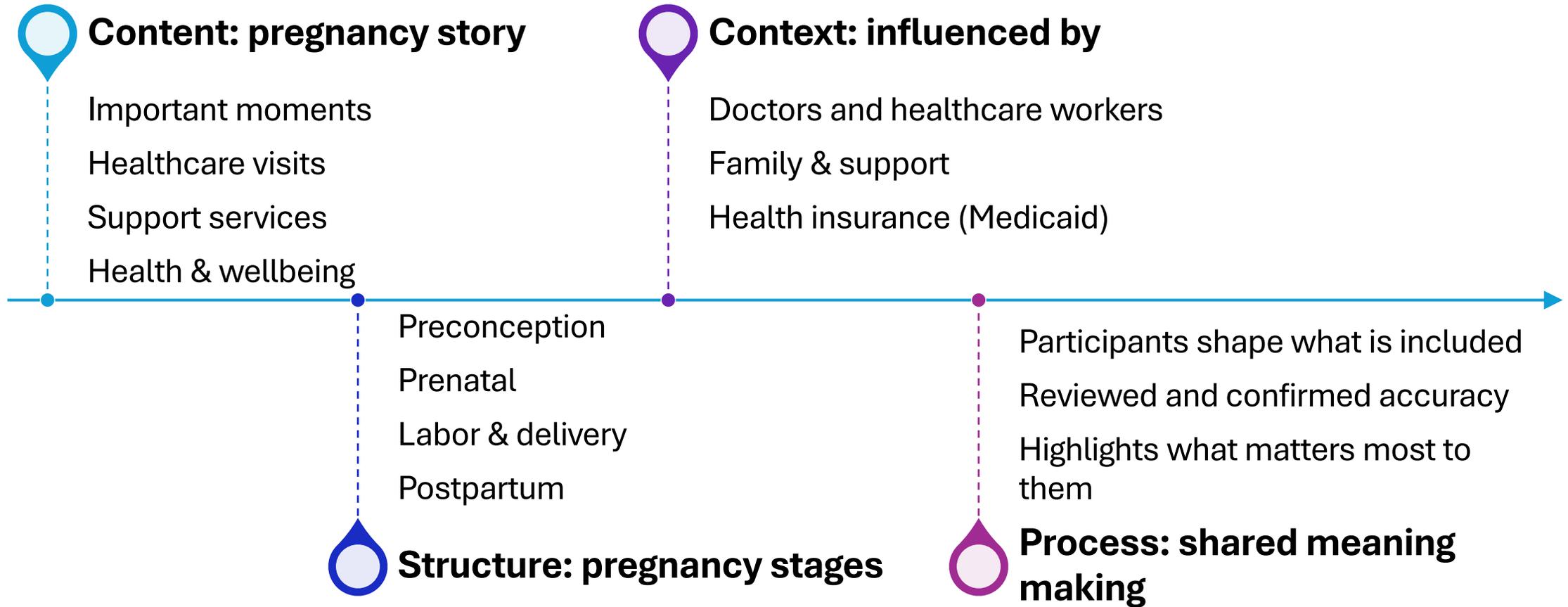
Timeline creation

- Interview questions encourage storytelling
- Timeline created off screen by second study staff during interview
- Built in feedback and reflection with participants

Participant engagement

- Understand process and see blank timeline before interview
- Present timeline for discussion
 - Walk through story to confirm accuracy
 - Add new information
- Participants answer reflective questions
 - Key events
 - Healthcare decisions
 - Impactful moments

What is timeline mapping for pregnancy experiences?



Understanding Pregnancy Experiences

We have connections to pregnancy and disability through lived experience, work, family, and community.

We see how pregnancy is shaped by

- Family and social networks
- Communities
- Healthcare experiences
- Policies and programs

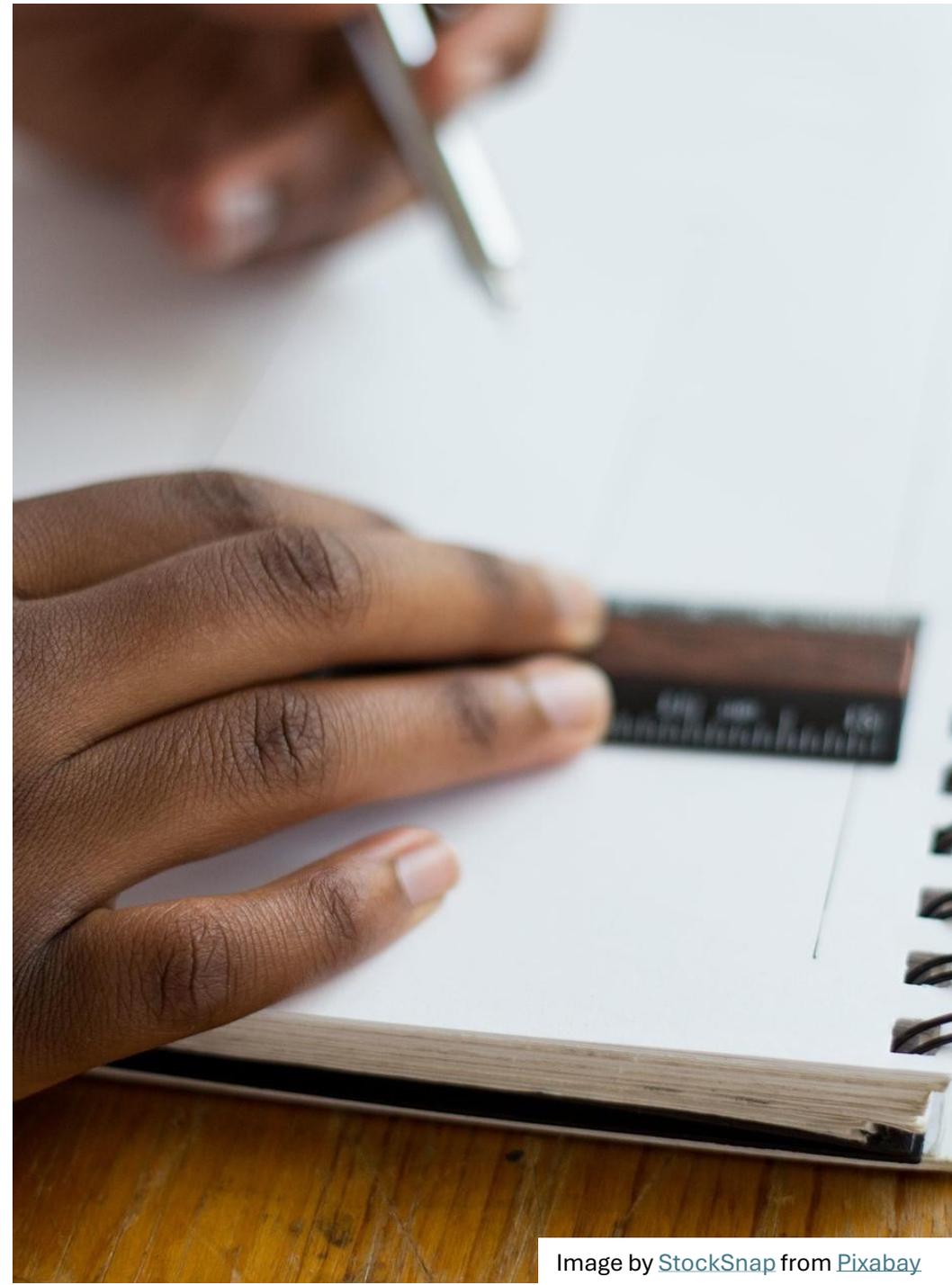


Pregnancy Timeline Activity

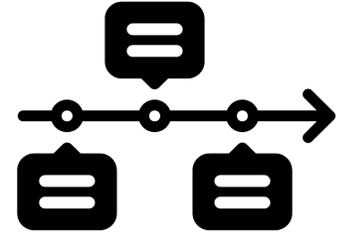
Timelines share what you have seen, experienced, or supported.

First, choose a perspective to draw your timeline:

- your own journey
- a journey you've supported or witnessed
- a system journey: how support is supposed to work



Pregnancy Timeline Activity



- 1. Draw key moments** in the pregnancy journey
Such as finding out about pregnancy, prenatal visits, birth, postpartum care
- 2. Identify supports** during those moments
People, services, or systems involved
- 3. Center lived experience**
Show what it was like, how it felt, what helped, or what was hard

Mapping the Pregnancy Journey



START

Planning for pregnancy
or when pregnancy
became real

END

Postpartum or when
the pregnancy
journey feels
complete



Activity Time

Individual Reflection

Circle where things changed the most
or took a new direction

Draw an arrow pointing to:

- where support mattered most
- where support was missing



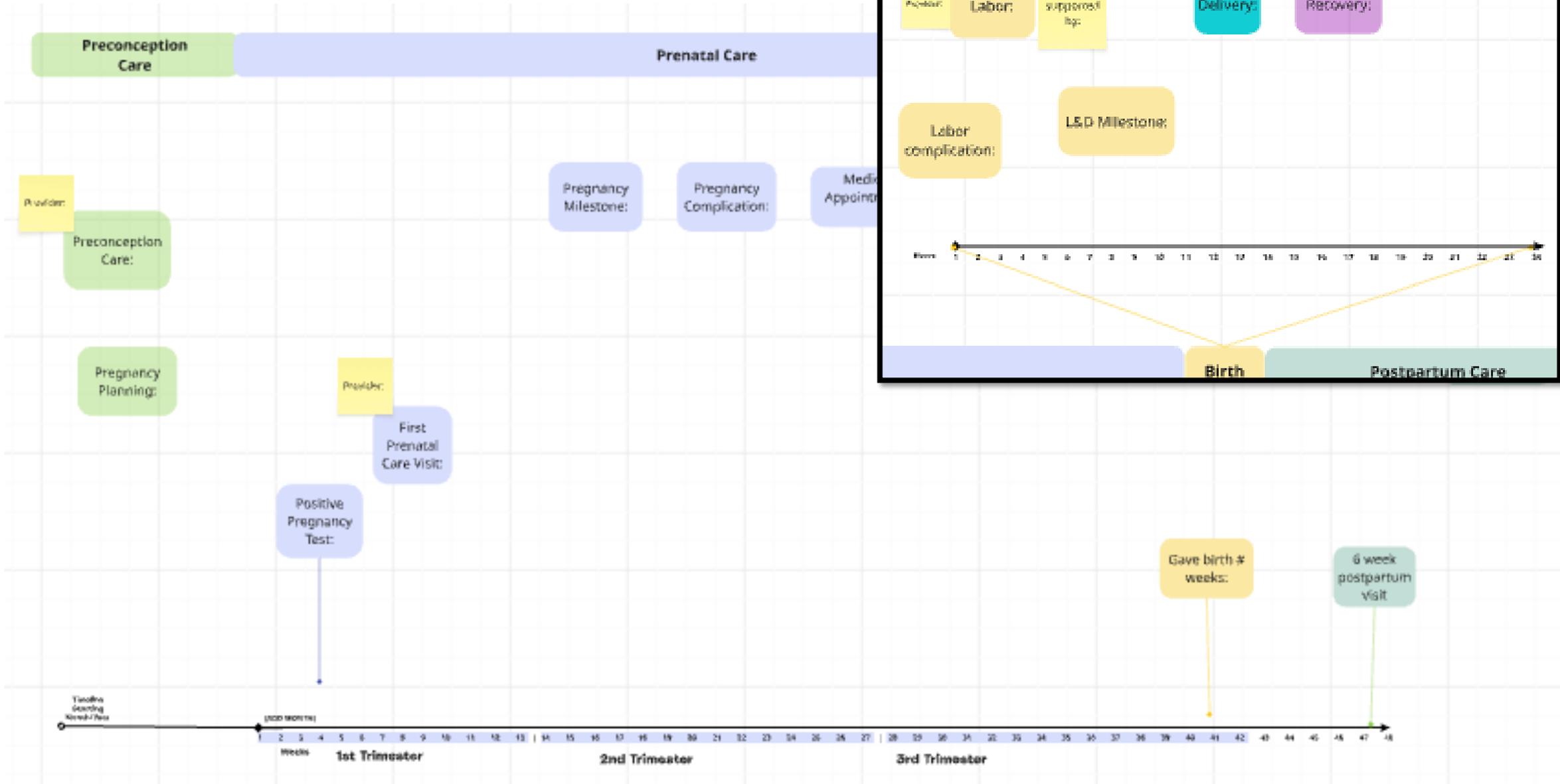
Debrief

Where on your timeline was support the strongest?

Where were the biggest gaps?

Where did the healthcare system, services, or programs make things easier? Harder?

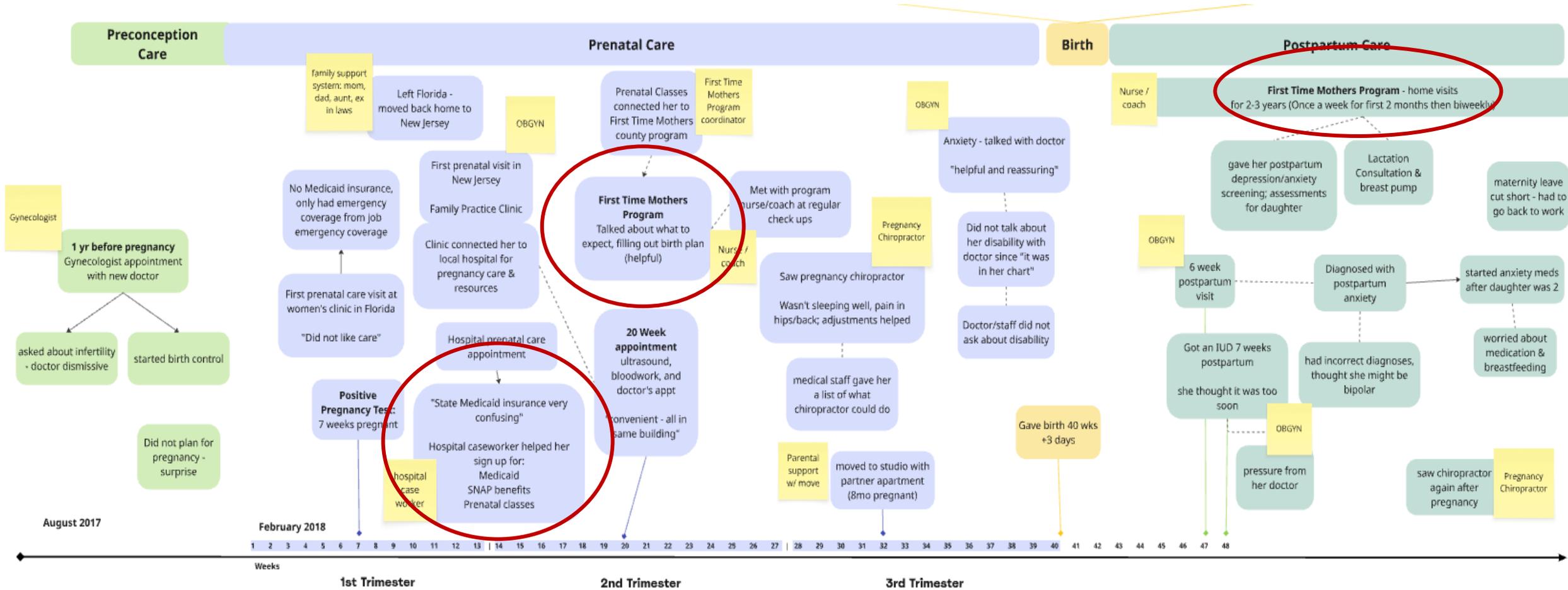
Timeline Template



Timeline Example 1

When care is supportive

Participant reflection: "I got lucky"



First Time Mothers Program - home visits
for 2-3 years (Once a week for first 2 months then biweekly)

First Time Mothers Program
Talked about what to expect, filling out birth plan (helpful)

hospital caseworker helped her sign up for:
Medicaid
SNAP benefits
Prenatal classes

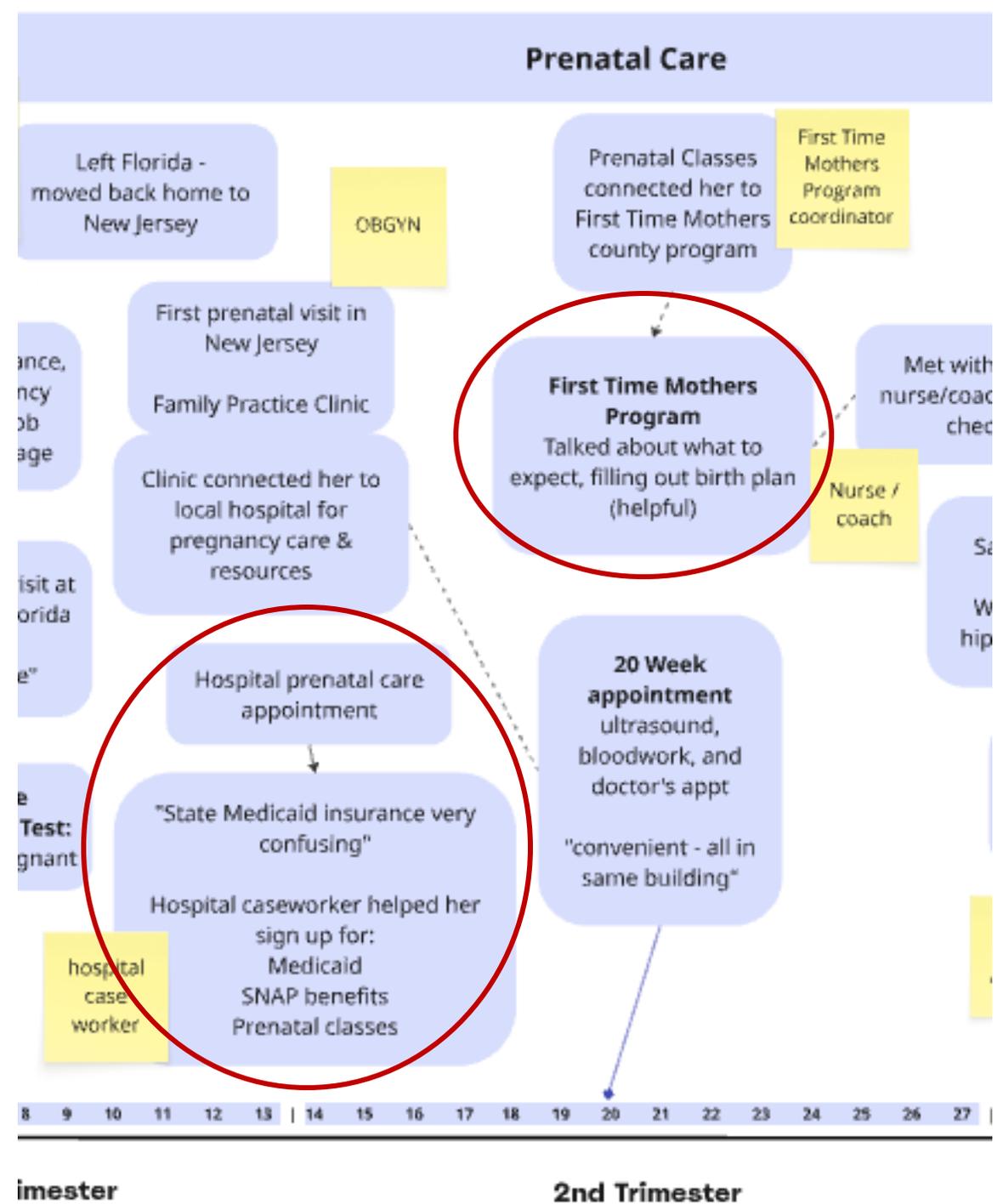
Diagnosed with postpartum anxiety
started anxiety meds after daughter was 2
worry about medication & breastfeeding

Timelines show key events

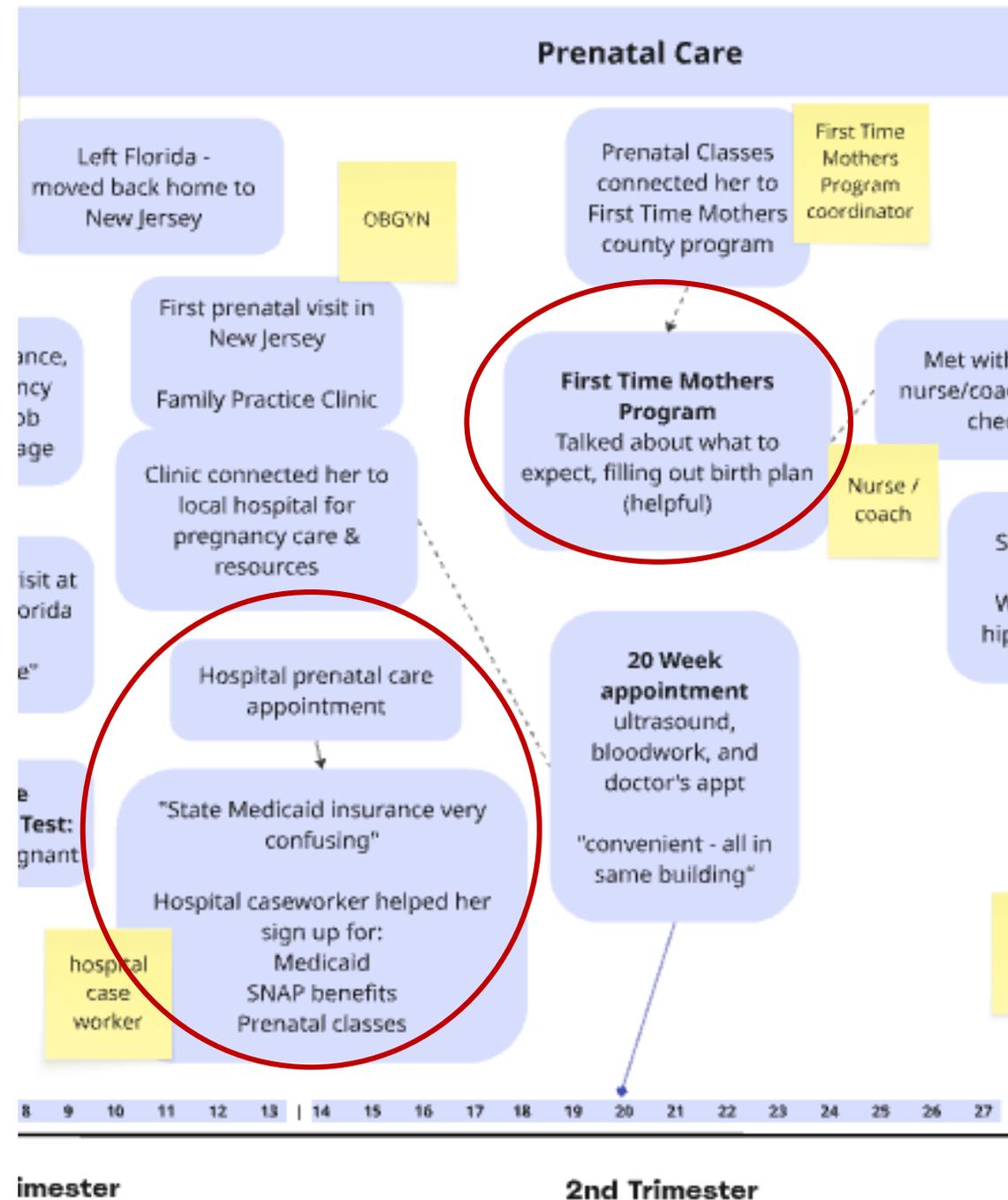
- Signing up for services:
 - Medicaid
 - Nutrition assistance
 - Prenatal classes
 - **First Time Mothers Program**

Participant reflections confirm their importance:

“I got lucky”



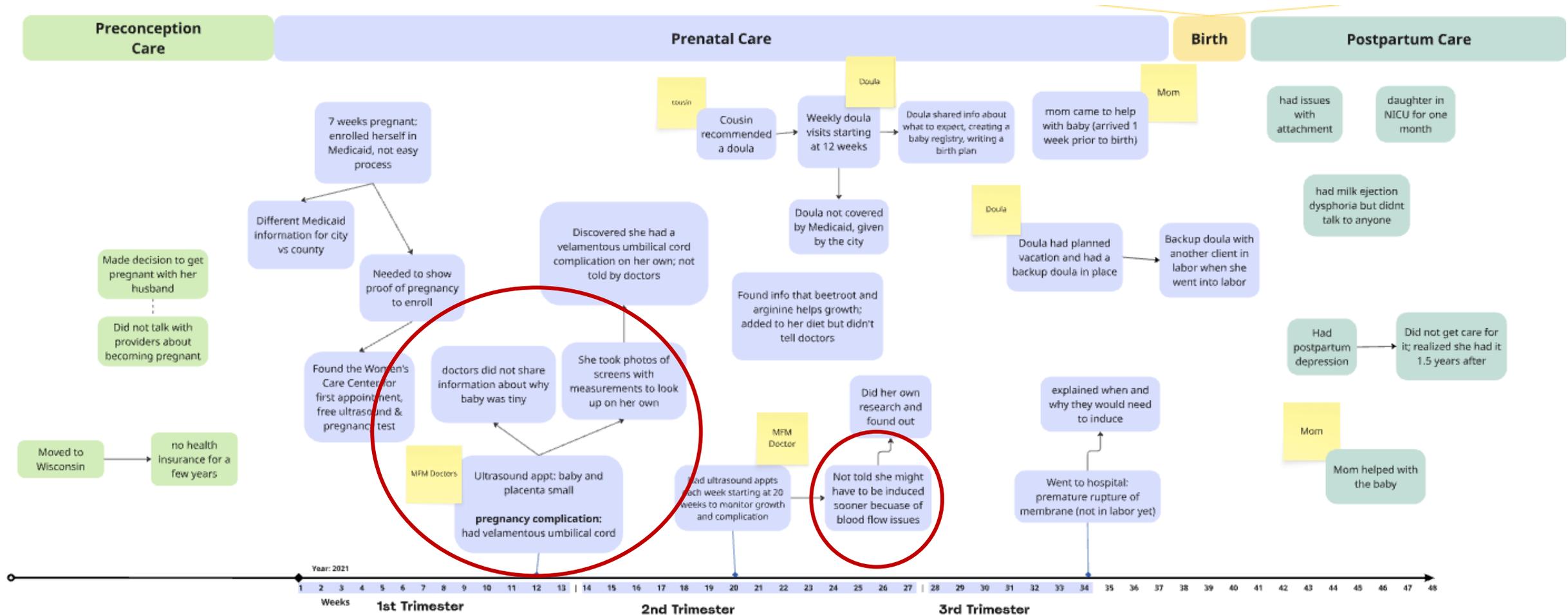
“I had like a first-time mother's nurse coach thing that would come see me... she would come with like a packet of what to kind of to expect. Like every visit, there would be like this monthly packet that we would kind of fill out... So yeah, I really lucked out with her.”



Timeline Example 2

When care is hard to navigate

Participant reflection: "I was on my own and I accepted that"

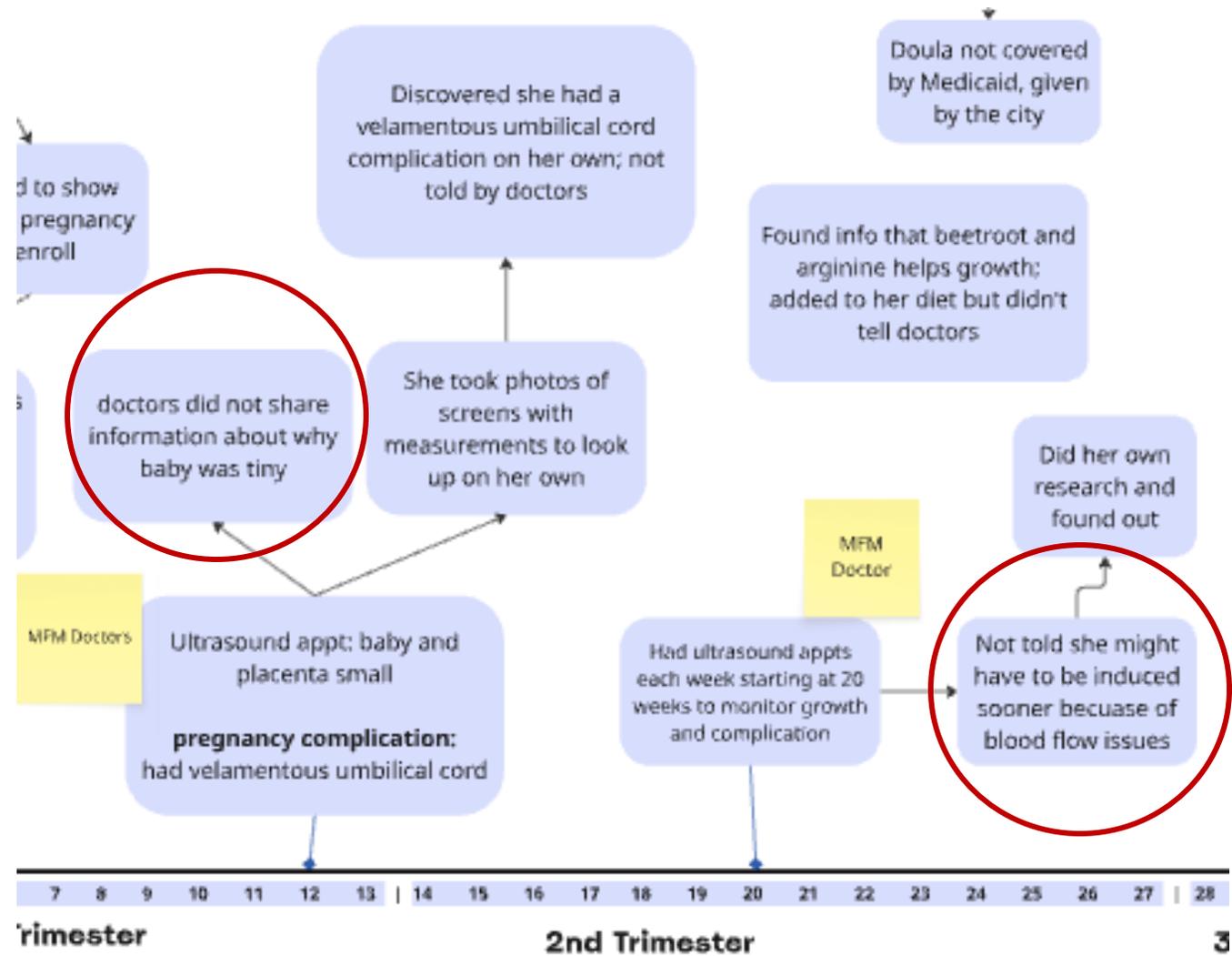


Timelines show key events

- Providers left out important information and risks

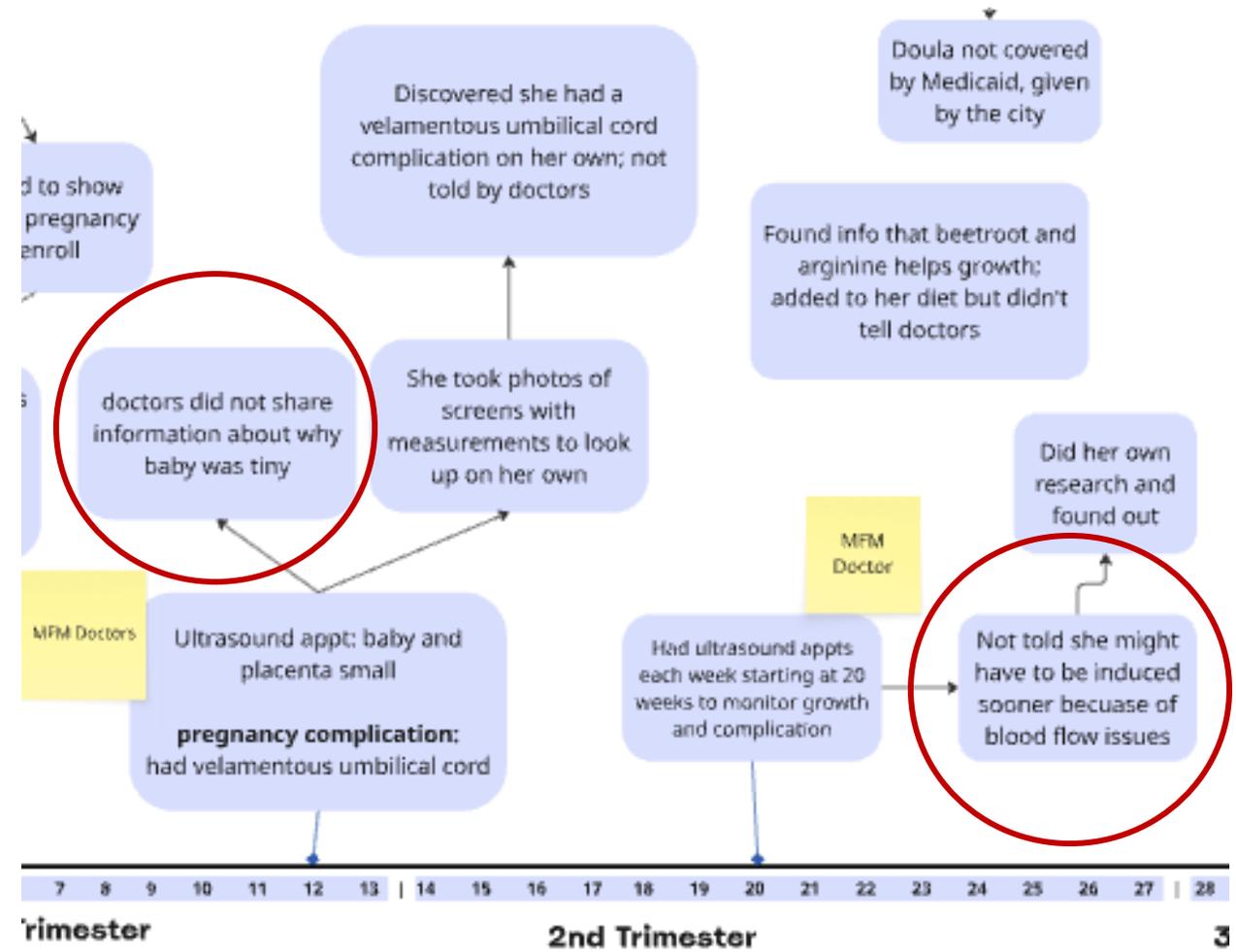
Participant reflections confirm their importance:

“I was on my own and I accepted that”



What decision or event changed your pregnancy experience?

"Well, you could say when I noticed they were just going to keep me in the dark. I'm like, OK, they're going to do their job without telling me anything and I'm just going to accept that and do my job without even also telling them anything 'cause there's no reason."



Analysis

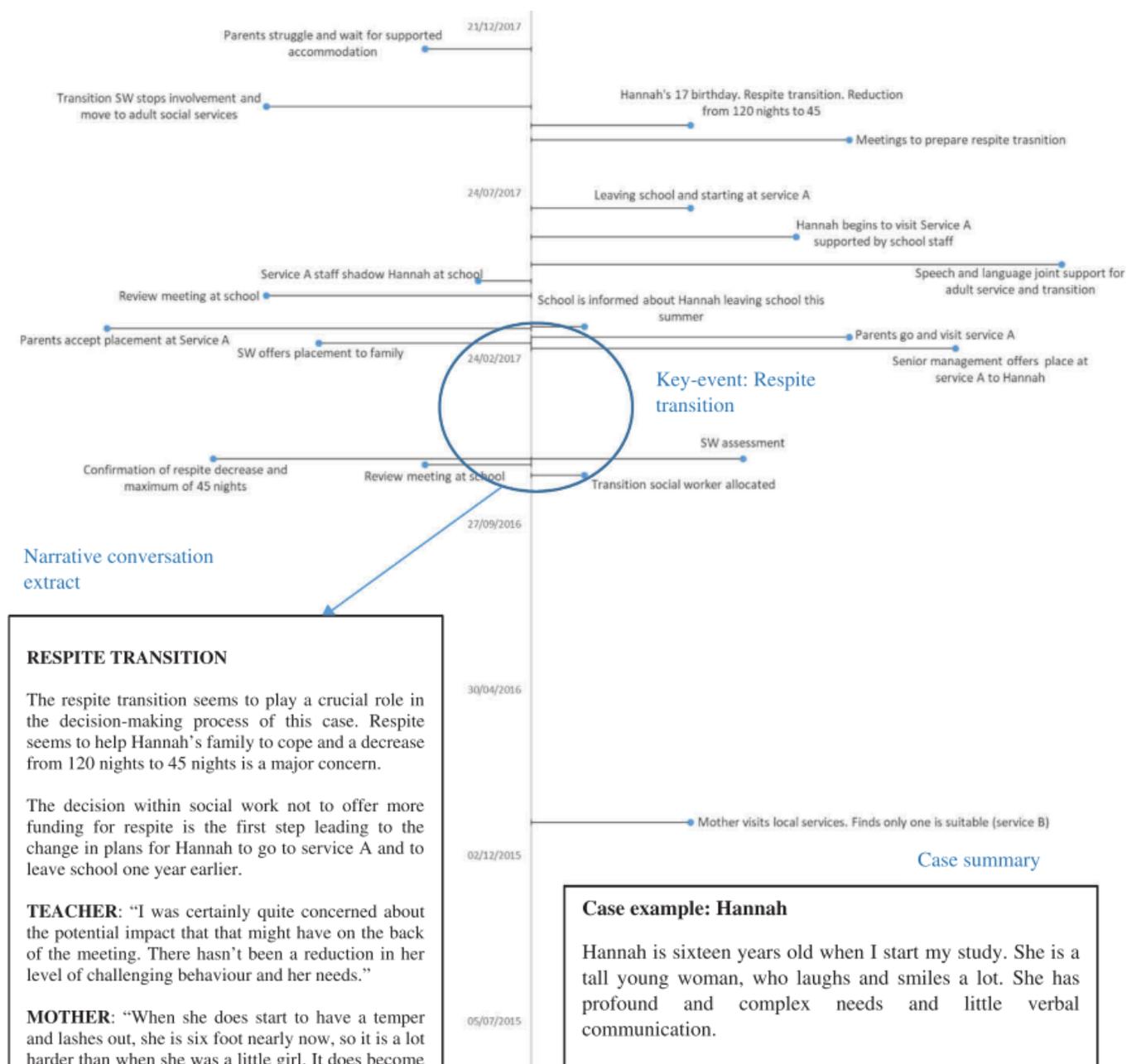
Narrative portraiture to value experience as expertise

Narrative Portraiture Analysis

Interview content connected to key events, centering participant experience

Why we chose this

- centers individual expertise
- Pregnancy narratives – preconception to postpartum

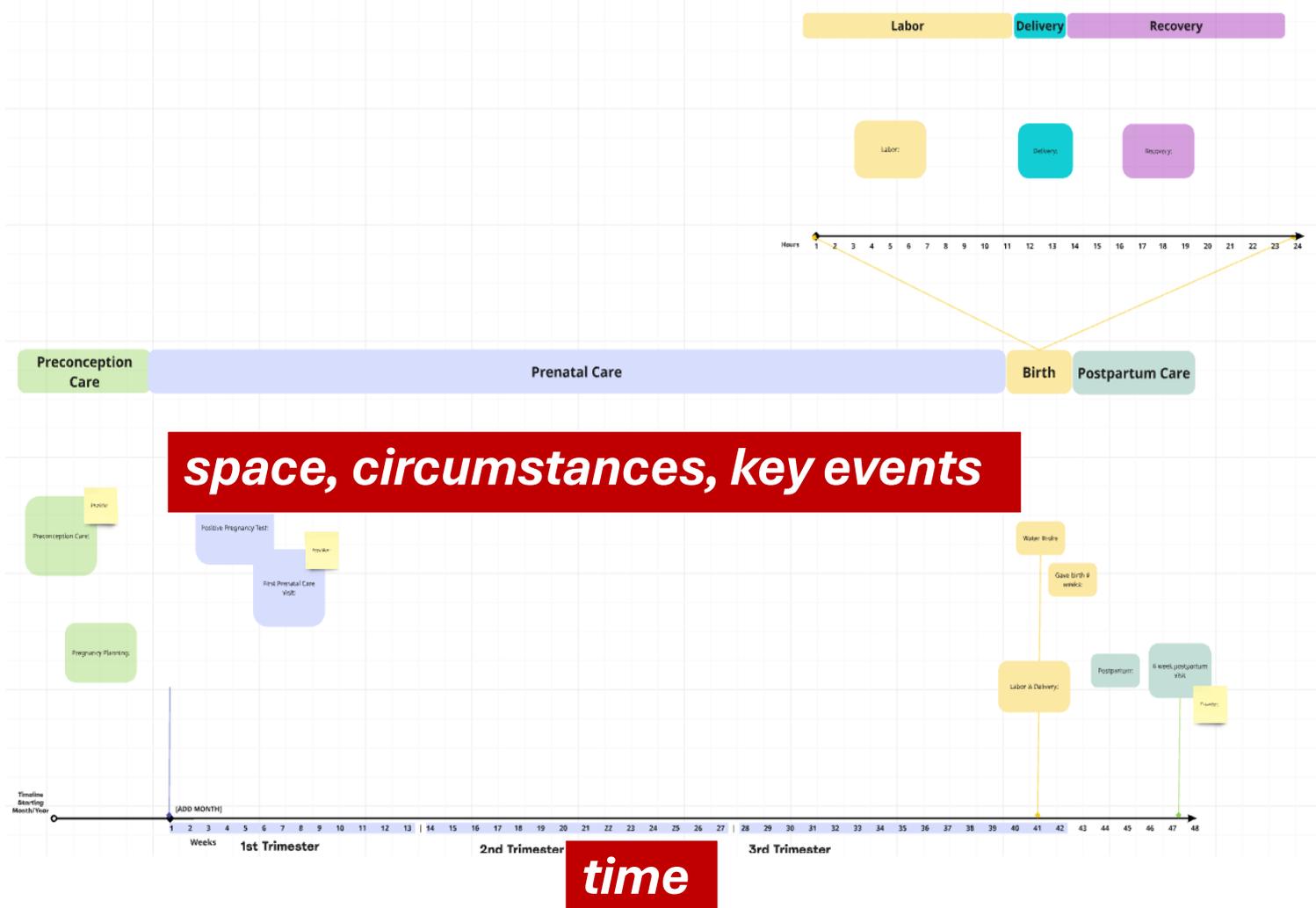
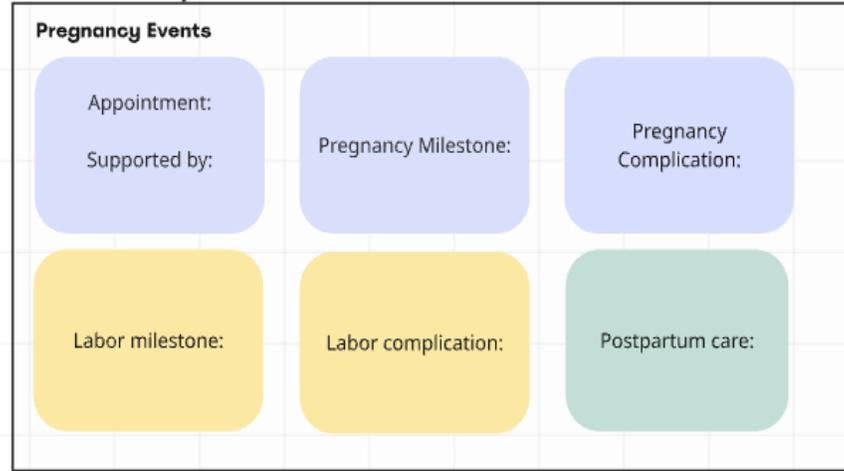


Narrative Portraiture Analysis

- Method's goal is to reflect, interpret, and communicate lived experiences
- What we look for (our codes):
 - Characters: health care team, social services, family
 - Time: preconception to postpartum
 - Space & circumstances: geographic location, political, social, cultural context, ableism
 - Key events: interactions with health system, turning points
 - Phenomena of interest: narrated pregnancy experience & Medicaid use
- Results are a portrait
 - written narrative that emphasizes participant's voice

Timeline Template

Timeline Templates



Narrative Portraiture & Timelines

- Timelines capture *who*, *when*, and *where* of key events
 - Shows a cascade: follow impact of events or decisions over time
 - Inclusive tool to engage participants about their experiences
- Narrative portraiture analysis reflects *how* and *why* of key events
- Participant portraits are research products – a written narrative of their pregnancy experience
 - Participants' words guide the portrait structure
 - Meaning is revealed through engagement, not researcher interpretation
 - Participants are experts on their pregnancy experience

Narrative Portrait: a reading

Pregnancy, disability, and healthcare – lived experience

- What stands out in this portrait?
- Where does healthcare shape their experience?
- Where does disability identity appear?
- Where does support or a lack of it show up?

Communicating pregnancy stories

- Narrative portraiture is a method to analyze and sit with participant experiences
- Audiences are not just observers
 - Connect the story to your experiences
 - Bring own perspective to interpretation
 - Become a witness to experiences typically unseen
 - Ask questions and draw conclusions



Thank you!

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<https://sites.bu.edu/rubenstein/promise-idd/>