SB19-228 Legislative Report

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

Draft language for new legisalation are suggested in appendices.

SUBMITTED BY: Center for Prescription Drug Abuse Prevention

REPORT HIGHLIGHTS:

- The Perinatal Data Linkage Project has connected child welfare and vital records.

- Generating population estimates of substance exposed newborns requires linking additional state administered data sources.

- Recommendations for new legislation to remove barriers to including Medicaid and Prescription Drug Monitoring Program data in the data linkage project.

- Federal guidance was secured to support the recommended legislation.

- A study was conducted on healthcare utilization and health-related risk and protective factors associated with removal of substance exposed newborns from the home, available here in January of 2021.

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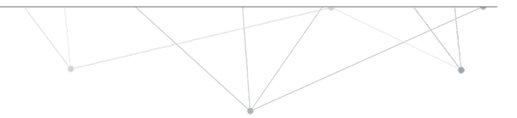
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Problems Addressed by Legislation

Legislators tasked with directing state investments and shaping policy aimed at strengthening families affected by substance use during a pregnancy need Colorado-specific information, incident rates of substance exposed newborns, and how perinatal services relate to health and well-being of mothers and infants.

It is difficult to estimate how many Colorado families are affected by substance use during a pregnancy without connecting information across data sources. From prenatal care to prescription drug monitoring, from initial hospital report of the births of substance exposed newborns to child protective services' recording of referrals, or from drug and alcohol treatment programs to early intervention services, dyads of pregnant people and infants may touch one or multiple systems. The data linkage project is designed to use a variety of state administered data sources to identify substance use during a pregnancy and then use birth certificate records to connect dyads of mothers and infants.

This project can yield annual population estimates of substance exposed newborns and trends in rates in the health and well-being of mothers and infants. The project is the foundation for research that can inform wrapping supports around families during the perinatal period and the use of state-managed funds for this population.

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 created the opportunity to connect information across state administrative data sources. Information generated from this connection can be used in Colorado to advance cross-system collaboration, investments in practices and interventions, and reform or create state policies to take a comprehensive, family-centered approach to improving the health and well-being of families.

> **SB19-228 authorized the data linkage project to consider administrative data of pregnant and postpartum women with substance use disorders and their infants that include: a) health care utilization and costs, b) human service and public health program utilization and costs, and c) vital records to link maternal and infant dyads.**

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 authorized building the capacity to routinely monitor population-level incident rates of prenatal substance use and health outcomes for mothers and babies.

Progress

1. **Began linking data sources to generate population incidents of substance exposed newborns.**

2. **Leveraged initial data linkage to conduct a study to inform preventing the need for foster care of child welfare involved infants with confirmed in utero substance exposure.**

Linking Data Sources

Experts from Colorado state agencies, universities, hospitals, the Substance Abuse Trend and Response Task Force, and advocacy groups were convened to inform developing a methodology for using administrative data to routinely track incident rates of substance exposed newborns. Figure 1 illustrates the information and data sources recommended by these experts to accomplish this goal and the status of data linkages.

Figure 1: Overview of data sources that can contribute to population estimates and research studies.
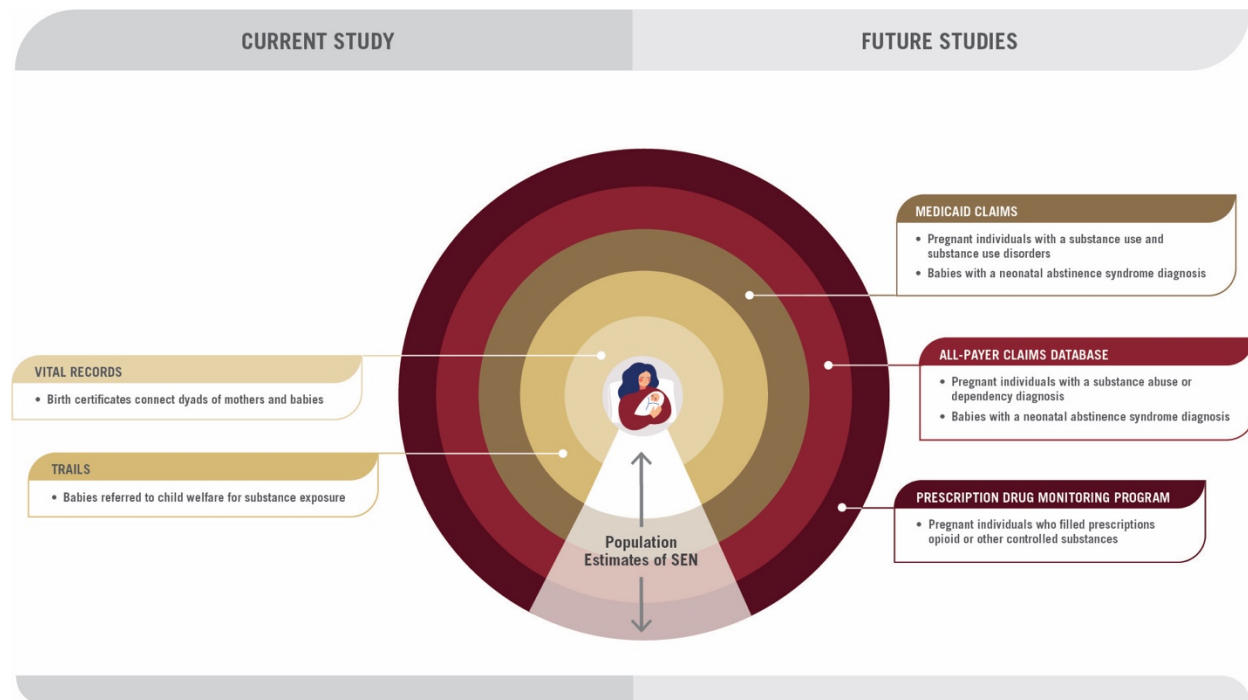
Note. CDHS's behavioral health data is relevant to phases of this project that examine how services relate to outcomes for mother-baby dyads.

The mechanism for connecting and then anonymizing the data sources authorized in SB19-228 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. Suggestions for addressing barriers to integrating Medicaid and Prescription Drug Monitoring Program Data (PDMP) data sources through legislation can be found in Appendix A.

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. Suggested language for creation of LINC in statute can be found in Appendix B.

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.

Fully Engaged in Project

- **Vital Records allows dyads of mothers and infants to be connected. Explicit authorization of this 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 infants who were confirmed by child welfare to have experienced in utero substance exposure.**

Partially Engaged in Project

- **Medicaid will complete the minimally required data partners to generate population estimates of substance exposed newborns in Colorado.**

Not Yet Engaged in Project

- **All-Payers Claims Data could strengthen the population estimates by ensuring they are not disproportionally driven by low-income families (i.e., Medicaid-enrolled only).**

- **Prescription Drug Monitoring Program Data (PDMP) could strengthen the population estimates by incorporate risk of substance exposure of a newborn identified through filled prescriptions of opioids and other controlled substances.**

- **Colorado Department of Human Services (CDHS) Office of Behavioral Health data could allow the examination of how state and federally funded-substance use treatment approaches relate to outcomes for Colorado families.**

Challenges and Strategies

There were three significant obstacles that stood in the way of allowing this project to meet its full potential of providing the legislature with a complete understanding of the size and nature of perinatal substance exposure in Colorado.

1. <u>Interpretations of federal and state data privacy regulations</u> that inhibited the inclusion of Medicaid, behavioral health, and PDMP data in this first report.

   Strategies:

   - Federal guidance was pursued indicating protected substance use data can be shared with LINC. Read guidance from the Center of Excellence for Protected Health Information, a Substance Abuse and Mental Health Services Administration -funded technical assistance team, [here](#).

   - Workflow created in collaboration with Medicaid staff to ensure only the minimally required data elements are shared with LINC to facilitate identity resolution.

   Status: The LINC team continues to work closely with the Colorado Department of Health Care Policy and Financing to implement a data sharing approach that protects the confidential Medicaid data per state and federal law. Progress is now being made for this project and it is anticipated that Medicaid data will be included in the next phase of the project. As written, legal representatives of the Colorado Department of Regulatory Affairs have determined that SB19-228 is not sufficient for PDMP data to be included in this project.

   <u>Resources to complete initial population estimates were not allocated.</u> The proposed fiscal note for SB20-028 included a $75,000 appropriation for population estimates and ongoing research in SFY21 and SFY22. These resources were not allocated during the 2020 legislative session. This represents a reduction in funds appropriated to support the SB20-028 work related to ongoing tracking of incident rates or studies that span the perinatal period.

   Strategies

   - The project team applied for local philanthropic grants and is preparing a federal grant proposal.

   - Addressing known barriers to data sharing through legislation will better position the project team to be competitive for federal research dollars (see [Appendix A](#) and [Appendix B](#)).

   Status: There are currently no resources to continue the data linkage project beyond June 2021. The Colorado Evaluation and Action Lab will provide in-kind time as available for onboarding data partners to LINC and fundraising/grant writing. Analytic work to generate incident rates and or conduct additional studies related to perinatal substance use will require a fiscal note.

Initial Research Findings

The first study from the perinatal data linkage project leveraged the data sources that were connected during the first year of the project: Vital Records and Trails child welfare data.

Researchers from the Colorado Evaluation and Action Lab at the University of Denver, Children's Hospital, and the Social Work Research Center at Colorado State University studied risk and protective factors associated with foster care placement of substance exposed newborns.

The full report will be released in January 2021 and will be available [here](#).

This study suggests that upstream prevention of foster care placement for substance exposed newborns begins with wrapping services around the family during pregnancy. Entry points are:

1. Consistent participation in prenatal care is associated with lower risk of child welfare removal. Less than one-third of mothers in this study began prenatal care early in their pregnancy _and_ participated in the recommended number of visits.

2. Higher household income levels are associated with lower risk of child welfare removal. The majority (72%) of mothers in this study indicated their household incomes was less than $25,000 a year.

3. Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) participation is associated with lower risk of child welfare removal. Household income suggests there were more women eligible for WIC than engaged in these services.

4. Infants with confirmed substance exposure tend to be more medically fragile and admitted to neonatal intensive care units at three times the rate of the general population. Infants who are medically fragile, such as having respiratory problems and/or being born preterm, are at higher risk of child welfare removal.

Prenatal care appointments and participation in WIC are opportunities to promote physical health and connections to substance use treatment during the pregnancy while also proactively addressing the underlying social and economic vulnerabilities (e.g., lower income, low educational attainment) that are often circumstances associated with child welfare involved population.

The study also underscores the need to plan for the health needs of infants affected by substance use during a pregnancy. These babies have unique care needs that may extend beyond the hospital stay. _Plans of Safe Care_ are among the ways to ensure the caregiver has received resources and referrals to address health care of the infant and mental health and economic security needs of the caregivers.

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

Recommendations to Fully Realize the Potential of the Perinatal Data Linkage Project

1. Additional authorizing legislation that specifically authorizes Medicaid, PDMP, and CDHS behavioral health data to be included in this perinatal data linkage project. Appendix A: Draft Senate Bill 19-228 Revised Language.
2. New legislation that paves the way for state agencies to partner on a variety data linkage projects. Appendix B: Draft Establishment of the Linked Information Network of Colorado in Statute.

Appendix A: DRAFT Senate Bill 19-228 Revised Language

S.B. 19-228, Section 12: 27-80-121, 2019 Reg. Sess. (Col. 2019).

WHERE FUNDING ALLOWS, the data linkage project WILL INTEGRATE MEDICAID, PRESCRIPTION DRUG MONITORING PROGRAM, TRAILS, IMMUNIZATION, BEHAVIORAL HEALTH DATA, AND DEATH RECORDS TO EXAMINE THE FOLLOWING:

(a)   Health care utilization by pregnant and postpartum women with substance use disorders and their infants;

(b)   Human service, ~~and~~ public health program utilization~~,~~ AND SUBSTANCE USE TREATMENT by pregnant and postpartum women with substance use disorders and their infants;

(c)   Health care, human service, and public health program outcomes among pregnant and postpartum women with substance use disorders and their infants; and

(d)   Costs associated with health care, human service, and public health program provisions for pregnant and postpartum women with substance use disorders and their infants.

(2)   The data linkage project shall use vital records to establish maternal and infant dyads beginning at the birth hospitalization and retrospectively link the prenatal period and prospectively link the first year postpartum.

(3)   THE DATA LINKAGE PROJECT MAY CONNECT ADDITIONAL STATE AND NON-STATE DATA SOURCES WITH THE PURPOSE OF IMPROVING POPULATION-LEVEL ESTIMATES OF PERINATAL SUBSTANCE EXPOSURE AND EXAMINING SYSTEM UTILIZATION AND OUTCOMES.

(4)   The governor's office of information technology will obtain data and perform secure linkage and anonymization on behalf of the state.

(5)   On or before January 1, 2021 AND ANNUALLY THROUGH THE DURATION OF THE PROJECT, the center shall report progress on the data linkage project and the results, if available, to the health and insurance committee and the public health care and human services committee of the house of representatives and the health and human services committee of the senate or their successor committees.

Fiscal Note:

Fiscal resources are available through the SFY21 allocation to onboard Medicaid data to this project and this amendment would reduce barriers to doing so. Additional resources are needed to strengthen researcher-generated population estimates of substance exposed newborns by integrating additional data sources, such as PDMP, and to conduct ongoing research.

Appropriation of $75,000 annually beginning in SFY22 to the Center for Prescription Drug Abuse Prevention.

Appendix B: DRAFT Establishment of the Linked Information Network of Colorado in Statute

Recommended Bill Language:

Concerning the establishment of the "Linked Information Network of Colorado," in the Colorado Governor's Office of Information Technology and the Colorado Evaluation and Action Lab at the University of Denver.

(1) The General Assembly finds that:

   (a) Public systems can better address community needs when they use data to understand the challenges people face. Data from just one agency is not sufficient because people interact with different public systems for different needs. Effectively responding to the complex needs of Colorado residents often requires data across multiple organizations.

   (b) In 2009, the General Assembly passed H.B. 08-1264, which called for the creation of cross-departmental data interoperability and protocols to enhance the efficiency of state government and improve the State's ability to deliver services. This legislation formally recognizes that cross-system data are necessary for the success of government policies and programs.

   (c) For H.B. 08-1264 to be realized, data sharing solutions must address a persistent tension: effectively sharing the right data, at the right time, for the right purpose while simultaneously respecting the privacy of individuals who rely on public systems to protect their most sensitive information.

   (d) In 2017, the State of Colorado's Governor's Office of Information Technology and the Colorado Evaluation and Action Lab at the University of Denver partnered up to design the Linked Information Network of Colorado, a data sharing solution which has effectively balanced these data sharing tensions.

(2) The Linked Information Network of Colorado, referred to in this section as "LINC," is established jointly in the Colorado Governor's Office of Information Technology, referred to in this section as "OIT," and the Colorado Evaluation and Action Lab at the University of Denver, referred to in this section as "Colorado Lab." LINC will:

   (a) Produce more effective Colorado policies and programs supported by timely and cost-efficient data analysis, research, and evaluation using integrated data from multiple systems.

   (b) Serve as a data sharing collaborative that includes partners from state agencies, local government, and non-profit organizations that hold administrative records on Colorado residents.

   (c) Establish an executive committee comprising one representative from each LINC data partner organization that is responsible for establishing all policies and procedures for LINC.

(d) Establish a review committee comprising at least one appointed representative from each LINC data partner organization with decision-making authority over the use of their data in LINC projects.

(e) Maintain the LINC Director at the Colorado Lab who is responsible for onboarding new LINC data partners and facilitating LINC projects from request to completion.

(f) Maintain a data scientist at OIT who is responsible for receiving approved data from LINC data partners, integrating the data, and removing personally identifiable data fields for approved end users.

(g) Collect project fees from end users as well as seek additional public and private funding to support the sustainability of LINC.

Fiscal Note:

Fiscal resources are available to partially support LINC through the SFY22 and project fees are the primary source of sustainability for the Linked Information Network of Colorado. Appropriation of $125,000 annually beginning in SFY22 to support base operational costs of LINC.