Data Quality: Race, Ethnicity, Social & Structural Drivers of Health
Pre-Workshop Activities

Step 1: Read the following narrative*

**Narrative 1: Peripartum Cardiomyopathy**

*Sara, 24 years old, AI/AN, urban setting*

When Sara found out she was pregnant with her first child at 19, she wasn't sure where to go. She had grown up with family and friends in her tribal community on her reservation but had moved to the city after getting married, since her husband had grown up in the area. She couldn't afford private health insurance, and she lived too far away to get care at the Tribal health clinic she had grown up visiting, so she didn't seek prenatal care at first. Sara had grown up surrounded by women having babies, and she knew from their experiences and traditions that she was strong and capable of having a healthy pregnancy and birth.

After a coworker recommended she look into WIC, she found an urban Indian health clinic a few miles away that had a WIC program. She took the bus after work and they helped get her signed up for Medicaid coverage and food benefits. She was also able to begin seeing a prenatal care provider that day. Her provider was also Indigenous, and she appreciated how she didn't have to explain her whole life story as a Native woman to the provider because they came from a similar background. Sara liked that she was also able to access traditional Indian medicine services offered by the clinic as well.

The rest of the pregnancy went well. Her delivery was difficult, and it took her a while to recover. She was treated for bronchitis repeatedly, despite having no prior history of bronchitis, and the doctors said her fatigue was likely the exhaustion experienced by most new mothers. She was a little concerned but didn't want to waste their time.

A few months later she found out she was expecting again - a shock to find out she was pregnant so soon after her first. Fortunately, because of her recent pregnancy, she knew about the health clinic and WIC program, and was able to sign up for Medicaid coverage and begin prenatal care early in her second pregnancy.

She and her husband had trouble paying rent on their one-bedroom apartment and decided to move in with her mother-in-law who lived on the other side of the city. With only one car that her husband needed to get to work and too far from her old job to take the bus, she decided to stay home to care for her first son and prepare for baby two. As a result, her husband had to pick up extra work and was gone most of the time.

Unfortunately, she was also too far away to easily continue care at the urban Indian health clinic, so she had to begin seeing a new provider in the health system of the nearest delivery hospital. Unlike her previous provider, this doctor wasn't Indigenous and didn't have much experience with her culture, so she had difficulty connecting and feeling respected. It was stressful to have to go under the care of someone who did not know her history and who she didn't feel comfortable with. She almost always felt tired and swollen, and still had some issues breathing at night, but was worried her concerns wouldn't be taken seriously or that she would be seen as a complainer. Instead, she wrote them off as part of the normal discomforts of pregnancy, even though her first pregnancy hadn't been this hard.

*Although inspired by the stories and experiences of birthing individuals, these narratives are a work of fiction. Any similarity to actual persons, living or dead, or actual events, is purely coincidental.*
Since her husband had to use their car to get to work, she was concerned about how she would be able to attend the appointments even at the closer facility. Her mother-in-law was willing to take her and watch her son so she could go to appointments, but she also worked and was only available to help sometimes. After the first appointment at the new clinic she was sent home with a ton of paperwork, including pamphlets and flyers for different community services. There was also information about getting Medicaid support to provide transportation to appointments, and she was able to arrange for rides to and from the rest of her visits, which was a relief.

She had a relatively easy birth of a little girl with no interventions. After delivery, she had some trouble staying awake. A nurse voiced some concerns and monitored her closely, but she said she felt fine and was probably just tired from the delivery. The doctor didn’t seem worried and there weren’t clear medical reasons to keep her under observation. She was discharged with some information about possible symptoms to watch for and went home.

The first few days at home went well, and she even thought she was starting to feel better. At her two-day appointment, no health issues were detected. However, after about a week it became more difficult to breathe, and she started feeling like something was wrong. She was worried that Medicaid wouldn’t cover an extra visit before her six-week appointment, so she waited, hoping she would feel better with some extra rest.

A few days later, her mother-in-law was looking over the warning signs materials sent home from the hospital and was concerned that Sara was showing some of the more serious symptoms. She finally convinced Sara to call the doctor. She was told to go in immediately to the ER, where they discovered she had heart failure, fluid in her lungs, and pneumonia. She was diagnosed with peripartum cardiomyopathy, a type of heart failure that is induced by pregnancy. The symptoms often mimic normal pregnancy discomforts, including fatigue, swelling, and shortness of breath, so they are often ignored. She had likely developed peripartum cardiomyopathy with her first pregnancy, but it went undiagnosed and mistreated as other more common conditions. With the new diagnosis, she was able to begin long-term care and treatment, and soon felt much better, thankful to be alive to care for her two young children.

**Step 2: Complete the exercise below**

*Come to the workshop prepared to share and talk about your answers to the questions.*

1. Read this brief overview of the socio-ecological approach to health: 
   [https://borgenproject.org/social-ecological-model/](https://borgenproject.org/social-ecological-model/)

2. Use the story from **Narrative 1** about Sara to map factors onto the most appropriate level of Socio-ecological framework on the following page. Factors can include both protective factors and risk factors as well as behaviors, policies, resources, and historical influences. Consider the following questions when completing this exercise;

   a. Where could impacts of racism and oppression appear in Sara’s story and on the framework?
   b. How would you identify indicators that could measure these factors? How do you prioritize these in modeling health outcomes?
   c. How might this framework or levels be adapted to better reflect different communities (i.e. when working with AI/AN communities considering tribal policy, Indian Health Care System, and impacts of colonization)?
   d. How do specific factors at different levels influence factors at other levels in the framework?
The Socio-Ecological Model

Step 3: Read the following narrative*

Narrative 2: Substance Use and Mental Health
Amanda, 21 years old, non-Hispanic White, rural setting

Amanda had struggled with drugs and depression for years. She started smoking and drinking after the death of her mother in middle school and began trying other drugs by high school. She had a good relationship with her dad, but he worked late hours, often leaving her on her own in the evenings, when her depression was the worst. As a result, she used substances to self-medicate, finding some relief and distraction. She was referred to her school counselor, who she felt safe with and developed a supportive relationship. After graduating high school, feeling that college was financially out of reach, she suddenly found herself outside of the comforts of routine and without the support of the teachers and counselor who had helped her while in school. She began to use substances even more frequently to cope as she struggled to find work.

By the time she turned 20, she found that her addiction had become more than she could manage, and she frequently slept on friend’s couches and worked odd jobs to support her habit. She had tried a couple of times to get clean, but felt it was nearly impossible without help, especially since all of her friends used. Her mental health continued to deteriorate, but lack of insurance or consistent employment made getting help feel even more impossible. A few times she went to the ER and was even admitted to a psychiatric hospital one time for a week. Meanwhile, she maintained a relationship with her dad who encouraged her to seek help and always offered her a place to stay until she could get back on her feet.

When she found out she was pregnant, she got even more adamant about beating her addiction and getting proper mental health care. She even entered a residential drug treatment program that accepted and worked with pregnant and postpartum parents. After rehab, she found that resources for pregnant women dealing with addiction in her area were extremely limited, and most were in the larger urban areas hours away. At the only Medication-Assisted Treatment (MAT) clinic in her town, she was told she couldn’t begin MAT while pregnant. Fortunately, her boyfriend was able to find a new job that offered health insurance for both of them, and she was able to begin prenatal care. Her doctor referred her to a mental health support group for pregnant women held at her clinic, and she enjoyed the sessions, finding the environment supportive and hopeful.

As part of getting clean, she also tried to start over with a whole new group of friends. Even with her new friends from the support group, she often felt alone. Her boyfriend was extremely supportive but worked full-time. The emotional ups and downs of pregnancy made it all even more difficult. She felt bad about becoming a burden on her boyfriend or her dad. She was able to remain sober for most of her pregnancy, focusing on the health of her baby as motivation, even when her mental health felt at its worst. She didn’t feel she could be truly honest with her OB/GYN about her history or concerns, worried that she might be judged or lose custody of her baby. She was also afraid of postpartum, unsure how she was going to be able to deal with addiction, depression, and a new baby, and concerned it might be more than she could handle.

After having her baby, she stopped taking medications, including antidepressants, concerned about how they would affect her baby while she breastfed. She tried to continue going to the support group, but found the process overwhelming with a new infant in tow. Her depression intensified, as did her anxiety and feelings of being alone. Two months after having her baby, her boyfriend found her in the bathroom after overdosing. She had relapsed. She was rushed to the hospital, where she was revived and stabilized. Before discharge, a care coordinator at the hospital was able to help her find an outpatient mental health clinic close to her home that accepted her insurance, and she was finally able to begin MAT to assist in her recovery.

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A lactation consultant at the hospital also convinced her she could safely take her prescribed antidepressants without harming her baby. She started to feel better, in a better place with her mental health and addiction recovery than before she was pregnant. She returned to the support group and was able to continue the new friendships with the other women there. She found joy in being a mother and was thankful to be healing and sober to care for her baby.”

**Step 4: Complete the exercise below**

*Come to the workshop prepared to share and talk about your answers to the questions.*

<< Watch this video on the Life Course Video to Health: [https://www.youtube.com/watch?v=6Zqr2Q90mgM](https://www.youtube.com/watch?v=6Zqr2Q90mgM)

3. Use the story from **Narrative 2** about Amanda to map factors and events onto sections of the life course on the next page below. Consider the following questions when completing this exercise;

   a. What are factors that are happening to Amanda? What are factors that are a result of or behavior in reaction to something that happened?
   b. What are some key timepoints where interventions could have had a bigger chance of success? How could this story have been different if Amanda had the resources to attend university after high school?
   c. How could Amanda’s experience impact her child short-term and long-term?
   d. What are the relationships with other people that impact Amanda’s health and how do they fit into this timeline?
The Life Course

Infancy

Childhood

Next Generation

Young adult

Adolescence

Mature adult

Elder