Colorado Evaluation & Action Lab
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"This was the first baby I got to take home with me…it was rough."

Lived Experiences of Prenatal Substance Use in Colorado (Findings Report)

REPORT HIGHLIGHTS:

Background: Solutions to address the prevention, treatment, and recovery of prenatal substance use must be data-informed and family-centered.

Purpose: This qualitative research study explored lived experiences of substance use during pregnancy.

Methods: The study used a grounded theory approach and in-depth interviews with 25 birthing individuals with a history of prenatal substance use in Colorado.

Innovation: Peer researchers with lived experience co-designed the study, led data collection, and supported analysis and recommendation development.

Findings: Five themes emerged that illustrate leading risk and protective factors influencing service navigation and family well-being.

Recommendations: Nine recommendations elevate family voice to drive policy and practice change.

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Executive Summary

Background: Solutions to address the prevention, treatment, and recovery of prenatal substance use must be data-informed and family-centered. The Colorado Department of Human Services, Office of Children, Youth & Families, partnered with the Colorado Evaluation and Action Lab to conduct a qualitative research study on lived experiences of substance use during pregnancy. This study is a companion to the perinatal substance use data linkage project. The data linkage project links administrative data from across systems to understand service patterns and outcomes of dyads affected by prenatal substance use. Pairing lived experience with administrative data can yield more holistic insights to inform policy and practice solutions.

Purpose: The purpose of this qualitative study was to identify risk and protective factors service navigation and well-being for families affected by prenatal substance use in Colorado.

Methods: This study used a grounded theory methodology and in-depth interviews to capture lived experiences from pregnancy through the first year postpartum. Peer researchers with lived experience co-designed the study, led data collection, and supported analysis and recommendation development. This innovation facilitated a trauma-informed, harm reduction approach. Use of peer researchers is known to increase rigor and accelerates the path from research to application.

Sample: 25 birthing individuals shared their story. All were in recovery or actively in treatment. Three locales were targeted: Denver-metro area, Pueblo and Colorado Springs, and San Luis Valley. About half the sample included pregnant people of color. About one-third of participants were part of the immigrant or refugee community. 55% of the sample had child welfare involvement. Polysubstance use during pregnancy was common (84%).

Findings: Five themes (with sub-themes) emerged from lived experience narratives. Together, themes illustrate how substance use during pregnancy is experienced and services navigated in Colorado.

- Theme 1: The perinatal period can be an empowering moment
- Theme 2: Birthing individuals face layers of barriers that impede access to help
- Theme 3: Financial stability is the foundation of family well-being
- Theme 4: Even a single, key relationship can make all the difference
- Theme 5: Birthing individuals experience disrespect from health care providers

Recommendations: Nine recommendations elevate family voice to drive policy and practice change.

1. Prioritize rapport-building and empathetic care
2. Expand opportunities for peer support, including investing in doulas and recovery coaches
3. Support scaling of Plans of Safe Care in voluntary, community-based spaces during pregnancy
4. Promote more respectful, person-centered health care
5. Promote anti-stigma initiatives and elevate spaces for storytelling and story-sharing
6. Promote financial well-being for childbearing families and co-locate concrete supports
7. Invest in regional systems-building to improve collaboration across services and supports
8. Require procedural transparency and clear communication about child welfare
9. Develop accountable standards for respectful care of incarcerated individuals

Conclusion: This qualitative study leveraged the power of lived experience data to inform practice and policy solutions. Findings can be used to improve parent-infant health and set families up for thriving.

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Thank you to our partners who provided subject matter expertise and guidance on this project. Project design was informed by the SuPPoRT Colorado (Supporting Perinatal Substance use Prevention, Recovery, and Treatment) Family Advisory Board and the Data and Research Advisory Group. Outreach and recruitment were supported by Illuminate Colorado, Hard Beauty, Elephant Circle, and Tough as a Mother. This qualitative project complements the longstanding perinatal substance use data linkage project, supported by the Colorado Evaluation and Action Lab (Colorado Lab), the Center for Prescription Drug Abuse, and legislation (e.g., SB19-228, SB20-228, SB21-137) passed by the Colorado General Assembly.

Our sincerest appreciation to the participants in this project, who openly shared their story and who inspire change each day. Thank you for being you.

Data Sources

This study used a grounded theory approach to qualitative research. Data sources include semi-structured, open-ended interviewing with n = 25 birthing individuals with lived expertise in three locales in Colorado, alongside iterative dialogue with the peer researchers. All findings are grounded in the best available research evidence about prenatal substance use prevention, treatment, and recovery.

Suggested Citation

Everson, C. L., Beletic, J., Clark, A., Miller, A., & Brown, S. (June 2024). "*This was the first baby I got to take home with me…it was rough."* Lived experiences of prenatal substance use in Colorado (Findings Report). (Report No. 19-08G). Denver, CO: Colorado Evaluation and Action Lab at the University of Denver.

Note on Gender-Inclusive Language

The Colorado Lab affirms our commitment to the use of gender-inclusive language. We are committed to honoring the unique gender identity of each study participant and validate that pregnancy, birth, and family formation are experienced by individuals across the gender continuum. Throughout this report, we follow the guidance of the Associated Press Stylebook and the Chicago Manual of Style and use the gender-neutral, singular "they" when appropriate and use gender-inclusive terms, such as "birthing individual," "parent," and "pregnant person" when referring to perinatal experiences. Because this study is rooted in participant voices, their words are also included throughout.

Trigger Warning: This report contains sensitive topics and real experiences, including substance use, sexual abuse, and mistreatment.

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Study Background

Introduction

Description of the Study

Sample

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Introduction

- **A qualitative research study was done to generate experiential data from birthing individuals with substance use during pregnancy through the first year postpartum.**
- **This study is a companion to the perinatal substance use data linkage project, which uses administrative records to understand outcome and service navigation.**
- **Pairing lived experience with administrative data can yield more holistic insights to inform policy and practice solutions that improve well-being for these parents and their infants.**

Comprehensively addressing prenatal substance use in Colorado requires robust, data-informed policy and practice. The Colorado Legislature's Study Committee on Opioid and Other Substance Use Disorders responded to this need with Senate Bill (SB) 19-228, a data linkage project that uses administrative records to examine perinatal substance use outcomes and service navigation (results here).

To elevate family voice and add context to the data linkage project, the Colorado Department of Human Services (CDHS), Office of Children, Youth, and Families, partnered with the Colorado Evaluation and Action Lab (Colorado Lab) to conduct a companion qualitative research study.[i] This qualitative study generated experiential data from birthing individuals affected by prenatal substance use, capturing their experiences from pregnancy through the first year postpartum. Pairing lived experience with administrative data can yield more holistic insights to inform policy and practice solutions that strengthen families.

Why This Study?

Initial findings[1] from the perinatal substance use data linkage project identified several risk and protective factors associated with child welfare involvement and removal of an infant from the home. Results point to the need for improved care coordination across systems. While the data linkage project identified the "what" of the issue (e.g., less than adequate prenatal care, low participation in Women, Infants, and Children (WIC), greater medical fragility of the newborn), only qualitative research can unpack the "why" (e.g., why do pregnant people with substance use avoid health care?). Solutions to address prevention, treatment, and recovery of prenatal substance use must be family centered. This qualitative research project leverages lived experience as a powerful form of data to inform feasible and meaningful solutions. This study uses an innovative approach that employs peer researchers with lived experience to promote rigor and improve relevance of findings and recommendations made.

Description of the Study

> **This qualitative study identified risk and protective factors that influence service navigation and well-being for families affected by prenatal substance use.**
>
> **A grounded theory approach with semi-structured interviewing was used.**
>
> **Peer researchers with lived experience co-designed the study, led data collection, and supported analysis and recommendation development.**

[i] The Office of State Planning and Budgeting provided funding for this project to CDHS.

Study Purpose and Research Questions

The purpose of this qualitative study was to identify risk and protective factors that influence service navigation and well-being for families affected by prenatal substance use in Colorado.

The primary research question was:

- What are the **lived experiences** of navigating substance use treatment, health, and human service systems in Colorado during the childbearing year?

Three sub-questions guided the study. For families experiencing prenatal substance use:

- What **resources and services** are most needed to support the health and well-being of caregivers and their infants?
- What **barriers** to accessing needed resources and services are faced?
- What **helps** caregivers navigate and best use needed resources and services?

Using these research questions, the following dimensions of family experience and person-centered outcomes were explored:

- **Facilitators and barriers** to cross-system care coordination and promotion of parent health, infant health, and family well-being;
- **Variation in outcomes and experiences** for families and communities to understand equity impacts and strategies; and
- **Internal and external factors** at play in perinatal substance use origins, treatment, and recovery.

Language Matters

In this study, we use inclusive language to reference experiences of childbearing and substance use. Language in this study also reflects how the health of the parent-infant dyad is intimately connected and the well-being of the whole family network impacted. Terms used interchangeably in this study to honor the gender identities and words of participants include:

- Pregnant persons
- Birthing individuals/childbearing families
- Parent-infant dyad
- Maternal-infant dyad
- Birthing individual-infant dyad
- Prenatal substance use
- Substance use during pregnancy

Terms such as “substance exposed newborn” are only used when referencing technical language from child welfare or other systems.

Methods

This was a qualitative research project that used narratives from birthing individuals as the primary source of data. A modified grounded theory methodology was used for data collection, analysis, and findings.[2] In grounded theory, researchers ask a series of semi-structured, open-ended questions and look for common or recurring themes in narratives. These themes are then translated into schema or models that map interviewees' responses and form the foundation for interpretations. Research is therefore "grounded" in the participants' experiences, as participant responses (and not the researchers' preconceived expectations) dictate the categories evaluated. The result is development of a local-level theory on how substance use during pregnancy is experienced and services navigated.

Peer Researchers to Promote Resonance, Relevance, and Rigor

Peer researchers with lived experience co-designed the study, led data collection, and supported analysis and recommendation development. Previous research documents that use of peer researchers promotes greater rigor and trustworthiness of results.[3] This is done by creating mechanisms for critical reflection and transparency that uncover and mitigate bias during data collection and analysis. Peer researchers can also accelerate the path from results to application, where practice interventions, policy decisions, and community supports are more appropriately developed, and findings more broadly shared. Most importantly, research with pregnant and parenting people affected by substance use requires novel strategies to ensure accurate data and ethical treatment of participants. Use of peer researchers in this study allowed for a trauma-informed, harm reduction approach during data collection activities with this vulnerable population. Telling one's story to a peer can also bring therapeutic benefits.[4,5] The authentic, robust integration of families with lived experience serves to increase the scientific strength of this qualitative study, while also promoting equity and access in the research and in associated practice and policy recommendations.[6] Peer researchers were provided training and ongoing support by the Principal Investigator throughout the project and were a core part of the study team.

Innovation in Qualitative Research

This project uses peer researchers with lived experience in prenatal substance use to promote a trauma-informed, harm reduction approach. This approach improves rigor in qualitative research and promotes more relevant policy and practice solutions that center family voice.

Recruitment and Outreach

Participants were recruited through community-based programs and statewide networks that serve pregnant and parenting people who may have personal experiences with prenatal substance use. Three locales were targeted to ensure rural, suburban, and urban inclusion: 1) Denver-metro area; 2) Colorado Springs and Pueblo; and 3) San Luis Valley. These study locales were prioritized because:

- Existing data indicate that these communities have high concentrations of substance use;
- Each area has substance use treatment providers serving pregnant persons or co-located care;
- Collectively, these locales represent the urban/suburban and rural/frontier landscapes of Colorado;
- Demographic characteristics of area populations reflect the racial, cultural, and social diversity of Colorado families and factors that previous research[7] from the data linkage project found to be associated with prenatal substance use and child welfare involvement.

Programs that supported participant recruitment have trusted connections with the target population, share the value of community- and family-led solutions, and can feasibly support qualitative projects of this nature. These recruitment sites were provided outreach materials to share online and in physical locations with participants (Appendix A: Copy of Outreach Material). The recruitment flyer was co-designed with peer researchers to promote resonance with the population and a harm reduction approach; it follows the University of Denver's (DU) Institutional Review Board (IRB) guidelines for recruitment materials. Snowball sampling was also used, where participants could let others in their network know about the study and share the recruitment flyer.

To protect confidentiality and ensure participation was voluntary, potential participants self-identified to the study team as being interested in learning more. This kept recruitment sites from knowing the identity of any study participant or unduly influencing participation. Potential participants contacted the study team using these methods: Scanning a QR Code that brought them to an online form to learn more and sign-up; or calling or emailing a dedicated project email/phone to be sent the online form directly and otherwise connect with a peer researcher. Providing multiple contact methods promoted more equitable access to participation, recognizing that not all families have the same access to technology and their privacy must be safeguarded when learning about the study. The online sign-up form gave information about the study, screened for eligibility, and provided resources around substance use treatment and perinatal health.

Resource Connections and Support

Ethical research means building in supports throughout the study. Some participants may not want to participate in the study, but may see the project as an opportunity to connect to resources or seek help. As such, substance use, health care, and mental health resources (specific to each locale) were embedded in recruitment, enrollment, and interviewing materials. The top five resources for each study locale were informed by peer researchers.

Data Collection

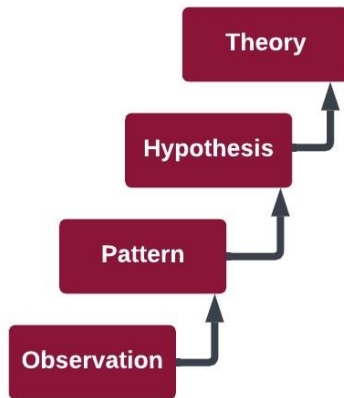
Eligible participants (see study sample) were invited to participate in a 60- to 90- minute virtual (video conference) or in-person interview at a safe and private location of their choice. All interviews were conducted by a peer researcher using the study interview protocol. Interviews followed an open-ended, semi-structured approach where questions had structure, but where the conversation could also unfold organically and probes used to delve deeper on an as needed basis. Before beginning the interview process, the peer researcher took time to build rapport, including sharing portions of their own story and otherwise finding ways to connect with the participant to open up a safe space for sharing. After rapport building, verbal consent was obtained for participation, using the approved IRB consent process. With permission, all interviews were audio-recorded for accuracy and then professionally transcribed. Fieldnotes were also taken to supplement where needed. Audio-recording allowed the research team to accurately document participant words and to record how their narratives were expressed with non-verbal communication, as applicable.[8] Transcriptions were then analyzed using a modified grounded theory approach. Participants received a $75.00 gift card as compensation and gratitude for their time.

Data Analysis

Interview narratives were analyzed by two members of the research team using NVivo qualitative analysis software, following the grounded theory approach. Each analysis included open-coding to generate categories, followed by focused and axial coding in which the relationships between categories were

identified, explored, and connections made. Theoretical coding was the final step, in which themes emerging from the original analysis were informed by existing literature. Inductive reasoning was applied throughout, where analysis stayed close to the data to inform theoretical codes from the ground up (Figure 1).

Figure 1. Inductive Coding in Grounded Theory Research



Interrater Reliability

Interrater reliability (IRR) in qualitative research helps promote rigor and richness in the analysis. IRR rates how cohesively different coders analyze the data. The IRR for this qualitative research study was evaluated using Cohen's Kappa coefficient. The calculated Kappa value was .89, indicating a high level of agreement among the researchers during analysis. In qualitative research, navigating through disagreements necessitates a commitment to the principles of iterative learning and flexible adaptation. Grounded theory thrives on the diversity of perspectives, allowing for a richer understanding of the data. When disagreements arose, the researchers engaged in reflective dialogue, examining the roots of their differing interpretations to deepen analysis and enhance robustness of findings. [9,10]

Member Checking

"Member checking" is a process where emergent findings are presented back to those with lived experience to explore areas of resonance and disagreement between researchers' interpretation and participant narratives. Member checking is a prime mechanism to promote validity and accuracy in qualitative research.[11] In this project, member checking was done as a workshop with the peer researchers, who drew on their personal lived experiences and professional knowledge as peer specialists to help refine emergent findings and co-design the data-informed recommendations.

Institutional Review Board Approval

This study was approved by the IRB at DU. To reduce harm, protect confidentiality, and meet IRB requirements, a verbal consent process was used. All recruitment, data collection, and analytic materials and procedures followed DU-approved IRB templates and requirements. The Colorado Lab's secure server was used for data management and to conduct all analyses. The server is accessed remotely with VMware Horizon virtual desktop infrastructure and two-factor authentication using DUO. All data are encrypted at rest and the server meets the FIPS 140-2 requirements for HIPAA and 45 CFR 160-164.

Sample

> **Purposive sampling was used to construct the sample, where a set of shared characteristics was the basis for selection.**
>
> **In total, 25 birthing individuals with a history of prenatal substance use completed in-depth interviews. Both rural and urban experiences were included.**

Purposive sampling was used to construct the sample, where a set of shared characteristics was the basis for selection. This approach helped meet project goals around understanding diverse geographic, demographic, and perinatal period experiences. To be eligible for the study, the inclusion criteria were:

- Have a history of prenatal substance use in the last five years;[ii]
- Planning to deliver or already delivered in Colorado in one of the three study locales (San Luis Valley, Pueblo/Colorado Springs, Denver-metro area);
- Be at least 18 years of age;
- Have capacity to consent and participate in English;[iii]
- Type of substance previously misused was opioids or other illicit substances (alcohol abuse or marijuana use, alone, was not an eligible substance); and
- Be in recovery and/or actively in treatment.

These shared characteristics align the sample with defined focus areas for the data linkage project. The cross-sections of pregnancy, birth/immediate postpartum, and first year of life were probed in each interview and tracked for depth across the sampling frame. These cross-sections match major childbearing and substance use recovery periods, which in turn facilitates better identification of cross-system opportunities. These inclusion criteria were also important to ensure a harm reduction approach, promote feasibility and testing of innovative approaches, and respect the boundaries of peer researchers.

Theoretical Saturation

Theoretical sampling (an extension of purposive sampling) was used to determine the final sample size, where qualitative data was collected until categories were considered "saturated" or when no new details relevant to the developing theory emerged.[12] Grounded theory studies commonly use a sample size of 10 to 25 to achieve concept saturation and to provide "thick description." Previous studies involving pregnant and postpartum persons affected by substance use have generally achieved saturation at 10 to 30 participants.[13,14] In this study, saturation of the emergent themes was achieved at n = 25 participants.

[ii] For some participants, their lived experiences became a catalyst for a professional career as a peer advocate, addiction counselor, or other type of community health worker. To capture a wider range of lived experience, voices, and the perspective of peer specialists as a growing field, some exceptions to the birth year window were made (i.e., three participants had birth years just outside of the five-year window).

[iii] Future studies in this area should expand to non-English speakers. Limiting to English-speakers was an intentional choice for feasibility, and a noted limitation of this study.

Individual and Community Characteristics

At the time of participation, 22 participants had given birth and three participants were currently pregnant. About 32% of participants represented rural experiences and 68% represented suburban/urban experiences. About half the sample included pregnant people of color, with Black/African American, Hispanic/Latinx, and Indigenous perspectives represented. About one-third of participants were part of the immigrant or refugee community, specifically African migrants. Some participants also had experiences with incarceration during the perinatal period. The diversity of the sample allowed deeper explorations into disparities and disproportionalities, and highlighted major barriers being experienced by the most underserved communities. All participants were actively in recovery at the time of the interview.

Underserved Communities and the Social Determinants of Health

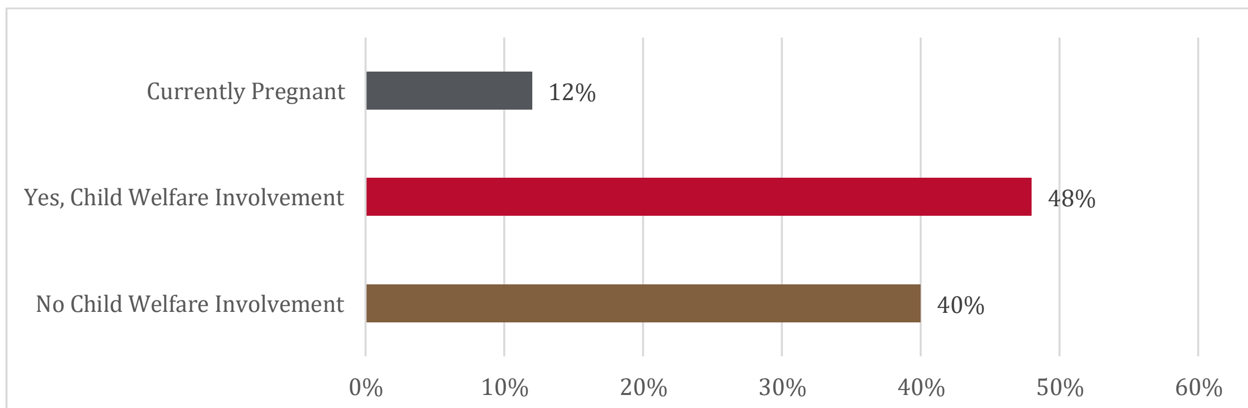
Substance use in pregnancy is a public health concern that is intricately linked with the social determinants of health. Disparities in built environments, such as inadequate housing and lack of access to health care facilities, can worsen the risks associated with prenatal substance use. These environmental factors, coupled with limited access to quality health care, often leave pregnant individuals highly underserved. Systemic issues like racism and poverty can lead to increased stigma and societal marginalization, making it even more challenging for those affected to seek help.

In this study, participants identified as indigenous with protections from the Indian Child Welfare (ICWA), as having lived experiences of being incarcerated, as a person of color, and/or as an immigrant or refugee—all of which add an extra layer of inequity and renders many invisible. Disparities can fuel a cycle of disadvantage, impacting not just the health of the parent and infant, but also relationships and community bonds. Addressing these issues requires a concerted effort to improve built environments, enhance the quality and accessibility of care, and dismantle structural inequity.

Child Welfare Involvement

Of those who had given birth, about half (55%; 12 of 22) indicated they had either prior or ongoing involvement with child welfare due to a substance exposed newborn or other circumstances. Figure 2 shows involvement in child welfare for the full sample, including those currently pregnant.[iv]

Figure 2. Participant Involvement in Child Welfare



[iv] Child welfare cannot become involved until the birth event for substance exposure of a newborn.

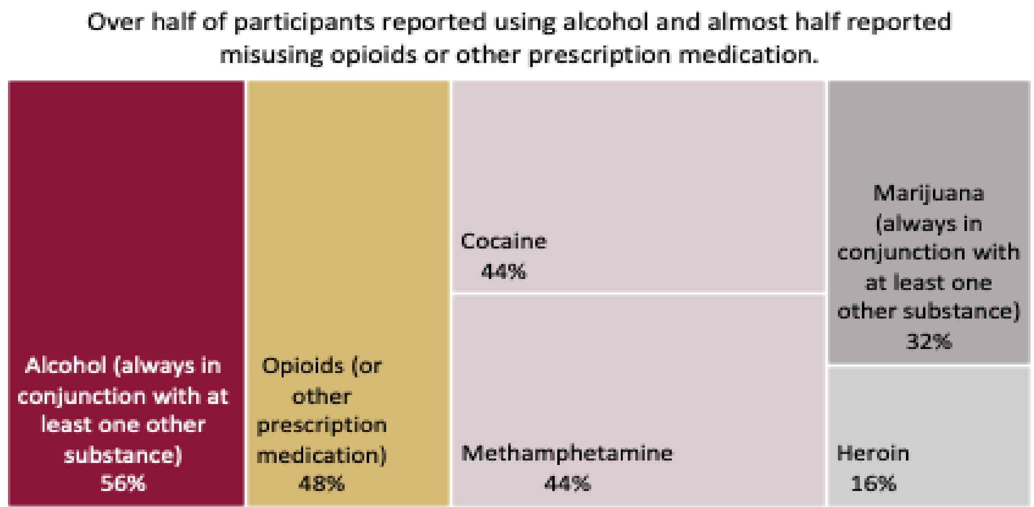
Type of Substance(s)

Substance use: Per the Centers for Disease Control and Prevention, substance use refers to any use of "selected substances, including alcohol, tobacco products, drugs, inhalants, and other substances that can be consumed, inhaled, injected, or otherwise absorbed into the body with possible dependence and other detrimental effects." Substance use describes the behavior, not the individual.

Substance misuse: Refers to any use of prescription medications outside of their intended purpose.

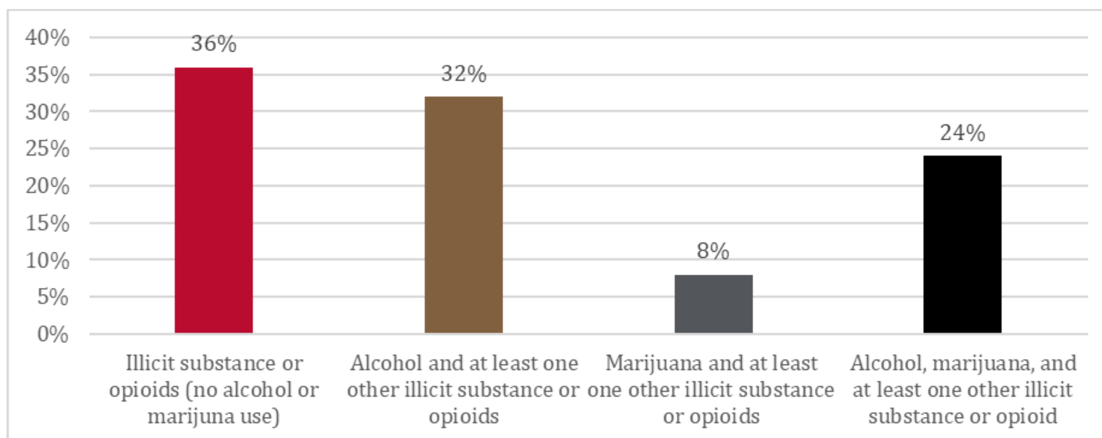
Polysubstance use during pregnancy is common.[15] This study focused on opioid misuse or use of illicit drugs during pregnancy. Alcohol or marijuana use was only eligible in conjunction with other substances. Figure 3 illustrates substances used during pregnancy (categories are not mutually exclusive).

Figure 3. Tree Map of Substances Used during Pregnancy



The tree map signals the high rate of polysubstance use among study participants: 84% of participants used more than one substance. Figure 4 illustrates the polysubstance use groupings.

Figure 4. Polysubstance Use Combinations



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Findings

Major Themes

Discussion

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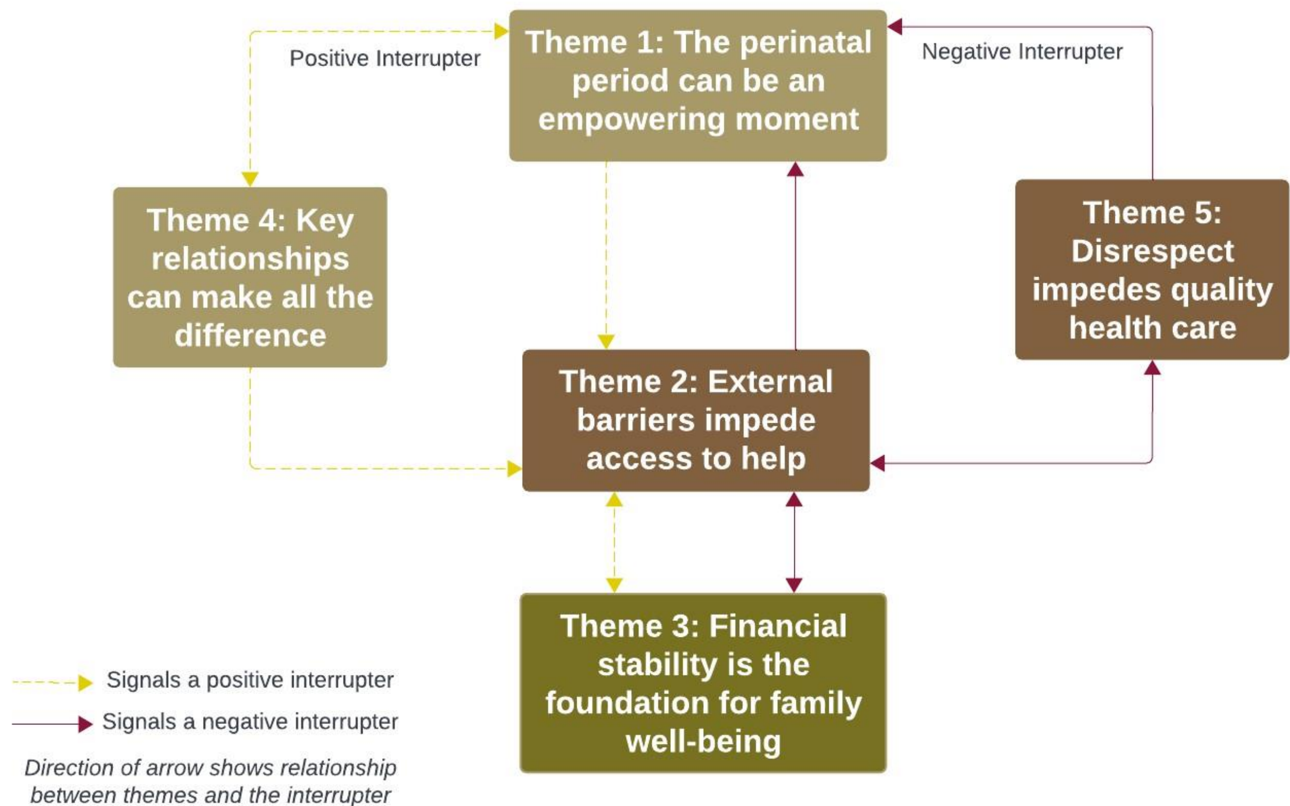
Key Findings

Below, we present key findings from this project. A total of five themes (with sub-themes) emerged. These are visually depicted in Figure 5: Grounded Theory Conceptual Schema. We end with implications and recommendations for policy and practice change.

Figure 5: Grounded Theory Conceptual Schema



In grounded theory, a visual (Figure 5) is created that illustrates major findings and their relationships. Together, themes depict a **local level theory of how substance use during pregnancy is experienced and how services are navigated**. Theme 1 shows the first catalyst that opens the possibility for treatment and recovery: factors motivated by the pregnancy. However, accessing services and supports is commonly made difficult by external barriers (Theme 2), from knowledge gaps to stigma and fear to cumbersome applications. Financial stability (Theme 3)—or the lack thereof—heightens access barriers, and economic well-being is deeply connected to overall family well-being. Relationships (Theme 4) are the number one driver of sustained change, acting to positively interrupt access barriers and help pregnant people harness their motivation. Throughout the pregnancy and recovery experience, health care is a crucial touchpoint and can act to either empower birthing individuals or—too often—disrespectful care can negatively interrupt progress made. By building protective factors (e.g., positive relationships) and mitigating risk factors (e.g., stigma, access barriers), the life course of families experiencing prenatal substance use can be changed and family strengthening across generations better promoted.

Each theme—and sub-theme—is elaborated on below. Pseudonyms are used to protect confidentiality.

Theme 1: The perinatal period can be an empowering moment.

> **Pregnancy and parenthood are key opportunities to promote resiliency and motivation that can empower birthing individuals to change.**
>
> - **The baby and desire to "be a good parent" were initial motivating factors, but internal self-love is what led to sustainable change.**
> - **Participants negotiated risk as they built self-efficacy and resiliency in the face of external barriers.**

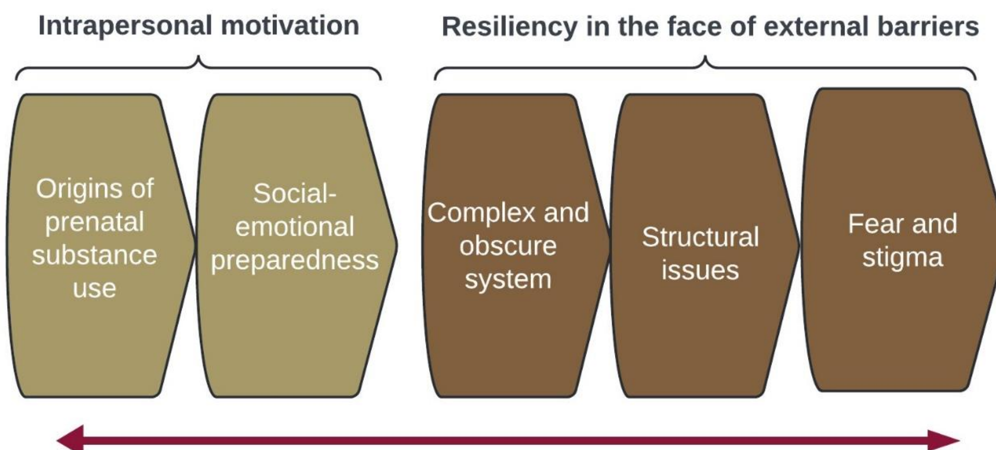
Participants discussed how pregnancy and parenthood can be motivating factors to take control of their situation and seek change. As previous literature [16] has documented, pregnancy is commonly a period for increased motivation toward behavioral change and individuals are more receptive to health promotion. Self-efficacy refers to the pregnant person's perceived ability to manage their behaviors, address barriers and needs, come up with solutions, and successfully transition to parenthood with confidence.[17] Self-efficacy is a modifiable protective factor and a predictor of healthy pregnancy behaviors, positive parenting relationships, and engaging in substance use treatment.[18] While self-efficacy can be inspired by the pregnancy and built through support, it can also be hampered by external barriers, including stigma.

In this study, participants experienced self-efficacy as a process in seeking help (Figure 6). The origins of prenatal substance use are the first reference point in developing self-efficacy, where substance use was often a result of coping with complex situations. Then, the pregnant person had to feel socially and emotionally prepared to seek help. Once these intrapersonal factors were present, self-efficacy was challenged due to multiple external barriers. Here, resiliency had to be fostered in the face of external barriers or progress was hurt. Barriers that threatened resiliency include:

- First barrier: Complex, obscure systems that make support hard to access (e.g., unclear eligibility);
- Second barrier: Structural issues that get in the way of access (e.g., transportation needs);
- Third barrier: Stigma and fear that permeate service navigation (e.g., fear of having their baby removed by child welfare).

Each barrier is elaborated upon in Theme 2. Here, we discuss how pregnancy can be a motivating factor for change and how negotiations of risk played into decision-making as self-efficacy was built.

Figure 6: Self-Efficacy as a Process: From Intrapersonal Motivation to Resiliency through External Barriers



Sub-theme 1: The baby's well-being and the desire to be a "good parent" are initial motivating factors, but self-love is needed to sustain change.

Initial motivation

Most participants had a history of substance use prior to their pregnancy. Several began substance use as a coping mechanism to combat feelings of depression or anxiety. Depression and anxiety stressors were commonly triggered by relationship issues/breakups, abusive relationships, loss of a previous pregnancy, and financial stress. For most, the pregnancy was not planned and resulted in practices of self-isolation because they were afraid of "what people would say" and felt "ashamed." Finley remarked, "When I found out I was pregnant…I stayed home crying for almost a week." Isolation also heightened mental health issues, including new or deepening depression.

> *"My mind was somewhere else. You know, my mind was all in the hole shame."*
>
> **- Yasmin**

Fear of being stigmatized kept many from disclosing their substance use and/or their pregnancy and self-isolation acted as an initial barrier to seeking help. Angela said, "A big challenge I had to getting resources was fear. I was scared. Like I was very scared telling anyone about it." Fear of harmful repercussions further kept them from seeking help, often hiding their situation from loved ones (natural supports) and systems (formal supports) alike. Finley said, "I really cared what people say and thought about me…The social status at that time. I think it kind of contributed to me not being interested in seeking any kind of services. So, you know, it's just kind of discouraging…I wasn't ready."

Concerns over the well-being of the baby commonly acted as an initial motivator to interrupt self-isolation and pursue change. Rowan felt unhealthy, and expressed concerns that their baby must similarly feel unwell, which motivated them to "do better." In her words, "And the thing that was horrible about that—it was really traumatic—was that I could tell when I was in withdrawal before I even started feeling it because she would start kicking and thrashing and just going berserk. Much more so than she would be normally. So, after like a couple months of that, I finally just had enough and I was like, so scared because I was throwing up everything…I felt so unhealthy. And I was scared for her, you know?"

Others discussed the impacts of substance on their relationship with their child or their ability to parent. Sawyer expressed, "I also got sober because I didn't want them to take my baby away, and that was the biggest concern because I felt like the doctor knew I was getting high." After pregnancy, parenting can be a motivating factor for sustained change or as an initial motivation factor when substance use is present postpartum. As Brianna remarked, "After childbirth, I used frequently, but as time went on, I gradually stopped using them [the substances] because I know it wasn't good for my health as a mother, a breastfeeding mother. It's not good for my heart."

Sustained motivation

Even with these motivating factors, participants had to be ready—socially and emotionally—to seek and accept change. In telling their story, Taylor tied the motivation of the pregnancy together with the importance of internal readiness and resiliency, saying: "Put your child first. Because I feel like that was what gave me the motivation, that push to do the right thing. I also have this determination that whatever happens…if anything happens

> *"I was kind of able to ignore the side talks and not pay attention. Though I still felt ashamed. But, you know, I started growing taller and when I say growing taller, I mean, like in terms of confidence."*
>
> **- Yasmin**

to my child, I am the one to blame because I was the one taking what was not good for my child. So, um, I decided that I was going to do better. It has to come from within—that decision has to come from within."

> *"If I am not ready, if I am not determined to get the help, it's very hard to help me. So, first of all, I have to be the one to seek help."*
>
> **- Finley**

The importance of "the decision has to come from within" cannot be overstated. Participants noted that while the pregnancy and thoughts about parenthood may get the ball rolling for seeking treatment, every individual must build self-love outside of the child alone to sustain recovery. Several participants mentioned that pregnancy or parenthood sparked a need to practice self-care. In the words of Alex, "I would say self-love…You know this is hurting you, and it's definitely going to hurt the child. So, you don't want to be doing this. You have to opt out and stop." Sawyer remarked that they wanted a different life for themselves and for their kids, and part of being able to care for the kids was realizing their own needs first. "I had to go to college and get a job for me to get my first [baby] back. So that's why I wanted to get sober…I was just tired of that lifestyle, you know? And now I was gonna have two kids. I felt like, horrible, horrible guilt for my first one. And then I just kind of added to it, added more guilt because of the second one and me [still] using. I wanted something different. I eventually got completely 100% sober off everything." Self-love may be learned through key relationships that model this love: When others demonstrated care towards participants, they were more likely to engage in caring for themselves, and subsequently practice love towards their baby. Key relationships are further examined in Theme 4.

Sub-theme 2: Birthing individuals negotiate risk and engage in purposeful decision-making during the perinatal period.

Developing self-efficacy also looked like negotiation of risk and purposeful decision-making. Navigating prenatal substance use doesn't look like a "on" or "off switch" with a perfect decision at every step. This study consisted of birthing individuals in recovery and who chose to keep the pregnancy. Participants expressed that this was a personal choice and a first moment of exerting agency, often in situations where their partners or relations did not support this decision. Yasmin said, "Like, the only decision I made was…not to kill the baby or not to abort the baby. But every other thing I wasn't thinking about. I wasn't thinking about how I was going to start or what to do, or how to take care of the baby, or how to take care of myself. I wasn't even thinking about all of that."

For others, feelings of being overwhelmed or depressed made it impossible to take full ownership of their situation and instead, they chose a harm reduction approach. Here, participants would actively try to make choices that would reduce harm to both themselves and the pregnancy. Rowan discussed negotiating risk like this: "I had an idea in my head, and I looked it up online before I relapsed on heroin… I had found out, like opioids themselves, besides NAS [neonatal abstinence syndrome] being a possibility, they're not as damaging as, let's say, alcohol is or methamphetamine is. Um, so I took a calculated risk and was using, you know, opioids."

> *"I won't say I was not using, but not as usual."*
>
> **- Emerson**

Risk perception also came into play. Several participants shared that their substance use was related to personal suffering and that they never had an intention to harm others. Rowan, recounting their partner's reaction to the pregnancy, said, "But he was like, how could you do that to our baby? And that has been a consistent problem between him and I is, how could you do that to other people? Because that's not the way I

ever looked at it. Yeah, I knew that I was pregnant, but I was never like, 'I'm gonna do this to you and you're gonna hurt because of it.' Like it was only because I was hurting. I never did it at anybody or intentionally to hurt other people, including my unborn child."

For participants that were unable to get support early on, they discussed how negotiating risk looked like trading one risk (e.g., no help) for another risk (e.g., justice involvement). In other words, they reached a point of being willing to suffer severe consequences to receive the help they needed for themselves and/or their child. For Elliot, this included potential criminalization: "I knew that I couldn't get clean on my own. Like just me and my history. It's 'Send me to jail!' That's how you're gonna get me clean. So, I knew I wouldn't be able to do it myself." For Rowan, this manifested as a willingness to withstand disrespect and shame to receive health care, and even potential loss of their baby to child welfare, to get the help needed: "I drove myself to the ER [emergency room] and I was like, I need help. Thinking I could get in to like an outpatient program and start Suboxone...But providers around me did not know this. They refused to do that. And they called child welfare, which I kind of expected and honestly wanted because I just needed help and I didn't know how to get it. I also told probation. The same day I called him, I was like, I've been using, I don't know what to do." While these options were expressed as far from ideal, they demonstrate how resiliency was necessary in the face of external barriers to help—the focus of Theme 2.

Theme 2: Birthing individuals face layers of barriers that impede access to help.

> **External barriers keep individuals from accessing medical and behavioral health care, concrete supports, and community-based supports.**
>
> - **First barrier: Complex and obscure systems**
> - **Second barrier: Structural issues**
> - **Third barrier: Fear and stigma**

Theme 1 illustrates how the perinatal period can be an empowering moment, where the seedlings of change are planted and self-efficacy begins to form. Self-efficacy toward change, however, is continuously threatened by external barriers that impede access to help. Theme 2 explores the barriers that birthing individuals face in seeking substance use treatment, health care, and parenting supporting.

Sub-theme 1: A complex and obscure system keeps birthing individuals from knowing how to access timely help.

Birthing individuals often don't know where to start due to complex systems that are hostile to the user. Participants shared story after story about how they were confused about what help they needed and where to get non-judgmental, meaningful support. This commonly started with knowledge gaps, either not knowing where to start, or having trouble articulating what they might need. Yasmin said "I wasn't well, um, educated enough. Should I say educated, or should I say I didn't really have a lot of knowledge on how to start and where to start…You know, there was nobody other than me to actually advise me, but sometimes you just need someone that knows better than you."

Participants commonly expressed not knowing what services were available or how to engage with them. Nina shared, "If only they mentioned something like that [a peer recovery support group], I would have joined because at that time I really needed things that could distract me. So, if only they had mentioned something to me like that, then I would. I'd have joined the groups." Many shared that the services they were connected to were not appropriate for their circumstances and needs. In Imani's experience, despite

their persistence, they had yet to find a therapist that was a good fit for them: “I’ve been transitioning through therapists, I still haven’t found one [that works for me], but I’m going to get there. I know I will. I have hope so I’ve just been kind of, I guess, winging it, trying to just self-guide myself and trying to find help in each direction.” These knowledge disparities were greater for participants from very underserved communities, particularly the African refugee and immigrant birthing community. Additional concerns, such as documentation status and language barriers, acted as a further blocks in being matched to appropriate services and engagement.

> *“[It was] discouraging. Well, you know, while I was pregnant, I tried accessing the services, but it wasn't available for me.”*
>
> **- Quinn**

Complex systems also manifested as administrative hurdles, such as unclear qualification requirements, cumbersome applications, or service delivery delays. Reese, discussing their years-long wait for housing, said, “There was like a four year wait list. I filled it [application] out for just about every county you could think of, and I did not hear back from anybody until last July.” Delays in such needed concrete supports (Theme 3) acted as a significant barrier to long-term recovery and caring for their child. Many participants were also confused by system terminology. For example, participants might work with case coordinators, case managers, and case workers from different systems. Their roles—who was there to help and who was there to punish—were commonly unclear, which led to poor care coordination and a distrust of all or most professionals trying to interact with the birthing person.

Child welfare involvement was called out as a particularly difficult system to navigate, with participants not trusting that the caseworker was there to help them (see sub-theme 3). There were also unclear expectations around how to reunify in circumstances when their infant was removed from the home. Imani spoke to this in relationship to the Indian Child Welfare Act (ICWA): “It is a hard process. I'm glad that I went in there [child welfare] with all the information that I had, like my tribal ID, my blood, my sibling, my certificate of Indian blood, and all my stuff backing me from my tribe. There was another Native American woman in there, but because she didn't have any of these documentations or anyone with her, her child had to go to the Mennonites [for foster care, after removal from the home], and she actually had to go through the state laws and everything.”

Navigating such system complexities was made even more difficult by other structural issues in the individual’s life, as discussed in the sub-theme below.

Sub-theme 2: Structural issues like child care, transportation, and affordability get in the way of accessing services.

When care is provided in a silo, the full needs of the birthing person are not considered. As a result, access barriers are created for all services. Participants discussed four key structural barriers that prevented the use of services:

- Insurance or affordability concerns
- Transportation needs
- Child care needs
- Scheduling conflicts

Kai recounted, "Services were not lining up with my childcare hours and transportation. I didn't have my license for the first year that she was born. And like, the bus system is not great in the suburbs. I mean… it's not great in Denver either. So, like, figuring out how to get places and it's hard to be on the bus with a car seat and a stroller." Similarly, Hayden expressed frustration that the lack of good transportation options, combined with inaccessible service locations, contributed to relapse: "You want me to come all the way to Arapahoe County? So that means you're not helping with transportation either. I'm eight months pregnant, just got out of rehab, and you want me to get on Colfax? ... That's just setting me up for failure. Yeah, and it worked. I relapsed. And I cried hard." This shows a failure of the system to not only attend to wraparound needs of pregnant individuals, but also not show sensitivity toward potential triggers (e.g., location) in what services are recommended and how they are accessed.

> *"Now, listen, what you're gonna do is stop making life hard for me. You want me to take three random UAs [Urinalysis] a week … meet me in the middle somewhere. I'll do your damn UAs, but can it be on the days I already go there?"*
>
> **- Eliot**

Such access barriers are often rooted in financial instability, which is further explored in Theme 3.

Sub-theme 3: Fear and stigma are major determinants of not seeking help.

One of the most powerful barriers to accessing and receiving support is stigma and fear of harsh consequences—a topic well-documented in the literature around prenatal substance use.[19,20] Participants discussed stigma and fear at length, including fear of involvement with the justice system and child welfare. Punitive laws and policies governing prenatal substance use are pervasive in the United States. A recent study found that nearly half of U.S. states have adopted policies that respond to prenatal substance use with legal system penalties, which research evidence shows is not associated with public health benefits and is ineffective policy.[21] For individuals of color, the threat of child welfare involvement is even more pronounced. Existing literature finds significant racial disparity in who is reported under The Child Abuse Prevention and Treatment Act (CAPTA) when substance use is self-disclosed prenatally, with Black mothers being twice as likely to have a report.[22] Stigma takes many forms,[23] from internalized to institutional, and all were represented in this study.

Participants gave depth to these national statistics, sharing their lived experiences of stigma, fear, and disrespect. Sawyer discussed that due to concerns about being judged, they didn't seek what they needed: "Like, I couldn't talk to anybody about it [prenatal substance use]. I felt like I was going kind of crazy during that time…I really wanted to get over that phase [of my life] already and just move on to the next. But I had so much judgment around that. If I didn't, I probably would have been able to get some kind of help sooner rather than have to do it by myself and later…[after it] already affected [the baby's] growth."

Institutional bias also added to the issue, showing the intersections of stigma, systemic racism, and access to family supports. Angela, a childbearing person of color, said, "My major problem is the health care sector, because I feel like I would have gotten better if we had a good relationship with the health care providers. There is like a big stigmatization… between the white [mothers] and the Black [mothers]. So, if they had given me like enough attention, probably my parenting process would have been easier."

> *"The biggest barrier is shame…and legal repercussions. I didn't want my child to be taken away from me."*
>
> **- Angela**

Fear of justice system and child welfare involvement permeated many stories. As noted earlier, participants expressed distrust and confusion around the intentions of providers and whether they would have to or would choose to involve child welfare. Kai experienced this fear at the time of birth, saying: "It was just like, 'we are going to test you and the baby.' I was like, okay, I don't like, I don't know... And my mom was there, and I remember my mom asking her [the nurse] like well what happens? And she's like, 'Well we'll just cross that bridge if we get there. Like, you know she's been in treatment and, like, doing all these things. But we have to [test].' I thought for sure they were going to take her [the baby] and I was never going to see her again."

This fear nearly always starts prenatally. Sawyer discussed how they chose to keep their substance use from their doctor, fearing that disclosing it would lead to their baby being taken: "I had to keep going to my prenatals [prenatal appointment], but I was scared to ask for help because of the fact that they were going to immediately be like, well, let's look into foster homes, you know?" Participants desired more procedural transparency and better communication about child welfare's goals and their rights as parents. Reese discussed how lack of transparency means lack of trust: "I think the county welfare, they need to be a lot more transparent about their goals…they say children's safety or children's welfare is the most important thing to them or whatever. But, um, I think a lot of times parents feel like, you know, they're being attacked. Yeah. And that they have to defend themselves against people's judgments when really if recovery is what you need in your life, then that shouldn't be judged. I think that it [child welfare] should be more of a supportive system. Not something where you feel like you're being crucified for everything."

This fear of harsh consequences impedes access and results in both parent and child becoming more likely to experience negative outcomes, such as health concerns and separation. Such negative outcomes could be avoided with the right support during pregnancy and outside of child welfare, given the deep fear and stigmatizing experiences of many families. In the face of stigma and fear, participants discussed how self-efficacy was threatened and to make progress, resiliency became crucial. Elliot translated what this looked like for them: "I really had to advocate for me and be there for me because DHS [Colorado Department of Human Services] isn't gonna do anything for you…you really just have to learn what you want and what you are allowed to ask for. And you have to push for those things."

Financial stability—or the lack of it—could either deepen access barriers or act as a remedy.

Theme 3: Financial stability is the foundation of family well-being.

> **Financial supports to assist with food, transportation, medical care, child care and housing are essential ingredients in the treatment journey and for the health of the parent-infant dyad.**
>
> - **Lack of financial supports is a significant cause of parental stress and a risk factor for child maltreatment. Building family economic well-being is an antidote and a protective factor.**
> - **Stigma of poverty adds to the stigma of substance use, making access to economic and concrete supports out of reach for many.**

Financial support for essential needs—including food, transportation, medical care, child care and housing—was a powerful and consistent theme. During the perinatal period, many participants faced significant challenges in seeking treatment and securing stability for their family due to limited access to concrete supports. Findings from this study align with other recent research identifying financial needs as a major obstacle for pregnant individuals experiencing substance use and seeking care.[24,25]

Economic and concrete supports are a leading protective factor for preventing child maltreatment. Financial well-being and family well-being are inextricably linked. Access barriers, stigma around substance use, and economic hardship combined to create high parental stress—all leading risk factors for child maltreatment (Figure 7). Mitigating these risk factors, while building protective factors, is critical to achieve healthy outcomes and family strengthening among those affected by prenatal substance use. In Theme 3, we focus on concrete supports in time of need as a leading protective factor for these families.

Figure 7: Leading Risk Factors and Protective Factors (Strengthening Families™ Framework)

Sub-Theme 1: Lack of financial support leads to high stress and directly hurts seeking treatment services and other supports.

During interviews, participants expressed their lack of financial support and experiences of poverty. They discussed at length how this lack of support caused stress, and how having more financial and economic resources would have made a fundamental difference in caring for themselves and their infants.

Lack of awareness was a commonly cited problem, where even when the birthing individual was in contact with services like prenatal care, they were not told about concrete and economic supports. Casey said, “No one talked to me about insurance or financial support or food support, and this would have really helped me and my baby.” Many discussed a lack of medical insurance as a primary barrier to seeking behavioral health care, especially in the postpartum period.[v]

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[v] Policies such as House Bill 22-1289, Cover All Coloradans, are important system-level solutions to this identified barrier. Many participants gave birth before this legislation or were unaware of coverage options. Further, even with coverage options in place, behavioral health was perceived by participants as inadequately covered by Health First.

Angela expressed, "I didn't even have medical insurance…If I had an insurance plan, it would have been easier to get a therapist for myself."

Transportation was also cited as a top stressor. Participants shared it was a challenge to pay for transportation, whether that be bus passes, gas, or expenses like car repairs. Beyond direct expense, many participants were limited to public transportation, which has extensive access barriers and can be logistically impossible to navigate daily. Notably, this included limited availability of reliable public transportation, especially in suburban and rural areas, as well as health care offices and social services giving out expired bus tickets. Lack of transportation directly impeded consistent participation in health care, and previous research in Colorado has documented high rates of no and inadequate prenatal care among families affected by prenatal substance use and involved in child welfare.[26] Lack of transportation also kept participants from getting their required UAs (urinalysis) and maintaining a job to support themselves and their family. Dakota remarked, "Mine [my biggest barrier] was transportation…Yeah, I don't have a car…then there are places that say that they help you with transportation, like bus tickets. And then all the bus tickets were expired…And so they kept handing them out, but the bus drivers weren't taking them."

> *"I don't really have funds to, you know, transport myself to meet my doctor or nurse. So, it was really, um, it was a very tough issue, like, because I was having financial problems."*
>
> **- Jordan**

Others discussed the stress of navigating public transportation, and how this was an additional barrier to accessing needed supports. Kai shared, "It's hard to be on the bus with a car seat and a stroller. It is so hard. It is. I remember, like, trying to take the bus to Denver for my Special Connections[vi] groups and, like, it's just really hard to have a full stroller and a diaper bag and a baby and, like, people are everywhere and nobody wants to help anybody anymore."

In the postpartum period, child care was a leading concern, as it is across Colorado for most families.[27] There were disparities present for rural communities in particular. Imani shared their experiences of trying to find child care in a rural setting: "[I kept asking] for help me with child care to find [my child], um, any type of child care…we don't find too many options just because we're in a rural area and there's not a lot of places that have a short waiting list…All the waiting lists are like a year out." Participants discussed how a lack of child care increased their parental stress and prevented them from working and getting to treatment and recovery services. The inability to show financial stability, and worries around long-term recovery without support, then led to fear of losing their child(ren) to child welfare. Such fear then further fueled non-disclose when they did need help.

As part of their process of developing self-efficacy, participants expressed desire to become self-sufficient, especially regarding finding a job and securing housing. Emerson shared, "I was actually looking for a job at that time because I wanted to support myself financially and also food services [i.e., Supplemental Nutrition Assistance Program (SNAP); WIC program]. I really wanted to access [these], but I couldn't. Then secondly, housing, I wanted to get a place on my own, but couldn't." Without economic and concrete supports in place, participants faced increased stress, and an inability to meet basic needs can create a spiral back into substance use. Existing literature has documented that not having stable housing can lead

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[vi] Special Connections is a Colorado Medicaid program for pregnant and parenting people using substances.

to lack of engagement in substance use treatment and health care, being food insecure, stigmatization and discrimination based on housing status during employment, and poor mental health, which can then lead birthing individuals back into substance use as a coping mechanism.[28]

For many participants, the professional services in their life (e.g., health care, treatment providers) did not help them secure these economic and concrete supports, treating only one part of the pregnant person's needs rather than seeing the whole person. Wraparound care was present for only some participants. When present, this fundamentally changed their experiences of parenting and ability to confidently provide for their child. Before being connected to concrete supports, including housing, Sawyer relied on stealing necessary items, which increased fear of child welfare and justice involvement. She recounted: "I didn't have a vehicle or anything…And you know, out of desperation, I've gotten to points where I would have to go steal formula, go steal diapers, go steal wipes. You know, I would have to resort to that."

Sub-Theme 2: Birthing individuals face deep stigma when trying to obtain financial supports.

The intersection of poverty and substance use stigma is a complex social issue where economic disadvantage and discriminatory societal attitudes meet. This often exacerbates the challenges faced by individuals affected by substance use. The pervasive narrative of "pull yourself up by your bootstraps" intensifies the intersectional stigma of poverty and substance use.[29] This narrative evokes victim blaming, which results in health and social service staff, especially child welfare, viewing parents as "not trying hard enough." As a result, they do not genuinely invest in helping families secure needed resources, then blame them when they are unsuccessful. The lack of resources can lead to a cycle of addiction and poverty, where each condition reinforces the other. The stigma associated with substance use on top of poverty can lead to discrimination, social isolation, and a lack of empathy from those in support roles, further hindering recovery efforts.[30] Changing narratives of poverty is thus crucial in caring for childbearing families affected by prenatal substance use.

Alex shared that her husband was the primary worker (i.e., income-earner) in their relationship, and when he left her because she was pregnant, she did not have any money. She reported that she was judged by the professionals who were assigned to help her, and this caused further stress, isolation and an increase in depression, which led to an increase in drinking: "I was so sad, I drank." Quinn noted the tension between trying to maintain a job and applying for concrete supports like health insurance, linking this back to greater stress: "I wanted to access insurance [Medicaid], but then I had to work [at the time of the appointment]. [The caseworker said] 'You never showed up so it [the application] wasn't successful.' It was difficult. Discouraging."

As discussed further in Theme 5, participants also shared many experiences of receiving poor care because they had public insurance, which signaled poverty and added to the stigma around substance use. Participants also felt Medicaid coverage did not provide them options that felt culturally respectful, including limited access to physical and behavioral health providers that accepted Health First clients, and lack of coverage for birthing options such as midwifery care and homebirth—quality care options that this population may seek out due to institutional bias and stigma by hospital systems.[31] Hayden shared their frustration with Medicaid not covering midwifery care in a homebirth setting, saying, "I originally wanted to have a home birth, but Medicaid wouldn't cover it. And I don't have enough money for even a deposit. So, you know, it's just, it sucks because I'm scared shitless."

Removing financial stressors and connecting birthing families to concrete supports is critical for short- and long-term success. Wraparound care often started with a key relationship that would unlock the potential for a new narrative of recovery and family strengthening—Theme 4.

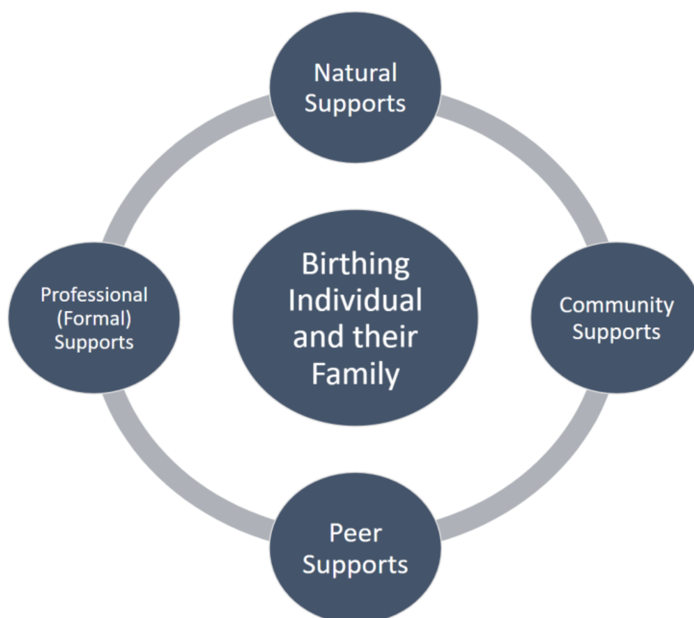
> *"I need help, financial support. That's the first thing I need."*
>
> **- Emerson**

Theme 4: Even a single, key relationship can make all the difference.

> **Key relationships interrupted cycles of poverty and prenatal substance use to create a new possibility. This was done through giving of emotional and concrete support, knowledge sharing, and care coordination.**
>
> - **Key relationships took many forms, including informal (e.g., friend) and formal (e.g., counselor) supports.**
> - **Emotional, informational, and concrete support were the most common forms provided by key relationships.**
> - **Peers with lived experiences are a key trusted relationship.**

Social support builds parental self-efficacy, including confidence and connection with resources.[32] Social support comes from both formal (i.e., professional services, usually paid) and informal (i.e., friends, families, neighbors, community members) networks.[33] Social isolation, or the absence of social support, is a risk factor for parental stress and child maltreatment.[34] Conversely, social connections are an identified protective factor and with strong social connections, parents experience fewer stressors and can build resiliency when challenges arise.[35] In this study, participants emphasized that having one key relationship, that was trusting and non-judgmental, could make all the difference. Participants found their key relationship across as a continuum of possible support options (Figure 8).

Figure 8: Continuum of Support Options



Sub-theme 1: Key relationships of trust can take various forms, from natural supports to professional supports.

Participants identified a variety of trusted people, from natural supports, such as family and friends, to professional ones, such as midwives, doctors, and probation officers. Several participants mentioned a parent being a lifeline, commonly their mother, but natural supports also took the form of friends or siblings. Malia expressed: “My baby was crying all the time, and I was new to being a mom and it was my first time. So, I couldn't handle it. But thanks to my sister…she was basically the one that got me through the situation.”

> *“I was really depressed, but thankful for my sister who was there for me.”*
>
> **- Malia**

Sawyer discussed how a key relationship helped them maintain indigenous cultural ties that were critical to her recovery and parenting journey. Sawyer recounted, “I found a Good Sweat Lodge… that's what helped me a lot…I found a lot of good people and friends that have supported me through that time [prenatal substance use]…I found a pretty good little circle out here…they check on me and stuff, which is pretty awesome.”

Other participants expressed appreciation for more formal—or professional—supports. While many times professional systems were experienced as stigmatizing, harmful, and difficult to access (as noted in other thematic findings), there were exceptions to this rule. What distinguished a formal support from one that hurts to one that helps was the ability to provide person-centered care and care coordination. Alex noted, “Well, the doctor we used was really nice. Kind. And he really helped; he advised me on so many things, even though I took his advice for granted sometimes. But he was really kind to call me back and remind me of things that I had to do.” Similarly, Sawyer discussed how their pediatrician's office came through for them via a case management staff member, “It was really one of the counselors, at my kid's pediatrician, who came up to me, and she told me, ‘Hey, we've seen this [substance use history] on your record. Doctor thought maybe it would be best if I come talk to you and see if you need help with anything. And, like, I kind of, like, broke down there because this was the first time I ever spoke to anybody about anything like that, you know? And, uh, from there, all these things started opening up for me…like therapy, groups for kids, clothing, all the things that, you know, all the essentials, like the bare necessities that I needed. And I was like, dang, that's crazy cool.”

As discussed in Theme 2, for most participants, child welfare and the justice system were significant sources of fear, stigma, and stress. Some exceptions were noted. A small set of participants shared that child welfare was a source of help in getting them resources, even if they wished they never had to become involved in child welfare or the judicial system to get those resources. Emerson said, “Child welfare was one of the best ones [best resources]; they helped with housing and food.” Rowan echoed this and added in judicial staff as well, saying, “Once my caseworker got assigned, she turned out to be a social worker…she was amazing. And drug court too, my probation officer, turned out to be amazing as well. They both were people I could call as soon as I relapsed, I'd be like, I used, like, I need help. I need help right now. And they'd be like, all right, we're not gonna put a warrant out for you. Just show up to court or I'll meet you at your house, like, whenever. Let's, like, figure this out.”

> *“[My recovery nurse and doula] were the best things for me… I couldn't have done it without them.”*
>
> **- Rowan**

Participants also forged key relationships with community-based providers, such as midwives, doulas, recovery coaches, and navigators.

Rowan expressed appreciation for their recovery nurse: "I was thinking about leaving with my baby this time, like out of the state, because there's no fucking way I can go through [treatment]. But I can't leave my son, so, damn it, so I stayed...[My recovery nurse and doula] were the best things for me… I couldn't have done it without them."

Sub-theme 2: Emotional, informational, and concrete support were the most common forms provided by key relationships.

The support provided by key relationships took three forms, aligned with the research on social support: emotional support (e.g., expressions of empathy, care, trust); informational support (e.g., advice, information on resources); and instrumental or concrete (e.g., tangible goods, aids, services).[36]

Angela discussed the emotional support provided by the network of friends that kept showing up for her: "During that moment [childbearing year], I had a few friends come over to cook for me, to clean. During that year…regardless of the fact that you're going to have a few people who would criticize you, there are also people who will look out for you during that moment…they were so supportive, emotional support. There were days that I chased them away. I didn't want to be around people. I just wanted to lock myself in, cry, be alone. But, you know, they didn't get mad at me. It didn't stop them from coming around. So, they actually understood what I was going through at that moment."

Natural supports could also be a source of financial and other concrete help. Participants discussed how this support was especially important when things were not going well, such as in times of relapse. Rowan shared: "My parents, who had sworn they weren't gonna help me really raise my kid at all...They sort of stepped up. They gave us a house to live in with them. And my dad was…up with her [the baby] in the night and would take her every morning from 6 a.m. to 9 a.m., which would allow me and my husband to sleep. Then my husband and I split shifts and my mother-in-law took her several days a week, and then my best friend also took [her, the baby], like, once or twice a week. And I wasn't even doing anything. I wasn't working…But the fact that I had that village to give me some time to decompress because they all recognized how hard the relapse had been on me, how hard the whole birth had been on me, and, like, how much support I needed."

Participants also appreciated those trusted individuals who provided valuable knowledge related to health practices and parenting tips. Yasmin, reflecting on a neighbor who identified she needed help and took the initiative to reach out, said, "She taught me the ways. And, you know, I could just be there and she might be like, okay, you need to attend the baby now. You need to change her diaper…if she wasn't in the picture, let me be honest, I wouldn't have really been able to go to ask [for help]…because I was still feeling ashamed and, you know, not too good and all of that."

Informational support often meant information related to how to get access to resources and how to overcome barriers. This was especially meaningful when a key relationship helped with care coordination. Sawyer recalled how their nurse advocate felt outrage at an inappropriate request by a social service agency and spoke up on their behalf: "WIC...they made me take a UA [urinalysis] after [the appointment]…But the nurse advocate lady was kind of mad about it because she was like, 'what the hell? Like you're not, you guys aren't supposed to do that. This place is supposed to be safe.'" Similarly, Rowan expressed appreciation for their recovery nurse that got them into treatment, which pivoted their life in a new direction: "She got me into a rehabilitation center that specialized in pregnancy and substance use."

Finding at least one trusted relationship is especially critical when discussing prenatal substance use, as often in the process of recovery, individuals lose current relationships. Several participants discussed poor or abusive relationships with the child's father, which was then exacerbated by the pregnancy. Relationship were often a root cause of substance use, where substances were used as a coping mechanism. Yasmin said, "My pregnancy was the result of sexual abuse…So, this one time I was like, 'I don't want to do it [have sex]. You know, I'm not in the mood.' And yeah, he said it, being like, why would I deny him sex and all of that? And then boom, he kind of forced me into it. And funny thing is that particular one, then I got pregnant." As such, the perinatal period can be a time when birthing individuals remove unhealthy relationships and develop new ones to support them in recovery and parenting goals.

> *"He [the father] asked me to abort the child. And I told him I wasn't ready. Yeah. He left. He left the house because according to him, he wasn't ready to be a father. And I was left all alone to face it."*
>
> **- Alex**

Sub-theme 3: Peers with lived experiences are best positioned to provide meaningful support.

Of all relationships discussed, participants highlighted people with shared lived experience as one of the most powerful ways to foster self-love, get connected with the right resources, and feel safe to engage in hard, complicated life changes as they care for themselves and their babies. Participants expressed that peers are best positioned to approach their situation from a place of understanding, acceptance, and non-judgmental support. They expressed that peers are more likely to have the knowledge about how to handle specific scenarios and know how to connect individuals to the help they need, even more so than professionals without lived experience. While professionals may have general information and education, they don't understand the nuance of situations involving prenatal substance use and fail to take a harm reduction approach.[37] Hayden discussed how their lived experience set them up to support others through a peer support model: "And now I go back to treatment centers and talk and…help them with resources. I go back all the time, everywhere, and just help those girls because that's what they're missing. When you get out [of treatment], you don't know where you're going and what you're gonna do… Like, it could be anything you could ask me. I can tell you where to go…I'm like, talk to me. Call me. I'll help you. Whatever you need, I'll be there. You know, I make it work. They go with me."

> *"It can be very isolating being a parent. And then it can also be very isolating being in recovery… having this double layer of isolation, and it's like you and this baby that doesn't talk….Like having more community and being vocal about it so that people feel comfortable to engage."*
>
> **- Kai**

Several participants expressed a desire for increased use of peer professionals across all services and supports in Colorado. Rowan said, "I've gotten really excited by the peer profession. Peer support specialists are becoming more legitimized and just, like, gaining traction over the past years…I think we need to make it so that people are encouraged to use their lived experience." Reese echoed, "He [peer counselor] gets it, too, like, he went through his own stuff. I wish that had been an option, but I am happy that they're, like, utilizing peer support staff so much more." Participant narratives make clear that peer supports are a key relationship that "walks with" the birthing individuals through their experience, and that this is an under-tapped potential in Colorado. In addition to recommending more individual-level peer supports, participants also mentioned a desire for more spaces in which they can hear from other parents with similar experiences, such as Circle of Parents.

Theme 5: Birthing individuals experience disrespect from health care providers.

Experiences of disrespect from health care providers and the health care institution impede quality care during the perinatal period.

- **Person-centered care was commonly not provided, including ignoring the lived experience of prenatal substance use.**
- **Stigma was a leading barrier to receiving quality health care.**
- **Birthing individuals were treated as less deserving because of their history with substance use.**

Experiences of disrespect and stigma within the health care system were pervasive in participant narratives. This finding aligns with the literature on institutional bias in the health care system. Individuals who use substances while pregnant commonly avoid perinatal care for fear of being treated with disrespect and irreverence.[38,39] Stigma from health care providers commonly reinforces a "blame the victim" narrative that leads to disparities in care and greater stress for the pregnant individual.

While the birthing experience can act as a key moment for establishing respectful relationships and ongoing care coordination, it is often a moment of great stress and negative repercussions. Disrespect from health care providers and a disempowering birth experience can lead to greater health concerns for the maternal-infant dyad, including premature birth, stillbirth, cesarean section, and preeclampsia, as well as shutdown the birthing individual from engaging in supports long-term.[40]

"It was challenging at first because the doctors would judge you. Yep. Because you're using drugs and you are pregnant."

- Malia

Sub-Theme 1: Person-centered care was not provided, and the lived experience of prenatal substance use was ignored.

Participants described feeling very disrespected at the hospital during the birth and in the immediate postpartum period, as their personal preferences, needs, and cultural values were not considered. Many discussed how health care providers cared for the baby, but not them as the parent. Comments of disrespect happening "so many times" became an expected part of their experiences where resiliency had to be built.

Rowan discussed a situation where their preferences for infant feeding (breastfeeding) were not only dismissed, but where informed consent was not given: "They already gave her [the baby] formula without my permission… And I've heard so many times from people about everything [not getting consent on many things]…women getting tested without their consent and more."

Participants expressed concern that the events occurring at the hospital did not honor nor reflect their lived experience of substance use. For example, providers would encourage pain medication during labor or recommend opioids after the birth to control pain, with no regard for the individuals history of substance use and the relapses or emotional trauma this could bring. Another way this showed up was around inserting IVs as a common medical procedure, without sensitivity or the knowledge to adequately do so on previous users. Kai recalled, "I felt, like, so confused by the whole thing [childbirth]. Like nobody was really explaining it to me…I remember I went into labor, I had been sober, I was an [previous] IV drug

user, so they were like trying to put a needle in me. And I'm like, 'you're never gonna figure this out.' And I was talking to the nurse and I was just very upfront with her about it, and I felt like that kind of was the trigger for them afterwards…[and they reported me] and the hospital social worker came in…she was not nice." Such experiences left participants feeling powerlessness to influence their care and directly threatened the self-efficacy they were building.

Feelings of powerlessness and the desire to avoid such disrespect led participants to disengage from the health care system and not share their needs or concerns with their providers. Alex shared their story of not disclosing their problems, thoughts, or concerns as a coping mechanism: "I kept things to myself. I didn't really tell my problems to the doctor or the nurses…I was scared of how they would see me, how they would perceive me. So, I usually keep things to myself."

> *"They [the health care team] couldn't just trust that I was sober, which I get it, but it hurt."*
>
> **- Elliot**

Powerlessness went even deeper when participants were inundated with information or procedures, without any respect given to explaining things in a way that was understandable. This led to participants often not knowing what was going on with their infant during the hospital stay, and especially if the infant was removed by child welfare upon birth. Birthing individuals felt no one would take the time to share with them what was happening, being made to feel they "wouldn't understand" because of their substance use history. Hayden shared, "And like [my baby] didn't cry. So, I was concerned. I'm like 'Hello? What's going on?'…Right after he came out, they were like wiping him down. Didn't even hand him to me, you know, do the body-to-body [skin-to-skin bonding] thing, like, they [the nurses, then child welfare] just took him." Not knowing what was happening with their infants not only violated their fundamental rights as parents, but it set them up for failure when and if they did take their baby home, as they did not know how to properly care for their needs or the infant's history.

> *"You get blood drawn every so often…then they are secretly testing it….without consent. And then using the results, you know, as weapons"*
>
> **- Rowan**

The lack of person-centered care and disregard for their substance use history was fueled by experiences of stigma, which in turn led to poorer quality of care.

Sub-Theme 2: Stigma acts as a leading barrier to quality care in the hospital.

Participants faced extreme judgment and discrimination during their birthing experience, which influenced the quality and timeliness of their care. This finding aligns with existing research that shows hospital policies, including toxicology testing, often discourage pregnant persons with substance use from using medical care and treatment.[41] Participants commonly were made to feel "ashamed," "guilty" and "embarrassed" by health care providers, which led them to feel more stressed and ill-equipped to move into the parenting journey. Yasmin was made to feel ashamed due to their baby's withdrawal symptoms and the side comments from the nursing staff: "You know, when I was told [about neonatal abstinence syndrome], I felt so ashamed…And the side talks from the nurses. That made me feel worse…maybe they didn't intend for me to hear them. But I felt so sad, you know, them saying that [I hurt my baby]. You know, they made me feel more guilty."

Imani shared their experience as an incarcerated individual delivering their infant at a hospital. They expressed that incarceration should not be an excuse for disrespect and inhumane care, including being

ignored when they needed medical care. Imani shared: "I got to the hospital. I was very much a prisoner. Um, they made me aware of that…There was a guard inside of my room. There was no nursing, no doctors or anything that were allowed in my room unless I absolutely needed it. I could feel my son coming out.…I let the nurse know. The nurse was like, 'I don't think the baby's coming, but I'll send the doctor.' The doctor gets there, sits down, lifts the bank blanket up, and he's like, oh my gosh, the baby's coming. And I was like, I told you the baby was coming like 20 minutes ago."

Participants also shared experiences of when disrespectful care at the hospital collided with child welfare involvement, making an already stressful situation worse. Reese said, "[Child welfare] showed up to the hospital, they made it sound like I was trying to go to a hospital outside of their jurisdiction in order to try to keep them from taking my son. But it's like you guys knew that's where I was going to deliver during the whole time."[vii]

Participants narratives identified that quality care was most detrimentally impeded when stigma combined with institutional racism among health care and child welfare. Hayden recounted: "They need to do more of a background [check] on these people [health care providers and child welfare]. Like, how the hell are you gonna let this woman [caseworker] just make these damn assumptions [about the family, their culture] and you just take my son [because of the color of my skin], like you don't think there's even one ounce of racism in here?"

Sub-Theme 3: Birthing individuals with substance use history were treated as "less deserving" of quality perinatal health care.

Underscoring the first two sub-themes was a finding of participants being made to feel "less deserving" because of their substance use history. Participants felt that they (and others they know, with similar histories) received worse care, and that their concerns were discredited and often not listened to by their providers. A discussed previously, participants often chose to keep things to themselves, as they were fearful of how health care providers would perceive them and "would this affect their care?"

Emerson reflected that they would have shared more with their health care provider and engaged more fully if they were not so fearful of being treated as "less than." They recounted, "If I had a good relationship with my health care providers, I probably I would have been able to share what I was going through, my substance use disorder, with one of them. But because we do not have like good communication, a good relationship, I did not even try to…there is, like, a big stigmatization… if they had given me, like, enough attention, probably my parenting process would have been easier. Because I would have gotten to share my experience with someone earlier. And probably I would have abstained from the substance use much earlier too, and I, my child, wouldn't have had to go through all that."

The act of "not listening" was noted throughout narratives, with participants feeling like their health care team didn't really try for them because they didn't "deserve" the help. Rowan explained, "I wanted to go to inpatient treatment and get on Suboxone…None of the providers of the hospital knew anything about addiction. They wouldn't listen to me and they're like, no, we can't help you at all. And they gave me a pamphlet with some Suboxone doctors and that's it."

[vii] Child welfare cannot get involved until after a baby is born, as there must be a child for a safety concern to be reported on. However, child welfare may already be involved in a family's life if they have other children.

Care experiences full of disrespect and stigma for the pregnant/parenting person stood in stark contrast to the care that providers showed for the baby. Reese shared, “My son's hematologist was helpful. He helped me with understanding what my son's condition was…But I can [still] feel the tension and the judgment [of me, the parent].”

Participant narratives made clear that the health care experience, especially the birthing event, holds strong potential to support birthing individuals in becoming parents and staying on a path of recovery. If trusting relationships can be established, this can open the door for more trusting relationships with other supports and professionals. If information can be explained, better infant care can happen in the long term. If non-judgmental support is provided, birthing individuals are more likely to disclose concerns and seek help. Too often, these potentials were interrupted by the negative experiences of care that permeated nearly all participant narratives, as captured by the word cloud in Figure 9.

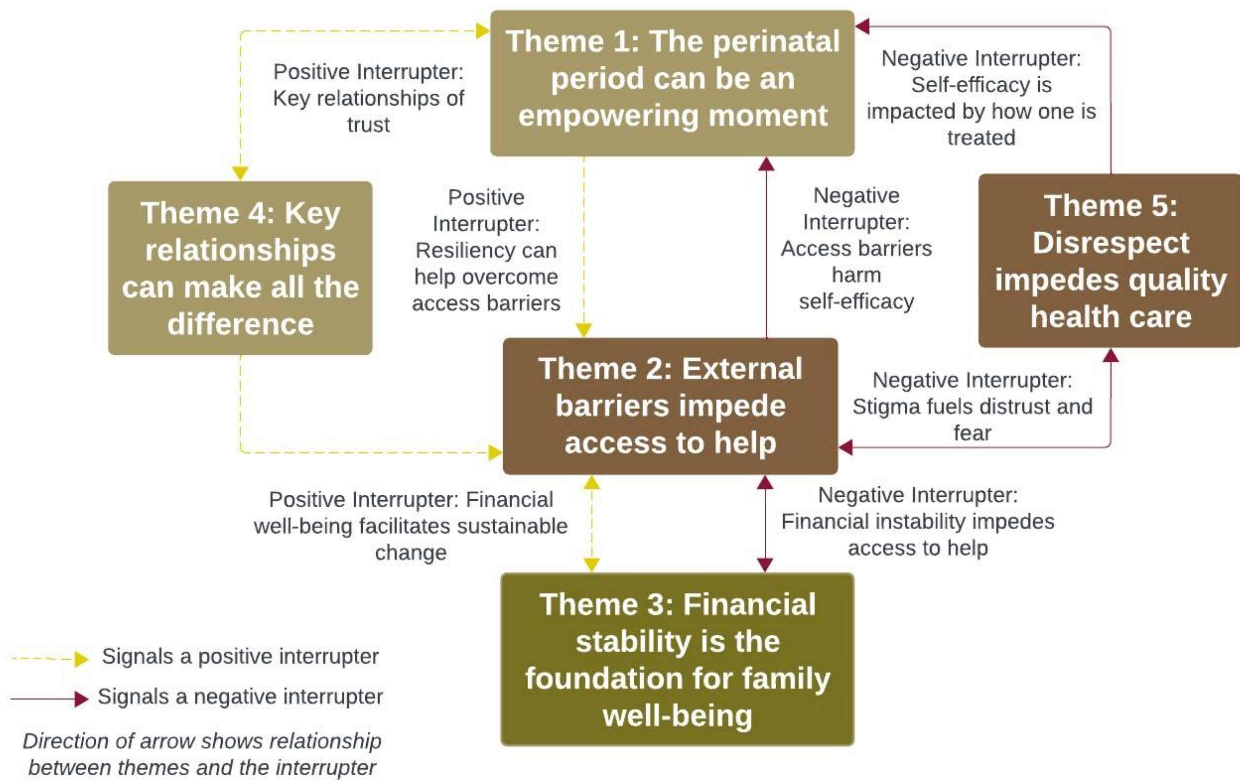
Figure 9: Common Words Used Within Theme 5 to Describe Health Care Experiences

Discussion

The five thematic findings are interrelated and highlight major factors in the negotiation of prenatal substance use and the parenting experiencing (Figure 10). Each finding is connected by drivers of change that act to positively interrupt bad experiences (i.e., changing the life trajectory toward one of recovery) or negatively interrupt progress toward change (i.e., holding individuals down and setting them up for failure). Having at least one relationship of trust is the most powerful protective factor that emerged in this study, followed by economic stability and self-efficacy. These findings align with the Strengthening Families™ Protective Factors Framework, where social connections, concrete supports in time of need, and parental resilience are all research-based protective factors known to prevent child maltreatment.[42] Conversely, major risk factors were also identified. These risk factors include poverty, parental stress, access barriers, pervasive stigma among the “helping” professions, fear of systems involvement, and disrespectful care. These risk factors align with existing literature on child maltreatment (broadly),[43] as well as prenatal substance use (more specifically).[44] Racial, cultural, and economic disparities permeated

these findings, with risk factors more prevalent among communities of color, those experiencing intergenerational poverty, and immigrant and refugee families.

Figure 10: Grounded Theory Conceptual Schema (expanded)



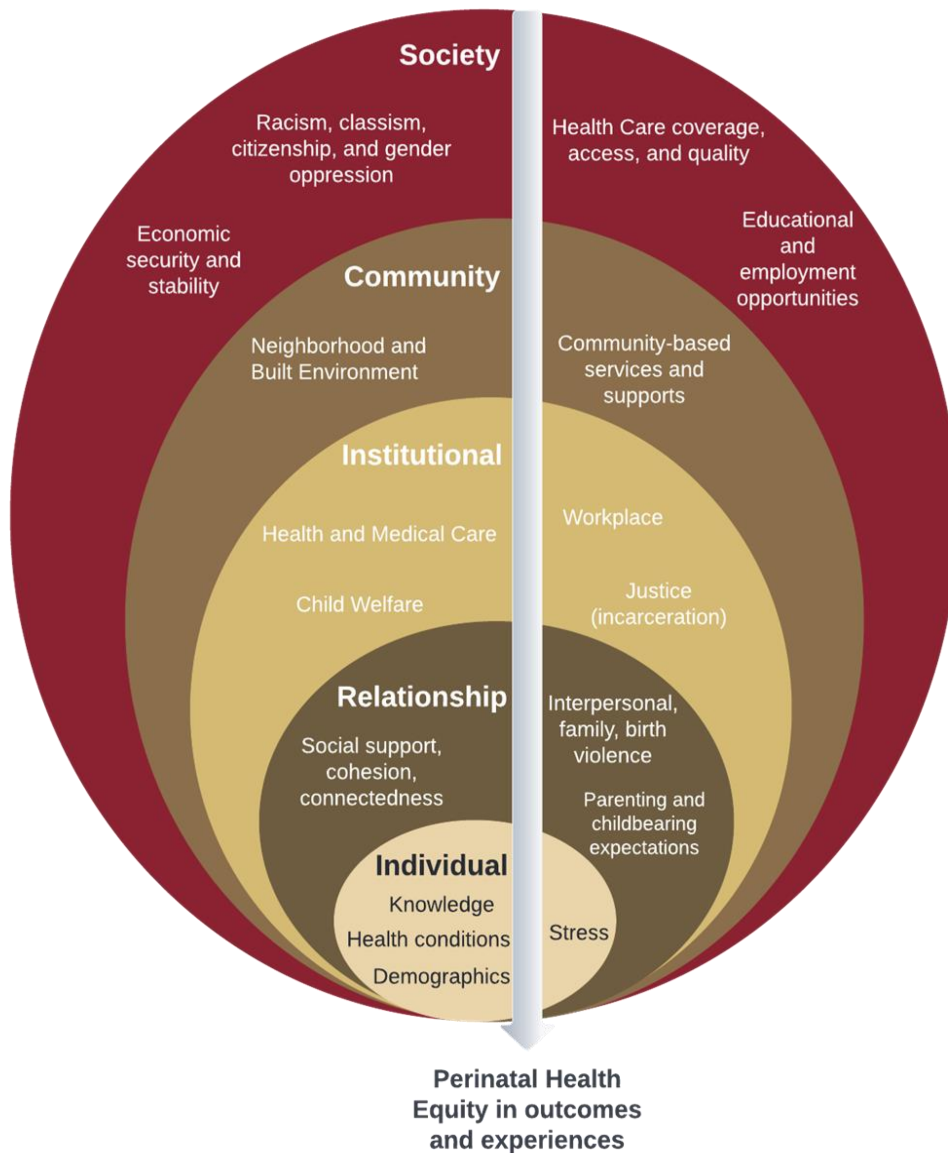
Applying the Social-Ecological Model

Findings from this study span the ecology of perinatal health (Figure 11, next page). Leading risk and protective factors exist at individual, relationship, institutional, community, and societal levels. Individual factors, such as stress and knowledge, impact the development of self-efficacy and resiliency. Participants identified key relationships across social-ecological levels, from natural support (e.g., parent) to community-based spaces (e.g., peer support circles) to institutional staff (e.g., recovery nurse). Findings indicate that trust in the health care system is vitally important, but currently lacking. Similarly, fear of child welfare and justice system involvement remain key barriers to care. For many, child welfare involvement perpetuates harm and impedes the process of recovery and family strengthening. Societal factors, such as the culture of stigmatization and institutional racism, seep into each of the levels.

Across the ecology of perinatal health, several risk and protective factors identified through lived experience narratives are modifiable. Findings indicate that health promotion is most impactful when it happens early in pregnancy, is empathetic, exists outside of systems perceived as punitive (e.g., child welfare, judicial), focuses on the birthing individual-infant dyad (as opposed to solely on the child), and is rooted in financial support. Underscoring this is the necessity for at least one key relationship that is trusted by the birthing individual; the trusted person should understand the nuances of prenatal substance use, be a catalyst toward care coordination, and ensure that wraparound support is given.

If individuals are able to overcome the multiple barriers discussed while receiving the support they need, they are more likely to engage in activities that promote long-term family strengthening and sustained health outcomes. Findings from this study align with and amplify results of the perinatal substance use data linkage project.[45] Results from this data linkage project led to a policy brief[46] on the role of Plans of Safe Care to promote care coordination and drive outcomes for this population. This policy brief inspired a Plan of Safe Care pilot in the San Luis Valley, resourced by the CDHS' Division of Child Welfare.[47] The essential elements underscoring the pilot are supported by findings from this qualitative research project and can be used to further inform design of the pilot—with implications for statewide scaling.

Figure 11: Ecology of Perinatal Health
This figure visualizes major drivers of perinatal health at each level of the social-ecological model.[48]



To accelerate progress in such existing efforts and inspire innovation, we end by translating findings into data-informed recommendations for policy and practice.

Colorado Evaluation & Action Lab
UNIVERSITY OF DENVER

Recommendations

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Recommendations

This project generated rigorous qualitative research on lived experiences of prenatal substance use, including modifiable factors that help or harm birthing individuals and their infants. Lived experience data is a powerful source of information that can be used to inform policy and practice recommendations. Below, we discuss nine recommendations that can reduce access barriers, improve service engagement, and promote healthy outcomes for the parent-infant dyad. Recommendations are anchored in results from this qualitative study, and informed by findings from Colorado's perinatal substance use data linkage project and national research evidence. The ideas for change identified directly by birthing individuals in this project are emphasized throughout recommendations.

Recommendation 1: Prioritize rapport-building and empathetic care.

> **Empathetic, person-centered care is critical for effective service delivery.**
>
> **Rapport-building with the birthing individual is essential to identifying their starting place, their goals, and the most meaningful supports.**
>
> **Audience:** Professional supports in physical and behavioral health care, human services, judicial, community spaces.

Even a single key relationship can make all the difference in the pursuit of substance use treatment and parenting goals. When rapport-building and empathy are prioritized, trusting relationships are more likely to be forged. Relationships of trust can be leveraged for care coordination across systems. Pregnant people may touch none, one, or multiple systems during the perinatal period and in treatment and recovery. It is critical that no matter what system or service a pregnant person interacts with, they can form a trusting relationship.[49]

> *"I think that if everyone had access to someone who's understanding and patient and wants to help. Who understands thought processes and why you're still using and what you need to stop, like your motivations. I think peer supports are huge. They're definitely the people in the situation that you can trust, because they've been through the same thing.*
>
> **- Elliot**

Trusting relationships are most likely to be formed in community spaces outside of systems that approach prenatal substance use with a punitive lens (e.g., criminalization) or the potential for harmful consequences (e.g., removal by child welfare). Across all systems and services, investments in training and technical assistance are needed to create a culture of non-stigmatizing support and to enact policies and procedures that enable a harm reduction approach. Accountability mechanisms should also be in place. Providers should consistently demonstrate empathetic behaviors with consequences for discriminatory or harmful care. Recruiting and retaining a quality workforce, skilled at rapport-building, can facilitate continuity through the ups and downs of recovery and parenting.

In building rapport and providing empathetic care, providers should work to uncover the motivating factors for that individual person. Supporting the birthing individual in developing self-efficacy can help sustain positive behavioral changes. In this process, it is essential that professionals show genuine care and investment *in the parent*, not just the baby. Providers must recognize that the health of the parent-

infant dyad is intimately connected. Disrespectful treatment toward the birthing person directly harms the well-being of the infant and whole family unit.

Recommendation 2: Expand opportunities for peer support, including investment in doulas and recovery coaches.

> **Build up the workforce of peer supports and embed them in every place a childbearing person may interact, from social services to prenatal care to parenting groups to treatment and recovery settings.**
>
> **Expand the number of peer support groups and spaces available from pregnancy to early parenting.**
>
> **Audience:** State and county agencies, community organizations, health care organizations, individuals with lived experience.

Peer supports leverage their lived experience to build trust, establish rapport, and tailor support. Peer supports may take the form of peer support specialists, peer navigators, peer advocates, recovery coaches, doulas, and more. Their effectiveness is highly documented in the literature[50,51] and Colorado has made significant progress in this area (e.g., SB23-002). Additional investments in peer supports, specifically for pregnant and parenting individuals affected by substance use, is a promising way to build social connections for parents, improve care coordination, and reduce disparities for underserved communities who are being rendered invisible by formal systems.

Investments should ensure that peer supports are available in the main spaces and places that pregnant and parenting people affected by substance use may interact. This includes prenatal care, the birthing hospital, pediatrician and postpartum care, child welfare, judicial and corrections, treatment and recovery, wraparound services like WIC, and community-based placed like Family Resource Centers. This may also include informal spaces, such as bus spots, as part of street outreach. Funding for training, education, and ongoing professional development for lived expertise to become peer supports is needed. Peers becoming doulas and recovery coaches are two of the most promising places for investment. Peers that can provide culturally and racially responsive support are essential.

In addition to direct peer support professionals, cultivating more peer spaces and groups is needed. Programs like Circle of Parents and spaces like Hard Beauty should be invested in and such successful models replicated. Rural areas should be targeted to advance equity.

Recommendation 3: Support scaling of Plans of Safe Care (POSC) in voluntary, community-based spaces during the pregnancy.

> **POSC can improve care coordination and help ensure families receive wraparound services. However, their effectiveness within child welfare is limited.**
>
> **POSC will be most effective when initiated in community-based spaces during the prenatal period, to combat the stigma and fear associated with child welfare.**
>
> **Audience:** Child welfare, health care providers, community partners, the SuPPoRT Colorado Plan of Safe Care Working Group.

Plans of Safe Care (POSC) have been a requirement in child welfare legislation since 2003. In 2016, the Child Abuse Prevention and Treatment Act (CAPTA) was amended by Congress with a requirement that states use a POSC for an infant born with and identified as being affected by substance use, withdrawal symptoms, or fetal alcohol spectrum disorder. While the legislation has potential, it is falling short of its intended impact to improve health outcomes and strengthen families. This is in large part because of the fear and stigma that permeates child welfare, where association of a POSC with child welfare can make it seem like a compliance exercise at best to a "gotcha" tool at worse. Additionally, Colorado struggles to find ways to consistently implement POSC in the prenatal period using community-based partners. This is critical since child welfare cannot become involved until after the birth event. Further, hospitals are put in a difficult position around mandatory reporting to child welfare if a POSC has not yet been initiated. The prenatal period is also a prime opportunity for behavioral change that can have lasting health effects (e.g., low birth weight) and provides time for families to receive wraparound supports and achieve stability, with the goal of keeping families together and preventing child welfare involvement.

A POSC Pilot is underway in the San Luis Valley to explore a community-based approach to POSC development, care coordination, and tracking. The pilot is being led by the Colorado Lab, Illuminate Colorado, and the Kempe Center with resourcing from the CDHS Division of Child Welfare. The pilot was inspired by results from Colorado's perinatal substance use data linkage project and ongoing efforts by health care organizations, state agencies, and SuPPoRT Colorado. The pilot gives Colorado a leading opportunity to test what it will take to meaningfully use POSC by leveraging community spaces, voluntary and collaborative approaches, and initiation prenatally. If results are favorable, investments in adapting and scaling the POSC framework statewide will be needed.

National legislation is also underway with CAPTA reauthorization that may change requirements for POSC, including the opportunity to move POSC ownership outside of child welfare entirely and to more trusted spaces. Leaning into this opportunity will be essential to achieving the spirit of POSC. This will require child welfare to relinquish some control over POSC so they can flourish in community spaces prenatally, and taking a step back so that community and health care partners can step up in the care of these families.

> *"It's just the system is broken. And so, like, if [child welfare] were more proactive instead of reactive."*
>
> **- Robin**

Recommendation 4: Promote more respectful, person-centered health care.

> **Increase educational opportunities around what respectful care looks like for birthing individuals with a history of substance use.**
>
> **Engage in whole-person, whole-family care that integrates physical and behavioral health care with other social care needs, such as housing.**
>
> **Treat birthing individuals as the most important partner in decisions about infant care and recognize that the health of the maternal-infant dyad is linked.**
>
> **Audience:** Health care providers, including prenatal, birthing hospital staff, infant care providers, specialized providers.

Person-centered (or patient-centered care) has received major traction over the last 15 years and is recognized as critical to health outcomes and care experiences. Person-centered care means providing integrated health care services in a way that responds to individual goals, needs, cultural values, and

preferences, and where care is seen as a collaborative process with shared decision-making. Person-centered care is threatened for individuals with prenatal substance use when stigma, judgment, and bias collide, resulting in less respectful care by providers. This becomes even more pronounced—and more harmful—when systemic oppression (e.g., racism, classism) is present.

To help combat, ongoing training, professional development, and coaching is needed for health care professionals in Colorado. This includes nurses, physicians, pediatricians, WIC professionals, midwives, counselors, therapists, specialists, and more. Understanding specific needs and triggers of birthing individuals with substance use histories (e.g., IVs for previous IV drug users) should be incorporated into sensitivity trainings. Accountability to enacting respectful care is crucial and hospitals should make transparent how providers are being held accountable to mistreatment during perinatal care. Models such as MICARES can be brought to Colorado for replication.

Part of respectful care is recognizing that the health of the parent-infant dyad is intimately connected. Showing love for the pregnant person—so that self-love grows—is one of the most important factors for sustaining recovery and building confidence. From here, whole-person, whole-family care can be done. This approach recognizes the wraparound support needs of families (e.g., housing, transportation), beyond just clinical care, and actively addresses those through care coordination. Colorado's investment in regional Social Health Information Exchange (SHIE) hubs can help facilitate this need.

Recommendation 5: Promote anti-stigma initiatives and elevate spaces for storytelling and story-sharing.

> **Anti-stigma initiatives are needed for both the general public and for systems that care for families affected by prenatal substance use.**
>
> **Storytelling is a powerful mechanism to combat stigma and increase understanding of lived experiences of prenatal substance use.**
>
> **Story-sharing among individuals with shared experience can reduce feelings of shame and build communities of support.**
>
> **Audience:** Natural supports, professional supports, the general public, individuals with lived experience.

Social connections are a protective factor and can provide childbearing individuals crucial social support, including informational support, concrete support, and emotional support. Such support can help overcome access barriers and help families become engaged with needed supports. This potential is threatened by extensive societal stigma around prenatal substance use. Even when family members and loved ones care, they are often at a loss as to how to meaningfully support those using substances during pregnancy. Anti-stigma campaigns like *Beyond Labels*, *Lift the Label*, *and* *Changing Minds: Stories Over Stigma* are opportunities and models to replicate. Pairing these with informational campaigns about services, supports, and resources can be especially powerful, as loved ones commonly want to "do something" but lack knowledge of available options.

In Colorado, Tough as a Mother is a successful anti-stigma, connection, and resource campaign that should be continuously grown with adequate investments. The campaign also facilitates direct support spaces, such as online support groups. Sharing stories can be an incredibly powerful way to combat stigma and

empower individuals in their parenting and recovery experience. This opportunity is exemplified by #RecoveringOutLoud, where childbearing people share their stories and communities of lived experience are fostered across Colorado.

Sharing stories with peers has therapeutic benefits, including receiving and giving emotional support. It also has the benefit of learning more about resources and other information-sharing. Spaces of acceptance can help shift the culture, alleviate internalized feelings of stigma, and forge new bonds. Forming new relationships is particularly important for pregnant people affected by substance use because many relationships are lost during the treatment and recovery journey.

Storytelling to professionals, loved ones, and the general public is an essential way to combat stigma. Stories illustrate variation in how prenatal substance use is experienced so that stereotypes can be dissolved, shed light on root causes and move blame away from individual shortcomings, and inspire positive change in how individuals with a history of prenatal substance use are treated in service engagement, in the workplace, and in the neighborhoods they live in.

Funding for storytelling and story-sharing initiatives and spaces should be prioritized. Adequate funding is necessary to help maximize their benefit and sustain impact overtime.

Recommendation 6: Promote financial well-being for childbearing families and co-locate concrete supports.

> **Economic and concrete support for childbearing families is critical to ensure acute needs are met around prenatal health and substance use treatment, as well as to promote long-term family strengthening.**
>
> **Priorities include transportation, housing, insurance coverage, food security, child care and infant care needs, and economic mobility support.**
>
> **Audience:** community spaces, state and county agencies, behavioral and physical health care providers, statewide collaboratives.

Economic and concrete supports reduce child maltreatment and can strengthen families long-term. Financial stability is crucial to breaking down access barriers and increasing service engagement for families affected by prenatal substance use. Concrete supports of priority include housing, transportation, food security, child care, and infant care needs (e.g., diapers). Economic supports of priority include insurance coverage with options for culturally-matched therapists, recovery networks, and perinatal providers that are trusted by childbearing families, including midwives, doulas, and peer specialists. Guaranteed income for childbearing families is a promising opportunity to break intergenerational cycles of poverty and address root causes of prenatal substance use. Models such as Philly Joy Bank, where pregnant individuals can receive $1,000 a month up until the child is one year of age, are promising potentials for Colorado to explore. The Colorado Partnership for Thriving Families has efforts underway to advance family economic well-being in Colorado and serve as a key pathway for activation. Given the high need for financial stability among pregnant people experiencing prenatal substance use, Colorado should explore a "co-location" model for economic supports. For example, intentionally embedding staff with expertise in economic and concrete supports into treatment centers, clinics, and peer groups. Using peer supports to walk alongside birthing individuals in securing financial stability is an especially fruitful strategy, given the stigma associated with both poverty and substance use.

> *"On LinkedIn, I see a lot of people who work in recovery and are very proud of their status being like, I never thought I'd get this far. I'm a strong advocate because this is my history. I would love to see people who are not just in the recovery field but who are lawyers, who are doctors or health care workers...they can get there too, you know. Just to encourage more of a recovery-oriented workplace."*
>
> **- Rowan**

Recommendations are Not Mutually Exclusive

Recommendations are connected and complement one another. For example, peer supports (recommendation 2) are well-positioned to provide rapport-building and empathetic care (recommendation 1). Developing a workforce of peer supports for family economic well-being can help accelerate progress (recommendation 6) while improving care coordination (recommendation 3).

Recommendation 7: Invest in regional systems-building to improve collaboration across services and supports.

> **Providing coordinated, wrapround care requires every essential service provider knowing what is available in the area and for whom, and where there is capacity.**
>
> **Building shared understanding of harm reduction approaches in caring for families affected by prenatal substance use is needed.**
>
> **Audience:** Regional health care providers, treatment and recovery providers, community organizations, social service providers.

The needs of families affected by prenatal substance use vary and evolve from pregnancy to birth to the first year postpartum. Care coordination is thus essential to wrap services around families in a way that meets their needs at the right time. Systems are cumbersome to navigate, with eligibility often being unclear and services like treatment centers commonly at capacity. Some services are also monolingual or otherwise don't have inclusive spaces and staff. These act as primary access barriers.

One way to address is to invest in regional-systems building. Regional and even local (versus statewide) systems-building is important because pregnant people should access services and supports in the communities they live in. When services are unavailable locally, pregnant people are forced to leave their support networks and face often-impossible transportation hurdles. This can lead to further access barriers or service disengagement. Quarterly coordination meetings can bring together local/regional agencies to build shared understanding of existing resources, eligibility requirements, and current availability. Similar to case consultations or family conferences where multiple providers meet together to figure out a care plan, regional coordination meetings replicate this exchange on a macro-level.

Regional coordination meetings can also be used to develop practice-based learning communities. Every provider and system have a different strength, and everyone has biases and areas for growth. Learning communities can be a way to build skills and knowledge, while also developing a shared approach to caring for families affected by prenatal substance use. This is important because the action of one

professional affects all services/supports. Families commonly do not distinguish between systems/services and roles can be confusing. This means that when one professional shows stigma or disrespectful care, that translates to other systems and fuels mistrust across the board. The National Harm Reduction Coalition has developed a *Pregnancy and Substance Use Harm Reduction Toolkit* that can be leveraged.

Recommendation 8: Require procedural transparency and clear communication about child welfare scope, goals, and parental rights.

> **Child welfare caseworkers should clearly communicate why they are involved with a family, what support they can and cannot provide, and how they hope to work together.**
>
> **Policies and procedures used by child welfare should be made transparent to families and options presented.**
>
> **Stigma and bias training for child welfare staff is needed, with accountability in place.**
>
> **Audience:** Child welfare staff, state leadership, state human service board.

Child welfare involvement is nearly always mandated and the trauma from systems involvement can last generations. Caseworkers in child welfare have titles similar to community supports and those within health care institutions, such as case manager, care coordinator, and social worker. Families are often confused about who provides what support and what their options are. Pregnant people using substances are commonly not given a clear picture of what their child welfare involvement will look like, including their parental rights and options. This can reduce the likelihood of infants staying at home, which is critical to bonding and child development, and impede timely reunification after removal. Making child welfare procedures around substance exposed newborns transparent and accountable is needed to build trust.

Child welfare staff should make clear their working relationship with the family and model collaboration. Modeling collaboration—paired with a non-stigmatizing approach—can improve family engagement in the case and better ensure family-centered goals are met. Stigma and bias training among child welfare staff is essential to moving towards a more collaborative relationship and reducing interactions that cause harm to the parent-infant dyad. Accountability for harmful service provision is also essential

Recommendation 9: Develop accountable standards for respectful perinatal care and substance use treatment for incarcerated individuals.

> **Health care, child welfare, and corrections should develop standards on how birthing individuals who are incarcerated will receive quality perinatal care, including during birth hospitalization and after birth for infant care and bonding.**
>
> **Incarcerated individuals should receive equitable access to supportive treatment and recovery services, including peer supports.**
>
> **Audience:** Health care, child welfare, judicial, corrections

Individuals who are incarcerated when pregnant face additional access barriers, stigma, and the potential for systems harm. Too often, a “good” or “traumatic” birthing experience for incarcerated pregnant people is a matter of what provider or hospital they happen to get when they go into labor. A facility-by-

facility approach is inadequate to ensure respectful, quality care is being delivered to all. Colorado should invest in standards for how incarcerated individuals will access perinatal care, treatment and recovery services, and wraparound supports. Standards should be made transparent, and agreements developed between health care, judicial, and child welfare so that accountability can be pursued. Standards should consider not only the birth event, but prenatal and postpartum too. Opportunities for close contact and bonding with the infant are critical. Peer supports can be especially effective in facilitating engagement.

Activating Recommendations

Each recommendation identifies target audiences that, together, can help activate recommendations. Below, we highlight additional opportunities to promote recommendations, sustainable implementation, and ongoing evidence-building to drive equitable perinatal health and family strengthening.

Policymakers

Policymakers at local and state levels can identify policies (e.g., legislative, rule, institutional) that can be revisited, removed, or created to mitigate identified risk factors and promote protective factors. This may include direct investments in promising strategies, such as peer supports, as well as technical changes like improving care coordination, or implementing accountability mechanisms around mistreatment.

Funders

Private and public funders can invest in the strategies identified in each recommendation. It is important that funding be flexible to meet unique needs and to reduce burden on organizations that receive funding . This is especially true for strategies like story-telling that require flexibility and trust to be effective.

SuPPoRT Colorado

SuPPoRT Colorado is the substance exposed newborns steering committee of the Colorado Attorney General's (AG) Substance Abuse Trend and Response Task Force. Bringing together cross-system, community, and family experts, SuPPoRT Colorado can effectively facilitate coordination around these recommendations, while elevating the recommendations to the policy-level through the AG Task Force.

Colorado's Perinatal Substance Use Data Linkage Project

Colorado's perinatal substance use data linkage project is the best mechanism to engage in ongoing evidence-building. In 2024, SB24-047 (Prevention of Substance Use Disorders) passed with provisions to strengthen the data linkage project and add in qualitative data. Qualitative research with vulnerable populations is a large undertaking; employing community-based approaches, such as peer researchers, adds both complexity and opportunity. The capacity built from this qualitative study will accelerate the mixed methods opportunities coming online with SB24-047.

Conclusion

This qualitative research leveraged the power of lived experience data to elevate family voice in practice and policy solutions for prenatal substance use. Findings and recommendations can be used to improve parent-infant health and set families up for long-term thriving. As one participant concluded:

"It felt okay to have a little one in my hands and stare right at his face. That joy. The joy was just so different. And I was just so glad that I got help." **– Alex**

Appendix A: Copy of Outreach Material

Lived Experiences of Perinatal Substance Use

We need to take better care of pregnant people – help us figure out how.

If you have experience with substance use during pregnancy, we want to hear from you!

The Colorado Evaluation and Action Lab (University of Denver) is conducting a research project to learn how to improve services and supports for people experiencing substance use during pregnancy.

You are invited to share your story through a **confidential peer interview**, either in-person or online. The interview will last about 60 to 90 minutes.

Participants will receive a $75 visa gift card to thank you for your time.

You can participate in this study if you are:

- 18 years of age or older
- Currently pregnant or gave birth in last five years
- Live in Pueblo, Colorado Springs, San Luis Valley or the Denver-metro area
- In recovery or receiving substance use treatment

To learn more and sign-up:

Email
COShareYourStory@gmail.com

Call
(720) 441-5025

Courtney Everson, PhD (principal investigator) at Courtney@coloradolab.org or 303-871-2116.

Colorado Evaluation & Action Lab
UNIVERSITY OF DENVER

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