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2021 Legislative Report

Progress on the Perinatal Substance Use Data Linkage Project
authorized under SB19-228, SB20-028, and SB21-137

SUBMITTED BY: Center for Prescription Drug Abuse Prevention

REPORT HIGHLIGHTS:

- SB21-137 authorized access to and linking of additional state administered data sources to generate population estimates of incident rates and health outcomes for maternal-infant dyads impacted by perinatal substance use.
- An update on progress and challenges associated with incorporating health care claims data and prescription drug monitoring program data is provided.
- A study was conducted on risk and protective factors associated with infant removal from the home by child welfare due to substance exposure of the newborn. A follow-on study of maternal and infant mortality was also completed. A summary of findings is reported.
- Recommendations for improving outcomes through implementation of Plans of Safe Care for families impacted by substance use during a pregnancy is outlined.

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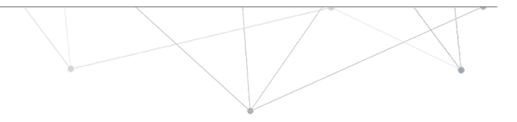


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About Policy and Budget Recommendations

Policy and budget recommendations are the opinions of the Colorado Lab authors and do not represent the budget or legislative agendas of state agencies, the Governor’s Office, or other partners.



Issues Addressed by Legislation

Legislators tasked with directing state investments and shaping policy aimed at strengthening families impacted by perinatal substance use disorders (SUD) need Colorado-specific information on incident rates, health outcomes, and service utilization patterns to inform policy and practice investments.

It is difficult to estimate how many Colorado families are impacted by substance use during pregnancy without connecting information across data sources. Dyads of pregnant people and infants may touch one or multiple systems during their childbearing and recovery journey, from prenatal care and prescription drug monitoring to parenting programs and early intervention to child welfare involvement and behavioral health treatment. As such, data from any one system cannot provide a complete picture of perinatal substance use in Colorado and cross-system actionable data is vital to developing a Colorado-specific strategy and response. The data linkage project is designed to accomplish the goal of generating population estimates by using a variety of state administered data sources to identify substance use during a pregnancy and then use birth certificate records to connect maternal-infant dyads and their outcomes across the multiple touchpoints of their journey.

Advancing Policy and Practice through Actionable Data

This project is designed to yield annual population estimates of perinatal substance use, trends in health outcomes, and service utilization patterns for impacted maternal-infant dyads.

The project is the foundation for research that can inform cross-system collaboration, investments in interventions, and reform or creation of state policies that take a comprehensive, family-centered approach to improving well-being.

Successful linking of data across state administrative sources is the essential ingredient for accomplishing this research and its goal of actionable data for policy and practice strategy.

Legislative History

SB19-228: Substance Use Disorders Prevention Measures

Section 12 authorized a Perinatal Substance Use Data Linkage Project for the purpose of planning, implementing, and evaluating public health actions to improve outcomes for families impacted by substance use during pregnancy.

This legislation set the initial vision for a perinatal substance use data linkage project by creating the opportunity to connect information across state administrative data sources. SB19-228 was a response by the Colorado Legislature's Study Committee on Opioid and Other Substance Use Disorders to the lack of comprehensive data available in Colorado to guide policy and practice decision-making. This inaugural legislation made the data linkage project possible.



SB20-028: Substance Use Disorder Recovery

Section 7 authorized the Perinatal Substance Use Data Linkage Project to conduct ongoing research related to the incidence of perinatal exposure or related infant and family health and human services outcomes with a specific focus on child abuse and neglect.

This legislation shifted the data linkage project from a one-time endeavor to an ongoing, long-term research agenda. The fiscal resources associated with this legislation enabled successful completion of the first study from this project on outcomes of child welfare-involved maternal-infant dyads.

SB21-137: Behavioral Health Recovery Act

Section 22 required the Perinatal Substance Use Data Linkage Project to use and link data from the Medical Assistance Program, the Prescription Drug Monitoring Program, Colorado Trails, the Colorado Immunization Information System, the Colorado Child Care Assistance Program, the Office of Behavioral Health in the Department of Human Services, and Birth and Death Records.

Section 22 authorized connecting additional state administered and non-state administered data sources for the purposes of improving population estimates and examining system utilization and outcomes.

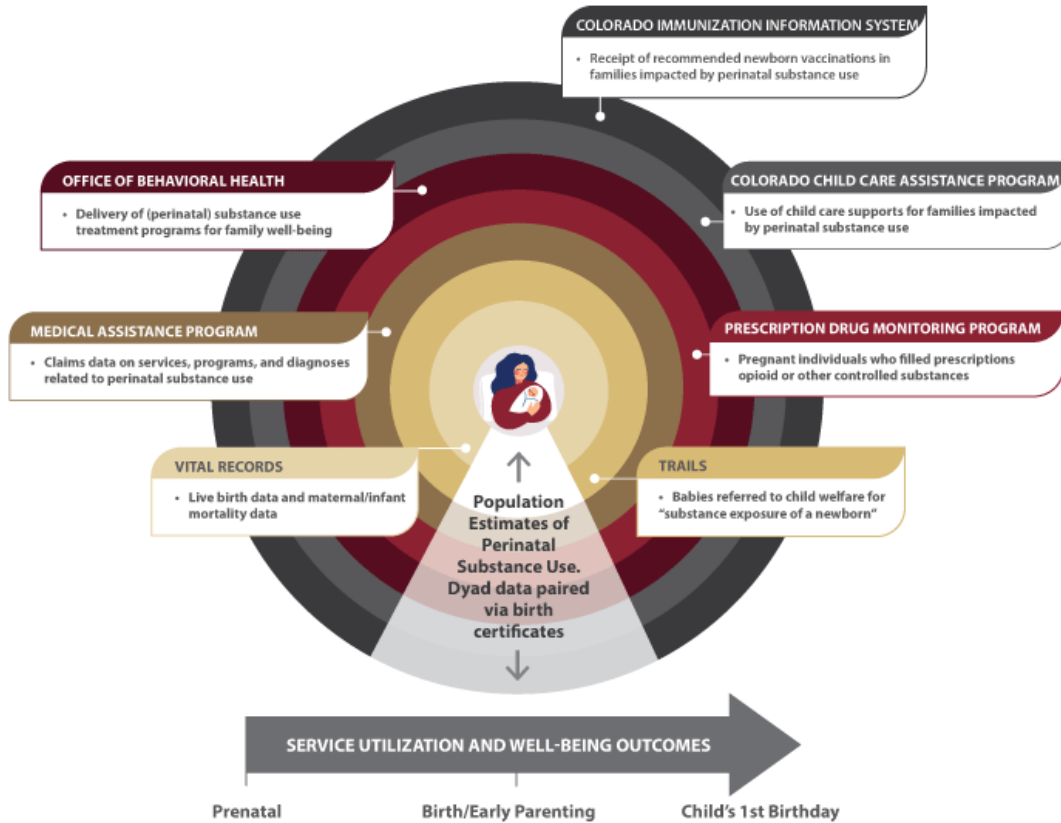
Stemming from lessons learned to date in the project, this legislation aimed to address identified barriers to incorporating the data necessary to fully achieving the goals of this project: (1) generate rigorous population estimates of maternal-infant dyads impacted by prenatal substance use; and (2) inform the planning, implementation, and evaluation of public health, human service, and health care actions to improve outcomes for families.

Progress on Linking Data Across Systems

Experts from Colorado state agencies, universities, medical providers, the Substance Exposed Newborns Steering Committee of the Attorney General's Substance Abuse Trend and Response Task Force, advocacy groups, and families were convened to co-develop a methodology for using administrative data to routinely track incident rates of perinatal substance use in Colorado and generate actionable insights, Figure 1 illustrates the information and data sources recommended by these experts to accomplish project goals. The state administered data systems in Figure 1 are required to be included in the data linkage project under SB21-137 and the non-state administered data sources were authorized to be connected to the state administrative data under SB21-137 when doing so meets the goals of the data linkage project.



Figure 1: Overview of data sources necessary to obtain population estimates and generate actionable data for policy and practice decision-making (approved for use in SB21-137).



The mechanism for connecting and then anonymizing the data sources authorized in SB19-228, SB20-028, and SB21-137 is by and through the Governor’s Office of Information Technology (OIT). Practically, that means that the Linked Information Network of Colorado (LINC) was used.

LINC is a collaborative based out of OIT that supports timely and cost-efficient research, evaluation, and analytics. LINC can securely connect then de-identify data across state and local agencies, including human services, health, labor and employment, higher education, housing, K-12 education, and criminal justice. This results in research-ready data that no longer contain personal identifiers and can be used to answer approved research and analytic questions that can drive important decisions about policy and programs. Through this process, LINC balances the power of data to improve the lives of Colorado residents with the need to protect privacy.

The rigor and comprehensiveness of population estimates necessary to inform investments and interventions are a direct reflection of the data sources that contribute to these estimates. The importance of each data source is briefly described below, organized by status of the data linkage for this project.



Fully Engaged in Project: Data have been successfully linked

- **Vital Records** allows dyads of pregnant people and infants to be connected. Explicit authorization of the use of vital records in SB19-228 made this foundational component of the project possible to launch during State Fiscal Year 2021 (SFY21).
- **Colorado Trails (Child Welfare)** incorporates into population estimates and family strengthening practices those infants who were referred to child welfare shortly after a birth event for substance exposure of the newborn and that referral was substantiated.

Partially Engaged in Project: A plan is in progress to request the data in SFY22

- **Medicaid** will complete the minimally required data partners necessary to generate population estimates of perinatal substance use in Colorado and robustly understand health outcomes and care strategies.
- **Prescription Drug Monitoring Program (PDMP)** data will strengthen the population estimates and prevention-focused strategies by incorporating early risk flags as identified through filled prescriptions of opioids and other controlled substances.

Not Yet Engaged in Project: Prioritized for SFY23 +

- **Colorado Department of Human Services (CDHS) Office of Behavioral Health** data will allow the examination of how state and federally funded-substance use treatment approaches relate to outcomes for Colorado families.
- **Colorado Child Care Assistance Program** will inform holistic family supports as a vital service to families navigating treatment and recovery.
- **Colorado Immunization Records** will inform efforts to improve early childhood health and close the gap on related health disparities.
- **Non-state partners such as Health Data Compass, All Payer Claims Database and the Colorado Hospital Association** could provide an understanding of how clinical medical records offer unique information about perinatal SUD that does not appear in medical claims, as well as help expand population estimates to include families without Medicaid as the primary payer for delivery.



Initial Research Findings

The first study from the perinatal substance use data linkage project leveraged the data sources that were prioritized for linking during the first year of the project: Vital Records birth and death certificate data and Trails child welfare data.

Researchers from the Colorado Evaluation and Action Lab at the University of Denver and the Children’s Hospital at University of Colorado Anschutz’s Medical Campus collaborated to study risk and protective factors associated with infant removal from the home by child welfare due to substance exposure of the newborn. By focusing on the subset of child welfare-involved maternal-infant dyads, this research offers unique insights into how health care, public assistance, and child welfare systems can coordinate efforts to strengthen families, prevent family separation, and decrease foster care placement for these Colorado babies. A follow-on study created a baseline understanding of infant and maternal mortality outcomes for families involved in child welfare and impacted by perinatal substance use, with an expressed focus on informing policy and practice aimed at preventing unnecessary deaths in the first year of life.

The full report was released in March 2021 and the follow-on study was released in June 2021. These reports can be found [here](#).

Study findings demonstrated the need for cross-system care coordination in wrapping services around families impacted by perinatal substance use, beginning prenatally and extending through the first year of life. Table 1 provides a synthesis of study findings and identifies promising perinatal opportunities for upstream prevention that can move the needle on health and social outcomes for families.

Table 1: Summary of Study Findings and Recommendations

Study Finding	Data-Informed Recommendation
<p>Prenatal Care. Consistent participation in prenatal care is associated with a lower risk of infant removal by child welfare. Less than one-third of mothers began prenatal care early in their pregnancy and participated in the recommended number of visits.</p>	<p>Prenatal care can provide guidance to pregnant persons and other caregivers on infant health and care (e.g., breastfeeding, safe sleep, postpartum depression), what to expect in terms of caring for newborns with prenatal substance exposure, and referrals to specialists.</p>
<p>Economic Security. Higher household income levels are associated with lower risk of infant removal by child welfare. The majority (72%) of mothers indicated their household income was less than \$25,000 a year.</p>	<p>Child welfare, early childhood agencies, and community-facing family support organizations can offer referrals and service support for building economic security and obtaining concrete supports such as child care, utility assistance, and diaper connections.</p>
<p>WIC. Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) participation is associated with lower risk of infant removal by child welfare. Household income data suggest there were more women eligible for WIC than engaged in these services.</p>	<p>WIC services can support prenatal food security and provide formula and lactation support, while also creating vital parenting and recovery support networks.</p>



Study Finding	Data-Informed Recommendation
<p>Newborn Medical Fragility. Families involved in child welfare due to prenatal substance use care for infants that tend to be more medically fragile at the time of birth and are admitted to the neonatal intensive care unit at three times the rate of the general population. Infants who are medically fragile, which is characterized by conditions such as respiratory problems and/or being born preterm, are at higher risk of infant removal by child welfare.</p>	<p>Health care providers can work together with pregnant people and their families during the prenatal period to put services in place that account for the unique medical needs of the infant and create proactive supports for the caregiver that best address the additional stressors that come from caring for a medically fragile newborn.</p>
<p>Maternal Mortality. The leading cause of maternal death for childbearing persons involved in child welfare and impacted by perinatal substance use was accidental drug overdose, mirroring statewide maternal death trends.</p>	<p>Human service, public health, and health care systems and community-facing family support organizations can partner together to overcome the stigma and structural barriers that prevent pregnant and postpartum persons from receiving the services and supports they need for acute crisis intervention and long-term recovery.</p>

Taken together, these findings make clear that comprehensively addressing perinatal substance use must involve investments and strategies that cross systems and match the unique touch points of any given maternal-infant dyad, beginning prenatally and extending through the first year of life. This recognition led to concrete policy and practice recommendations around how Colorado can expand, leverage, and effectively implement Plans of Safe Care in the prevention and treatment of perinatal substance use disorders.

Limitation: This study was not able to explore substance use treatment or type of substance use. Integration of Medicaid, PDMP, and/or CDHS behavioral health data into the project, through LINC, is needed to address this limitation in future studies.

Recommendation: Plans of Safe Care for Improving Cross-System Care Coordination

Based on initial study findings, opportunities identified from local practice investments, and national legislation and guidance, Plans of Safe Care (POSC) were identified by policy, practitioner, community, and family stakeholders as a lever for improving cross-system care coordination and health outcomes for families impacted by perinatal substance use.

The Colorado Lab developed a policy brief (linked [here](#)) outlining a vision for using Plans of Safe Care as a key activation pathway to: (1) guide cross-system policy and practice investments that improve outcomes for family; (2) support our state agencies in meeting state and federal responsibilities around caring for infants and caregivers impacted by perinatal substance use; and (3) cultivating a culture of collaborative responsibility for ensuring these Colorado families have every opportunity to thrive.



A vision begins with establishing a State Intermediary for Plans of Safe Care in Colorado that shall:

- Initiate Plans of Safe Care prenatally or as soon as prenatal substance use is recognized.
- Create multiple entry points for developing a Plan of Safe Care.
- Incentivize cross-system collaboration and ownership.
- Develop a comprehensive data collection system.

Creating a Strategic Roadmap for Colorado

A state intermediary for POSC is essential to creating a data-informed strategic roadmap for coordinated POSC service delivery and tracking across Colorado.

This vision and the key considerations outlined in the policy brief were co-developed and refined through partnership with key leaders from CDHS, the Colorado Department of Public Health and Environment, medical providers, research experts, community-facing providers, and families. During these partnership discussions, a resourced-opportunity to move this vision from concept to execution was identified. The Colorado Lab is currently working with the CDHS Division of Child Welfare to design and launch a Colorado pilot to explore feasibility and acceptability of the proposed approach. Findings from this pilot will be used to inform future legislation and state investments that advance the health and well-being of Colorado families impacted by perinatal substance use. Future reports to the General Assembly on the progress of this data linkage project will include updates on the pilot and any legislative support necessary to ensure the pilot reaches its full potential.

The Colorado Lab is currently working with the CDHS Division of Child Welfare to design and launch a Colorado pilot to explore feasibility and acceptability of the proposed approach for Plans of Safe Care. Findings from this pilot will be used to inform future legislation and state investments that advance the health and well-being of Colorado families impacted by perinatal substance use.