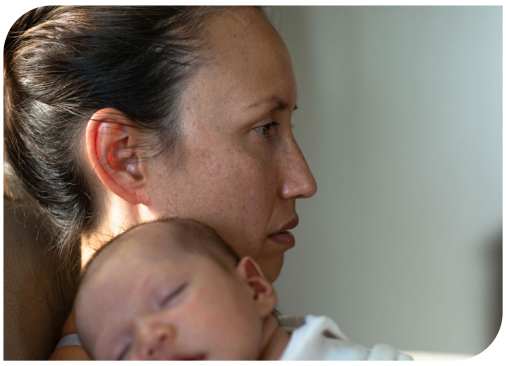
Colorado Evaluation & Action Lab
UNIVERSITY OF DENVER

Lived Experiences of Prenatal Substance Use in Colorado

Elevating Family Voice to Drive Policy and Practice Change

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.

Lived experience is a powerful form of data to inform feasible and meaningful policy and practice change. This qualitative study identified risk and protective factors that influence service navigation and well-being for families affected by prenatal substance use.



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

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

Study Approach

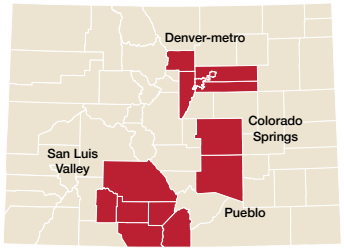
This study used a grounded theory methodology and in-depth interviews to capture lived experiences from pregnancy through the first year postpartum. Peer researchers joined as core members of the research team. Using peer researchers increases rigor and accelerates the path from research to application.

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. This innovation facilitated a trauma-informed, harm reduction approach during research with this vulnerable population.

Who Participated

25
birthing individuals shared their story. All were in recovery or actively in treatment.



Participants represented rural and urban perspectives.

50%
had child welfare involvement

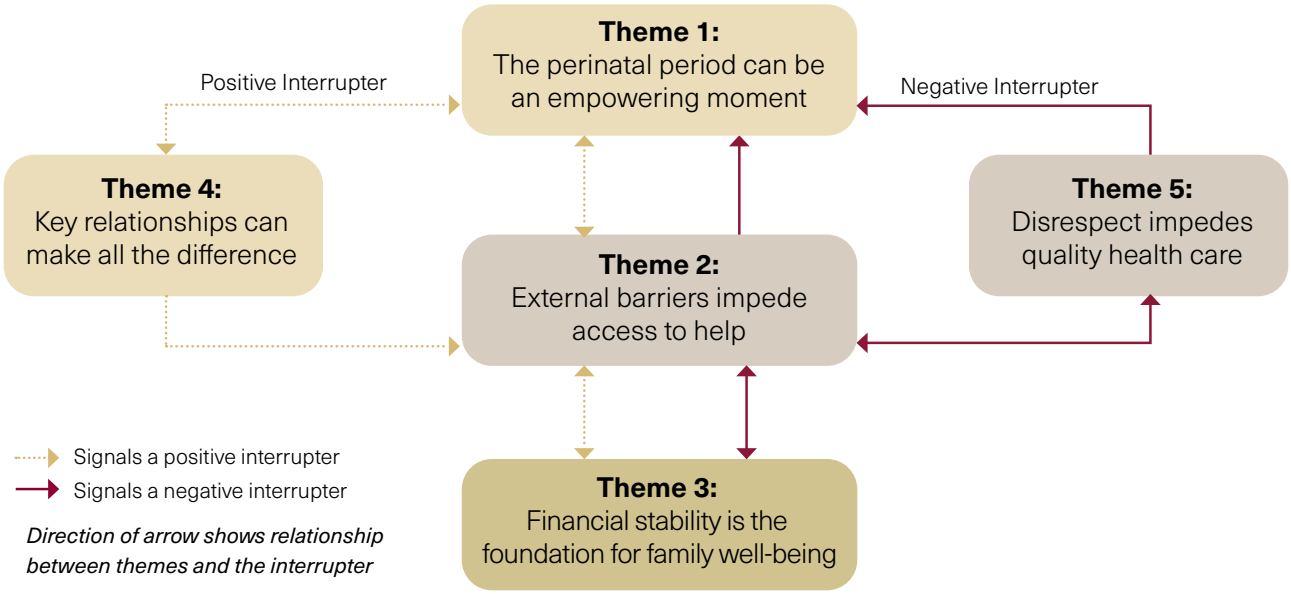
Half the sample included families of color, with Black/African American, Hispanic/Latinx, and Indigenous perspectives represented.

About one-third of participants were part of the immigrant or refugee community.

Polysubstance use during pregnancy was common (84%). Almost half (48%) of participants reported misusing opioids or other prescription medication, followed by cocaine and methamphetamine use (44%, each).

What We Learned

Five 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

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" are initial motivating factors, but internal self-love is what leads to sustainable change.
- Pregnant people negotiate risk as they build self-efficacy and resiliency in the face of external barriers.

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

"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

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.

Barrier 1: Complex, obscure systems make support hard to access (e.g., unclear eligibility).
Barrier 2: Lack of child care, transportation, and affordability get in the way of accessing services.
Barrier 3: Fear and stigma are major determinants of not seeking help.

"You [service providers] 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." – Hayden

"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. Having more community and being vocal about it so that people feel comfortable to engage." – Kai

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

Financial support 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 support leads to high stress and directly hurts seeking treatment and support. Building family economic well-being is an antidote.
- Stigma of poverty adds to the stigma of substance use, making access to economic and concrete support out of reach for many.

"No one talked to me about insurance or financial support or food support, and this would have really helped me and my baby." – Casey

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

Key relationships interrupt cycles of poverty and prenatal substance use to create a new possibility. This is done through emotional and concrete support, knowledge sharing, and care coordination.

- Key relationships take many forms, including natural (e.g., friend) and professional (e.g., counselor).
- Peers with lived experiences are a key trusted relationship with high promise.

"[My recovery nurse and doula] were the best things for me ... I couldn't have done it without them." – Rowan

Theme 5: Birthing individuals experience disrespect from health care providers

Experiences of disrespect from health care providers impede quality care.

- Person-centered care is commonly not provided and ignores lived experience needs.
- Birthing individuals feel treated as "less deserving" because of their substance use history.

"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." – Yasmin

How We Can Better Serve Families Affected by Prenatal Substance Use

This project identified leading risk and protective factors that work to either help or harm birthing individuals and their infants. Many of these factors are modifiable. Recommendations are anchored in results from this qualitative study, and informed by findings from the Colorado perinatal substance data linkage project and national research evidence.

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 identify their starting place, their goals, and the most meaningful supports.
- **Audience:** Professionals in physical and behavioral health care, human services, judicial, and community spaces

"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

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 with, from social services to prenatal care to treatment settings.
- Expand the number of peer support groups and spaces available from pregnancy to parenting.
- **Audience:** State and county agencies, community organizations, health care organizations, lived experience.

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 remains 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, SuPPoRT Colorado Plan of Safe Care Working Group

"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

- 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 (prenatal, birthing hospital, infant care providers, specialized)

Recommendation 5: Promote Anti-Stigma Initiatives and Elevate Spaces for Storytelling and Story-Sharing

- 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, general public, lived experience

Recommendation 6: Promote Financial Well-Being for Childbearing Families and Co-Locate Concrete Supports

- Economic and concrete support is critical to ensure acute needs are met and to promote long-term family strengthening. Priorities include transportation and housing.
- Co-locating financial support services within other common spaces (e.g., treatment centers) is a promising strategy.
- **Audience:** community spaces, state and county agencies, behavioral and physical health care providers, statewide collaboratives

Recommendation 7: Invest in Regional Systems-Building to Improve Collaboration across Services and Supports

- Providing coordinated, wraparound care requires every essential service knows 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

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 with the family.
- Stigma and bias training should be an accountable and transparent requirement.
- **Audience:** child welfare staff, state leadership, state human service board

Recommendation 9: Develop Accountable Standards for Respectful Perinatal Care and Substance Use Treatment for Incarcerated Individuals

- Health care, corrections, and child welfare should develop standards on how incarcerated birthing individuals will receive quality perinatal care.
- Incarcerated individuals should receive equitable access to supportive treatment and recovery services, including peer support.
- **Audience:** health care, judicial, corrections, child welfare

This qualitative research study leveraged the power of lived experience data to elevate family voice in practice and policy solutions for prenatal substance use. Findings can be used to improve parent-infant health and set families up for long-term thriving. Policymakers, professionals, funders, and communities all have a part to play in moving recommendations into action.

"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

Click here or scan the QR code for the research report to hear more from families and their ideas for change.

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