

# *Addressing Gaps in Care: Health Outcomes of Infants with Gestational Exposure to Substances in Nevada (2018-2020)*

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*Office of Analytics  
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**Joe Lombardo**  
*Governor  
State of Nevada*

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**Richard Whitley, MS**  
*Director  
Department of Health and Human Services*

---

## Acknowledgements

### Prepared by:

Natalie Bladis, MS  
Biostatistician III  
Office of Analytics  
Department of Health and Human Services  
State of Nevada

Kanan Castro  
Biostatistician II  
Office of Analytics  
Department of Health and Human Services  
State of Nevada

### Thank you to the following for providing leadership, data, and technical support for this report:

Kyra Morgan, MS  
Medical Epidemiologist  
Division of Child and Family Services  
Department of Health and Human Services  
State of Nevada

Alexia Benshoof, MS  
Health Bureau Chief  
Office of Analytics  
Department of Health and Human Services  
State of Nevada

Amy Lucas, MS  
Management Analyst IV  
Office of Analytics  
Department of Health and Human Services  
State of Nevada

Aidan Hernandez  
Health Resource Analyst I  
Office of Analytics  
Department of Health and Human Services  
State of Nevada

Vickie Ives, MPH  
Bureau Chief  
Child, Family and Community Wellness  
Division of Public and Behavioral Health  
Department of Health and Human Services  
State of Nevada

Shannon Litz  
Deputy Director, Programs  
Department of Health and Human Services  
State of Nevada

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For more information about this report, please contact [data@dhhs.nv.gov](mailto:data@dhhs.nv.gov)

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## Introduction

Women are more likely to be prescribed an opioid than men, with 21.8 per 100 women receiving prescriptions compared to 16.4 per 100 men (Centers for Disease Control, 2017). In Nevada in 2023, 59% of all opioid prescriptions were given to women. In Nevada in 2023, 15% of opioid prescriptions were filled by women of childbearing age (15–44 years), and 31% of Medicaid-covered opioid prescriptions were filled by women in this age group. Given that half of all pregnancies in the U.S. are unplanned and often not detected until the sixth week of gestation (American Pregnancy Association), women in this age group who use opioids, whether prescribed or illicit, risk exposing their fetus to the drug during a critical developmental stage (Ailes et al., 2015).

The prevalence of opioid prescriptions among pregnant women is alarmingly high, with an estimated 14–22% filling such prescriptions during pregnancy (Ailes et al., 2015). Over the past decade, the rate of opioid dependence among pregnant women in the U.S. has been on the rise, with about 0.9% of pregnant women aged 15–44 reported misusing opioids in the past month (Smith and Lipari, 2017). This opioid misuse poses a serious risk to the developing fetus, as 60–80% of infants exposed to opioids in utero suffer from Neonatal Opioid Withdrawal Syndrome (NOWS) after birth (Patrick et al., 2012). The incidence of NOWS in the U.S. has surged by over 400%, from 1.2 per 1,000 hospital births in 2000 to 5.8 per 1,000 in 2012, equating to roughly one NOWS infant born every 25 minutes (Patrick et al., 2015). Given that general rates of opioid use are currently at their highest, it is safe to assume that the incidence rate of NOWS has also increased since then.

These figures underscore the profound impact of the opioid crisis on pregnant women and their infants. This study examines infants born between January 1, 2018 and December 31, 2020 to Nevada residents. Infants born in this timeframe were separated into a prenatal substance-exposed cohort and non-prenatal substance-exposed cohort, and outcomes for these cohorts were compared.

This study explores missed opportunities for intervention at birth for the prenatal substance-exposed cohort. The frequency with which required interventions for substance-affected infants are utilized for this substance-exposed cohort are presented along with an analysis of outcomes broken down by interventions received (the distinction between substance-affected and substance-exposed is articulated in the [background](#) section of this report). Two interventions in place for substance-affected infants are the creation of a Comprehensive Addiction and Recovery Act (CARA) Plan of Safe Care and a mandatory Child Protective Services (CPS) referral. Outcomes for children who were gestationally exposed to substances and received neither a CARA plan or a CPS referral, a CARA plan only, a CPS referral only, and both interventions were compared. CPS referrals are restricted to those made within six months of birth.

The study looks at outcomes in six-month intervals from birth up to age two. It compares substance-exposed infants with non-exposed counterparts in terms of hospital admissions and emergency room diagnoses, subsequent CPS involvement, and mortality. This report aims to provide a clearer picture of the impact of gestational exposure to substances, identifying gaps in current interventions, and highlighting areas for improvement in support and care strategies for affected infants and their families.

## Background

To provide context for this study, it is crucial to review existing research on the outcomes of gestational substance exposure in infants and interventions required under Nevada law. This literature review will

focus on three main areas: health outcomes at birth, developmental outcomes during infancy and early childhood, and intervention strategies and their effectiveness.

### Health Outcomes at Birth

Infants exposed to opioids in the womb face a higher likelihood of premature birth (before 37 weeks) and low birth weight (under 2,500 grams) (Fill et al., 2018; Hunt et al., 2008). As mentioned earlier, around 60–80% of these infants will develop Neonatal Opioid Withdrawal Syndrome (NOWS) post-birth (Patrick et al., 2012). The symptoms of NOWS in infants mirror those seen in adults withdrawing from opioids, including disturbed sleep, tremors, seizures, increased muscle tone, sweating, fever, gastrointestinal issues like diarrhea and vomiting (Ainsworth, 2014), and incessant high-pitched crying (Ko et al., 2016). Additionally, these infants may suffer from reduced brain volume and a heightened risk of sudden unexpected death (Ko et al., 2016; Patrick et al., 2012). Complications secondary to NOWS can include rapid breathing, meconium aspiration, respiratory distress, jaundice, and sepsis (Patrick et al., 2015). Infants with NOWS often require Neonatal Intensive Care Unit (NICU) admission, staying on average 17–23 days, at a total cost of \$66,700–\$93,000 depending on the necessity for pharmacological intervention (Ko et al., 2016; Patrick et al., 2012, 2015). In stark contrast, a full-term infant typically has a two-day hospital stay costing about \$3,500 (Patrick et al., 2015).

### Developmental Outcomes During Infancy and Early Childhood

Data on the behavioral outcomes of perinatal opioid exposure is limited, but recent studies have identified significant cognitive, motor, and sensory deficits. Children with a history of NOWS show markedly lower scores in cognitive and motor skills during early childhood (Hunt et al., 2008; Baldacchino et al., 2014) and are more prone to learning disabilities, developmental delays, and speech and language disorders compared to their peers (Maguire et al., 2016; Fill et al., 2018). The exact mechanisms behind these cognitive deficits are unclear, but rodent studies suggest that prenatal opioid exposure impairs neural and glial development (Sanchez et al., 2008; Robinson, 2006), and reduces dendritic length and branching in somatosensory cortical neurons (Lu et al., 2012). These findings align with reports of reduced brain volumes in regions like the basal ganglia, thalamus, and cerebellar white matter in school-aged children exposed to opioids before birth (Sirnes et al., 2017). Moreover, prenatal methadone exposure is linked to decreased white matter microstructure in neonates, indicating less organized and more immature fiber tracts (Monnelly et al., 2018).

These findings indicate significant and concerning impacts on the neurological development of children exposed to substances before birth. Developmental brain disorders, like neural and glial development, and reduction in dendritic length and branching mentioned above, have been linked to delays and difficulties in sensory processing, motor skills, and cognitive functions in children (“Childhood Brain Disorders”). Autism and ADHD may also be associated with developmental brain disorders (“Childhood Brain Disorders”). Reduced brain volumes in critical regions like the basal ganglia, thalamus, and cerebellar white matter further imply potential challenges in areas such as coordination, learning, memory, and emotional regulation (Monnelly et al., 2018). These neurological deficits can manifest as developmental delays, learning disabilities, and behavioral problems, necessitating early intervention and ongoing support to help mitigate these adverse outcomes.

Bakhireva et al. (2019) found that infants aged 5–8 months with NOWS exhibited more negative affect and lower self-regulation compared to healthy controls. These infants were also more prone to “sensation seeking,” engaging in behaviors like biting, mouthing, and touching for additional sensory stimulation.

Mother-child interactions tend to be more negative in NOWS cases (Konijnenberg et al., 2016). Mothers with opioid use disorder (OUD) during pregnancy often show lower sensitivity, less positive affect, and limited engagement with their children at both 12 months and 4 years of age. Correspondingly, children with a NOWS history showed lower positive affect, less interest in activities, and less engagement with their surroundings compared to peers (Konijnenberg et al., 2016). Compounding these challenges, women with OUD during pregnancy are more likely to be single, less educated, of lower socioeconomic status, and to have more children, all of which contribute to increased maternal stress and reduced quality of maternal care (Bakhireva et al., 2019).

### Substance Exposure in Infants: An Inclusive Approach to Cohort Analysis

This analysis focuses on infants who were exposed to substances in utero. This analysis was not confined solely to infants officially identified as affected by gestational substance exposure. This rationale was based on the understanding that not all infants exposed to substances show immediate signs of being affected. Therefore, to capture a comprehensive dataset, all infants exposed to substances were included, regardless of whether they displayed symptoms at birth.

For instance, consider the case of an infant born to a mother who overdosed two months prior to delivery but whose baby exhibited no withdrawal symptoms or observable effects at birth. Such infants would be included in the substance-exposed cohort of this report. It is important to note that current regulations, discussed in depth in the next section, require an infant to show signs of being affected at birth to qualify for interventions. In this report, a **substance-exposed infant** is defined as an infant exposed to substances in utero, regardless of whether they show signs of being affected by that exposure at birth. A **substance-affected infant** is defined as a newborn infant that has been affected by prenatal substance abuse (licit or illicit) or has withdrawal symptoms resulting from prenatal drug exposure or Fetal Alcohol Spectrum Disorder (Nevada Revised Statutes (NRS) 432B.220). These infants show clear signs of impact from substances which are observable to health care providers.

The approach of studying substance-exposed infants broadly was chosen intentionally to support the argument for extending screening for the effects of substance exposure into later childhood. Broadening the criteria for inclusion of the substance-exposed cohort will better inform and enhance ongoing discussions regarding the necessity of early and continued screening. This is crucial because many infants who are affected by prenatal substance exposure may not present symptoms immediately at birth, potentially bypassing early intervention opportunities described in the next section.

### Intervention Strategies in Nevada

In Nevada, there are two initial interventional touchpoints for substance-affected infants: a CARA Plan of Care and a CPS referral. These are governed by Nevada Administrative Code (NAC) and NRS as well as federal law.

The initiator of these interventions is a health care provider who “delivers or provides medical services to an infant in a medical facility and who, in his or her professional capacity, knows or has reasonable cause to believe that the infant was born with a fetal alcohol spectrum disorder, is affected by prenatal substance abuse or is experiencing symptoms of withdrawal from a substance as a result of exposure to the substance in utero” (NAC 449.947, NRS.432B.220).

There is currently no legal requirement for intervention for substance-exposed infants who **do not** show adverse effects at birth. The existing legal requirements for interventions are targeted only to substance-

exposed infants who show signs of impact from gestational exposure when born, such as neonatal withdrawal symptoms – in other words, these interventions are targeted to substance-affected infants only.

### CARA Plan of Care

The federal Comprehensive Addiction and Recovery Act (CARA) of 2016 governs requirements for states regarding the development of a CARA Plan of Care for substance-affected infants. In Nevada, [NAC 449.947](#) specifies that health care providers who deliver or provide medical services to a substance-affected infant must “ensure that a CARA Plan of Care is established for the infant before the infant is discharged from the medical facility.”

The CARA Plan of Care aims to assess and address the health, developmental, and well-being needs of the infant, alongside the health and substance use treatment requirements of the parents or caregivers, ensuring that both infants and families receive the necessary services to meet these needs. The CARA Plan of Care is developed collaboratively with the mother, other caregivers, and health care professionals. This process identifies existing strengths, support systems, needs, and coordinates referrals to services. Mothers can decline to participate in the development of a CARA Plan of Care.

Health care providers must document a CARA Plan of Care using a form provided by the Nevada Division of Public and Behavioral Health (DPBH). They must provide a copy of the plan to parents or guardians of the infant to whom the plan pertains and to DPBH within 24 hours after the infant is discharged from the medical facility. In Nevada, DPBH is responsible for monitoring the implementation of CARA Plan of Cares to ensure infants and families or caregivers are receiving appropriate services ([NAC 449.948](#)). DPBH may also provide aggregated data to the Nevada Division of Child and Family Services (DCFS) to support compliance with federal reporting requirements in accordance with the Child Abuse Prevention and Treatment Act (CAPTA) which was modified by the 2016 CARA law to require states to report the number of infants identified to be substance-affected, the number of infants for whom a plan of safe care was developed, and the number of infants for whom a referral was made for appropriate services, including services for the affected family or caregiver. These data are collected and reported in accordance with CAPTA by DCFS. However, in this report, the population of substance-affected infants examined is not necessarily the same as what is reported by DCFS for CAPTA compliance due to methodology differences and data collection constraints.

### CPS Referral

[NRS 432B.220](#) requires that health care providers who deliver or provide medical services to a substance-affected infant must “as soon as reasonably practicable but not later than 24 hours after the person knows or has reasonable cause to believe that the newborn infant is so affected or has such symptoms, notify an agency which provides child welfare services of the condition of the infant and refer each person who is responsible for the welfare of the infant to an agency which provides child welfare services for appropriate counseling, training or other services.”

The health care provider’s notification to the child welfare agency is known as a CPS referral. CPS is part of child welfare services. Child welfare services include child protective services, in-home services, foster care, adoption, independent living services, and foster care licensing among other activities. Nevada uses a bi-furcated system with state-supervised and both county administered and state administered child welfare services. DCFS, under the umbrella of the Nevada Department of Health and Human Services



(DHHS), provides oversight of all child welfare activities in the state. In counties with a population of 100,000 or more, the county provides direct child welfare services. Clark County Family Services (Clark County FS) and Washoe County Human Services Agency (Washoe County HSA) provide direct child welfare services to children and families located in Clark and Washoe counties. DCFS provides direct child welfare services to the remaining 15 counties in the state through its Rural Region offices (DCFS Rural Region).

Regarding CPS, the first stage of the process is known as Intake which is when incidents of suspected child abuse and neglect are received by agencies. Information gathered by staff is used to make decisions regarding child safety and the type of CPS response required. Anyone may contact a child welfare agency to report suspected child abuse and neglect; an incident of alleged child abuse or neglect that is reported to the agency is first recorded as referral. Thousands of CPS referrals are received and processed by statewide staff each month. Referrals are then reviewed by supervisors and a screening decision and disposition is made, at which point the incident becomes known as a report. Multiple referrals may be linked to one report if they relate to the same incident. Report screening and disposition assignment is based on various factors; for more information about report dispositions or Intake practices, refer to the statewide Intake policy [here](#).

When a referral is made to CPS, it is evaluated by child welfare staff and may be screened in for further investigation or screened out. Screened-in reports are a subset of all CPS reports received by child welfare agencies and “screened-in” means that agency personnel will respond and attempt to make face to face contact with the children and families to assess child safety and family functioning. Screened-in reports may have a final report disposition of Investigation, Institutional Investigation, Agency Assessment, or Differential Response.

CPS referrals from health care providers regarding substance-affected infants, like all referrals received, are recorded in UNITY (Unified Nevada Information Technology for Youth), Nevada’s statewide child welfare information system managed by DCFS. A referral from the health care provider regarding the substance-affected infant does not automatically mandate that the child welfare agency screen-in the family for investigation and further child welfare services; rather, the agency makes a screening decision based on the criteria in the statewide Intake policy. It is important to note that using illicit substances while pregnant or as a mother does not in and of itself qualify as abuse or neglect. Health care providers who have identified a substance-affected infant must notify a child welfare agency, regardless of whether abuse or neglect is indicated. Additionally, child welfare agencies may screen a report out as “information and referral” which means that the child welfare agency has determined a response is not required, but referred the family for services in the community. The child welfare agency is then responsible for determining if there may be safety issues present for the infant and family and what further action, if any, should be taken by the child welfare agency. Child welfare agencies may be provided a copy of an infant’s CARA Plan of Care from DPBH upon request (NAC 449.948).

### [Barriers to Accessing Care](#)

The multi-faceted barriers pregnant women with substance use disorders face when seeking treatment, as underscored by the findings of Penn State researchers Dr. Kristina Brant and Hannah Apsley, can significantly hinder access to essential medications and support services (Apsley et al.). Among these obstacles, health care providers' hesitance to prescribe medications, the scarcity of resources in rural areas, and the complexities of decentralized health systems are prominent. These factors are compounded by additional challenges for women who are also mothers, including a lack of childcare

during medical appointments, fear of losing custody of their children, and the prioritization of their children's needs over their own treatment (Bohn).

The stigma associated with drug use during pregnancy is profound and pervasive, affecting interactions with the criminal justice and child protection systems. These systems often remove newborns from mothers who test positive for drugs but fail to provide the necessary support to address the root of the problem: the mother's substance use disorder (Hoffman). This punitive approach can discourage women from seeking prenatal care or addiction treatment, fearing negative consequences like losing custody of their children.

Efforts to improve access to care should consider integrating substance use treatment with prenatal and postpartum care, thereby reducing the need for multiple appointments and easing the burden on these women. Moreover, expanding telehealth services and supporting programs that cater specifically to mothers and their children could provide more accessible and less stigmatizing treatment options (Apsley). These initiatives could help mitigate the fear of custody loss and encourage more women to seek the help they need, ultimately benefiting both the mothers and their children.

In Nevada, interventions such as the CARA Plan of Care and CPS referrals, described in the previous section, aim to capture substance-affected infants, ensuring they and their families receive the necessary support and services. Despite the State's efforts, barriers to accessing care remain a significant challenge for pregnant women using substances. The CARA Plan attempts to address these barriers by coordinating care and connecting families with services, but the stigma, resource scarcity, and health care system complexities still hinder access. Many women fear the repercussions of seeking treatment.

This inclusive approach to analyzing substance-exposed infants underscores the importance of early and continuous screening, as not all infants show immediate signs of effect at birth. By extending screening into later childhood, those who may develop adverse effects later can be better identified and supported. This analysis aims to inform and enhance discussions on funding and improving intervention strategies to ensure these children do not fall through the cracks.

## Methodology

### Data Sources

In this report, infants who were determined to have gestational exposure to substances were identified using four data sources:

1. Birth Records
2. CARA Plan of Care Records
3. Hospital Billing data
4. Medicaid Claims data

The sources used are described in more detail below:

### Birth Records

A list of all babies born between January 1, 2018 and December 31, 2020 to Nevada residents was compiled using Nevada's electronic birth registry data. These data contain information from birth certificates and self-reported information related to substance use during pregnancy provided by

mothers. Because substance use during pregnancy is self-reported, it is likely underreported as mothers may be reluctant to be forthcoming for a variety of reasons.

#### CARA Plan of Care Records

A CARA Plan of Care, as previously described, is an intervention plan for a substance-affected infant and the caregiver(s). CARA data was obtained from the Division of Public and Behavioral Health (DPBH) and is currently available for the years 2018 to 2020.

#### Hospital Billing Data

Nevada hospitals are required to report patient discharges and associated billing records to DHHS per NRS 449.485. Nevada's statewide hospital billing database for the years 2017 to 2022, including both emergency department (ED) and inpatient (IP) records, was used to identify mothers and infants with diagnosis codes indicating gestational exposure to substances.

#### Medicaid Claims Data

The Division of Health Care Financing and Policy (DHCFP) data warehouse is comprised of claims data submitted by over 35,000 Medicaid providers from within Nevada and across the country. Medicaid claims data for the years 2017 to 2022 were used to identify mothers and infants with diagnosis codes indicating gestational exposure to substances.

#### Child Welfare Data

To analyze the utilization of interventions and touchpoints for care, in addition to the CARA records mentioned above, statewide child welfare data compiled from all agencies into UNITY (Unified Nevada Information Technology for Youth) was utilized. UNITY serves as the official repository for child welfare records and activities across Nevada. CPS data for this analysis was extracted from the UNITY system.

#### Defining the Cohort of Infants with Gestational Exposure to Substances During Pregnancy

These four datasets were linked and used to split infants born in 2018 to 2020 into two cohorts: infants with an indication of prenatal substance-exposure (PSE Cohort) and infants with no indication of prenatal substance-exposure (No-PSE Cohort).

An infant was identified as having PSE if one or more of the following indicators was present:

- Mother self-reported drug use on the infant's birth certificate.
- Infant had a CARA Plan of Safe Care.
- Mother had a hospital visit (emergency room or inpatient) with a diagnosis code indicating substance use within the period of 280 days prior to birth up to the day of birth.
- Infant had a post-birth hospital visit (emergency room or inpatient) within the first 6 months after birth with a diagnosis code indicating the newborn was affected by maternal substance use or had neonatal withdrawal symptoms.
- Mother had a Medicaid claim with a diagnosis code indicating substance use within 280 days prior to birth up to the day of birth.
- Infant had a Medicaid claim with a diagnosis code indicating the newborn was affected by maternal substance use or had neonatal withdrawal symptoms within the first 6 months post-birth.

In this analysis substances include but are not limited to alcohol, opioids, cannabinoids (cannabis), sedatives or hypnotics, cocaine, other stimulants, hallucinogens, narcotics (general category for drugs of addiction, unspecified), amphetamines, tobacco. ICD-10-CM Codes used for identifying substance use for mothers with hospital visits or Medicaid claims are listed in [Appendix A](#). ICD-10-CM Codes used for identifying infants with post-birth hospital visits or Medicaid claims indicating newborns were affected by maternal substance use or had neonatal withdrawal are listed in [Appendix B](#).

In **Table 4.1**, the distribution of births per cohort from 2018-2020 is depicted, along with the percentage of births per year within each cohort. Between 2018-2020, Nevada mothers gave birth to **12,901 infants identified as gestationally exposed to substances. That is 12.4% of infants born in the time period.**

**Table 4.1: Births by Cohort in Nevada, 2018-2020**

Year of Birth	PSE Cohort		No-PSE Cohort	
	N	%	N	%
2018	4,378	12.3%	31,164	87.7%
2019	4,286	12.3%	30,699	87.7%
2020	4,237	12.6%	29,353	87.4%
Total	12,901	12.4%	91,216	87.6%

## Results

With the cohorts defined, the following analysis was conducted to explore health outcomes and the touchpoints with social services between the groups.

### Cohort Comparison for Selected Birth Outcomes

This section compares critical birth outcomes among the PSE cohort and those not exposed (No-PSE cohort). The data underscores significantly higher birth outcome-related risks among the PSE cohort, reinforcing the necessity for early and targeted health care interventions.

**Table 5.1 highlights several concerning birth outcomes for the PSE cohort, including abnormal conditions, congenital anomalies, inadequate prenatal care, preterm births, and low birthweight.** Complete definitions of these factors can be found in [Appendix C](#). All these factors are significantly more prevalent in the PSE group than the non-exposed group.

**Table 5.1: Health Outcomes by Cohort**

Health Status Indicator	PSE Cohort		No-PSE Cohort		Risk Ratio~
	N	%	N	%	
Abnormal Birth	4,239	32.9%*	20,064	22.0%	1.49 (1.45, 1.54)
Congenital Anomalies	194	1.5%*	1,022	1.1%	1.34 (1.15, 1.56)
Inadequate Prenatal Care	4,368	33.9%*	20,525	22.5%	1.50 (1.46, 1.55)
Low Birthweight	1,978	15.3%*	7,190	7.9%	1.95 (1.86, 2.04)
Preterm Birth	2,096	16.3%*	8,796	9.6%	1.68 (1.61, 1.76)

\* Tested for significance using a one-sided Z-test and yielded a p-value less than 0.0001.

~ A risk ratio is a measure used to compare the probability of a certain event occurring between two groups. It is calculated by dividing the risk of the event in the exposed group by the risk in the unexposed group. A risk ratio greater than 1 indicates a higher risk in the exposed group. The 95% confidence interval is represented in parentheses after the risk ratio.

**Table 5.2** analyzes Neonatal Intensive Care Unit (NICU) admissions and ventilator use at birth as indicated on the birth certificate between the two cohorts. Based on a chi-square test of independence, there is a statistically significant difference between the PSE cohort and the No-PSE cohort regarding NICU visits and ventilator use among Nevada residents from 2018 to 2020. Specifically, the PSE cohort had a higher proportion of infants requiring NICU visits (18.7% vs. 9.1%) and ventilator use (6.6% vs. 4.5%) compared to the No-PSE cohort. **These findings suggest that substance exposure is associated with an increased need for intensive medical interventions at birth, highlighting the importance of targeted health care strategies and interventions for PSE infants as upstream as possible.**

**Table 5.2: NICU and Ventilator Use by Cohort**

Specialized Care at Birth	PSE Cohort		No-PSE Cohort		Risk Ratio~
	N	%	N	%	
NICU Required	2,417	18.7%*	8,323	9.1%	2.05 (1.97, 2.14)
Ventilator Required	856	6.6%*	4,097	4.5%	1.48 (1.38, 1.59)

\* Tested for significance using a one-sided Z-test and yielded a p-value less than 0.0001.

~ The 95% confidence interval is represented in parentheses after the risk ratio.

## Summary of Infant Health and Outcomes

The table below presents the distribution of PSE and No-PSE infants who received various services and experienced different health outcomes from birth up to 24 months. Counts represent number of interactions (such as number of reports to CPS, visits to the Emergency Department, etc.) not number of infants. This allowed the computation of crude rates, which are more representative of the differences between the two cohorts. For example, infants in both cohorts tend to visit the emergency room, but the PSE infants visit the emergency room more times than their non-exposed counterparts. Crude rates are the best illustration of this. All crude rates are calculated per 1,000 cohort-specific live births.

A more in-depth analysis that considers health and outcomes of the two cohort in six-month intervals from birth up to two years of age is presented in [Appendix D](#). [Appendix E](#) contains a ranked list of primary

diagnosis codes for each infant death for both cohorts. [Appendix F](#) contains a ranked list of primary diagnosis codes for hospitalization (emergency department visits and inpatient admissions) for both cohorts. Emergency department visits and inpatient admissions are broken down into top 3 by primary diagnosis grouping.

**Table 5.3: Two-Year Health Outcomes: PSE vs. No-PSE Infants**

Birth – 24 Months					
	PSE Cohort		No-PSE Cohort		
Cohort Size	12,901		91,216		
	Count	Crude Rate	Count	Crude Rate	Risk Ratio^
<b>CPS Reports</b>	<b>7,130</b>	<b>552.7*</b>	<b>5,506</b>	<b>60.4</b>	<b>9.16 (8.89, 9.43)</b>
<b>Emergency Department Visits</b>	<b>17,076</b>	<b>1,323.6~</b>	<b>77,015</b>	<b>844.3</b>	<b>1.57 (1.57, 1.58)</b>
<i>J00-J99: Diseases of the respiratory system</i>	4,945	383.3*	19,942	218.6	1.75 (1.71, 1.80)
<i>R00-R99: Symptoms, signs, and abnormal clinical and laboratory findings</i>	3,631	281.5*	17,376	190.5	1.48 (1.43, 1.52)
<i>S00-T88: Injury, poisoning and certain other consequences of external causes</i>	1,939	150.3*	11,053	121.2	1.24 (1.19, 1.30)
<b>Inpatient Admissions</b>	<b>1,746</b>	<b>135.3*</b>	<b>9,031</b>	<b>99.0</b>	<b>1.37 (1.30, 1.43)</b>
<i>J00-J99: Diseases of the respiratory system</i>	643	49.8*	2,527	27.7	1.80 (1.65, 1.96)
<i>P00-P69: Certain conditions originating in the perinatal period</i>	234	18.1	1,939	21.3	0.85 (0.75, 0.98)
<i>R00-R99: Symptoms, signs, and abnormal clinical and laboratory findings</i>	153	11.9*	595	7.0	1.82 (1.52, 2.17)
<b>Mortality</b>	<b>134</b>	<b>10.4*</b>	<b>387</b>	<b>4.2</b>	<b>2.45 (2.01, 2.98)</b>
Premature birth-related	46	3.6*	142	1.6	2.29 (1.64, 3.19)

\*Tested for significance using a one-sided Z-test and yielded a p-value less than 0.0001.

~Tested for significance using a Poisson Rate Test and yielded a p-value less than 0.0001.

^The 95% confidence interval is represented in parentheses after the risk ratio.

Key metrics from this analysis reveal substantial disparities between the two cohorts, emphasizing the need for enhanced intervention strategies for all infants who are gestationally exposed to substances.

#### CPS Reports:

- PSE infants had a notably higher rate of reports generated by CPS across all age intervals. For instance, the **report rate for PSE infants was 552.7 per 1,000 compared to 60.4 per 1,000 for No-PSE infants in the first twenty-four months.**

- PSE infants have CPS reports generated for them at a rate 9.2 times higher than non-exposed infants.

#### Emergency Department (ED) Visits:

- PSE infants had a higher rate of ED visits throughout the study period. The crude rate for ED visits among PSE infants was **1,323.6** per 1,000 compared to **844.3** per 1,000 for non-exposed infants.
- Within the first two years of life, infants gestationally exposed to substances visited emergency departments **1.6 times more often** than No-PSE infants.

#### Inpatient (IP) Admissions:

- Inpatient admission rates were also higher for PSE infants. The crude rate for IP admissions among PSE infants was **135.3** per 1,000 compared to **99.0** per 1,000 for non-exposed infants.
- PSE infants were **1.4 times more likely** to be admitted as inpatients compared to non-exposed infants.

#### Mortality Rates:

- Mortality rates for PSE infants were generally higher than for non-exposed infants. Notably, the mortality rate related to premature birth was **3.7** per 1,000 for PSE infants compared to **1.5** per 1,000 for non-exposed infants in the first six months.
- Infants gestationally exposed to substances were **2.5 times more likely** to die before reaching the age of two.

### Maternal Characteristics

This section examines the population of mothers of the PSE infants in the cohort in this report. Number of substance-exposed births to a unique mother is presented along with historical involvement of mothers with CPS from 2000-2020.

The racial/ethnic composition of mothers in **Table 5.4** shows distinct differences between the PSE cohort and the No-PSE cohort. There is a statistically significant difference in the distribution of race/ethnicities between mothers in the PSE cohort and those in the No-PSE cohort ( $\chi^2(6, N = 95,099) = 3098.61$ ,  $p\text{-value} < 0.001$ ). This suggests that the ethnicity of the mothers is significantly associated with whether they have substance-exposed births or not. This significant association suggests that certain race/ethnic groups (such as Non-Hispanic White and Non-Hispanic Black) are disproportionately represented in the PSE cohort compared to the No-PSE cohort. This finding may warrant further investigation into the underlying causes, such as socioeconomic factors, access to health care, cultural attitudes toward substance use, and other related issues. Identifying these causes can help tailor more effective intervention strategies to support PSE infants and their families.

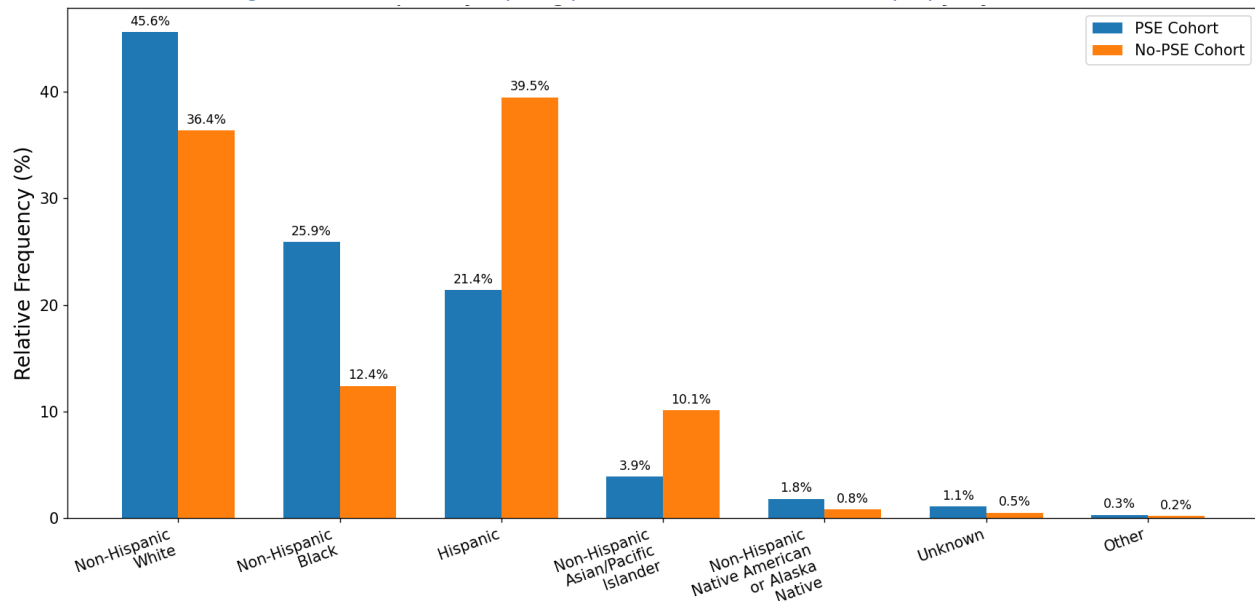
**Table 5.4: Distribution of Mother's Race/Ethnicity**

Race/Ethnicity of Mother	Mothers with at least 1 Birth in PSE Cohort*		Mothers of No-PSE Cohort	
Non-Hispanic White	5,402	45.6%	30,319	36.4%
Non-Hispanic Black	3,064	25.9%	10,323	12.4%
Hispanic	2,531	21.4%	32,919	39.5%
Non-Hispanic Asian/Pacific Islander	463	3.9%	8,445	10.1%
Non-Hispanic Native American or Alaska Native	209	1.8%	676	0.8%
Unknown	132	1.1%	404	0.5%
Other	37	0.3%	175	0.2%
Total	11,838	100%	83,261	100%

*\*Tested for significance with a Chi-square test of independence at the  $\alpha = 0.01$  level and yielded a p-value of less than 0.001.*

The impact of race/ethnicity on gestational exposure to substances is illustrated in **Figure 5.1** below.

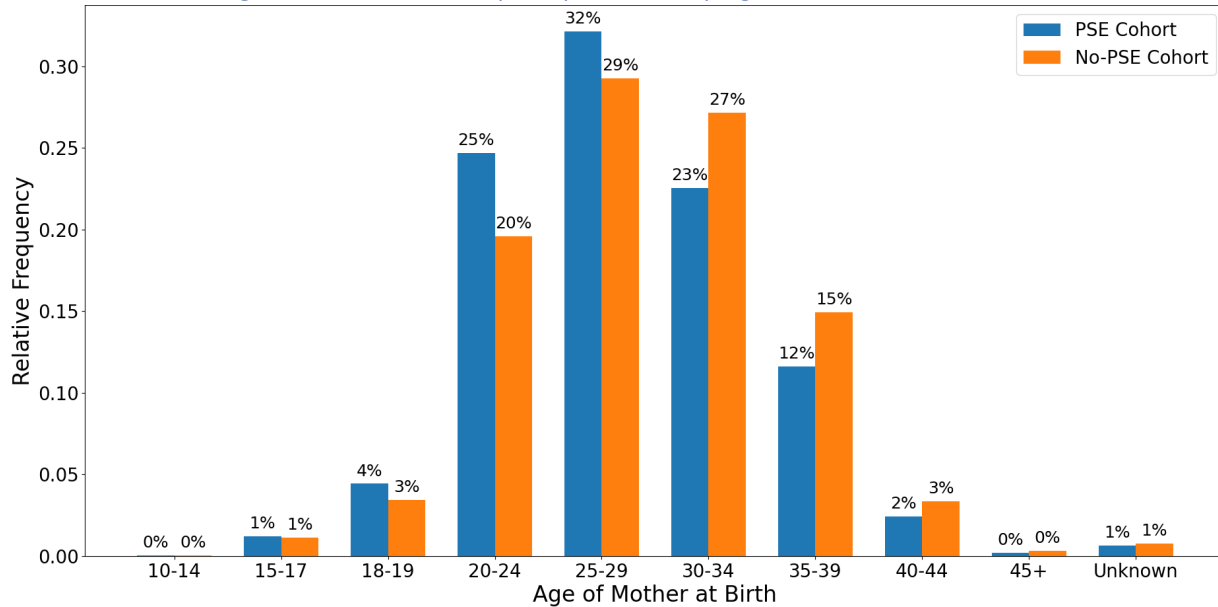
**Figure 5.1: Relative Frequency of Mother's Race/Ethnicity by Cohort**



**Figure 5.2** shows the distribution of ages of mothers at birth in both cohorts. The median age of mothers was 27 for the PSE cohort and 29 for the No-PSE cohort.



Figure 5.2: Relative Frequency of Births by Age of Mothers and Cohort



**Table 5.5** shows the breakdown of the mother's age at birth for both the PSE Cohort and the No-PSE Cohort. A chi-square test of independence was conducted to examine the relationship between the age of the mother at birth and whether they belong to the PSE Cohort or No-PSE Cohort. The test revealed a significant association between these variables ( $\chi^2(2, N = 104,117) = 376.95$ ,  $p\text{-value} < 0.001$ ).

Table 5.5: Distribution of Mother's Age

Age of Mother at Birth	PSE Cohort		No-PSE Cohort	
	N	%	N	%
< 30	8,067	62.5%*	48,746	53.4%
≥30	4,748	36.8%*	41,766	45.8%
Unknown	86	0.7%*	702	0.8%
Total	12,901	100%	91,216	100%

*\*Tested for significance with a Chi-square Test of Independence at the  $\alpha = 0.01$  level and yielded a p-value of less than 0.001.*

These tables illustrate the varying demographic profiles of mothers in the PSE and No-PSE cohorts, showing the need for nuanced approaches to maternal and infant health care services.

Table 5.6: 2018-2020 Birth Indicators: Cohort Comparison, Nevada

Births, 2018-2020		
Indicator	PSE Cohort	No-PSE Cohort
Total Number of Infants	12,901	91,216
Number of Unique Mothers	11,838	83,261
Number of Mothers with Repeat Births in Respective Cohorts	828	5,822
Percent of Mothers with Repeat Births in Respective Cohorts	7.4%	7.0%
Average Days Between Births	546	604

**Table 5.7** below shows subsequent births in the respective cohorts. Only mothers who have multiple births between 2018 and 2020 are considered. **If a mother had two births in the study’s timeframe of 2018 to 2020 and the first birth was substance-exposed (N=1,190), it was found that the second birth was also substance-exposed 70% of the time (n=827).**

**Table 5.7: Mothers with Repeat Births in Respective Cohort, Nevada Residents**

Births Between 2018-2020	PSE Cohort		No-PSE Cohort	
	N	%	N	%
First birth	1,190	-	6,142	-
Second birth	827	69.5%	5,819	94.7%

**Table 5.7** is crucial for guiding medical interventions for mothers with subsequent pregnancies. **For health care providers working with a mother whose previous pregnancy involved substance exposure, there is a 70% likelihood that their next pregnancy will also be substance exposed.** Conversely, among mothers whose first child was not substance-exposed, there is a 5.3% chance that their next child will be substance-exposed. This information is valuable for targeting preventive measures and support.

Some mothers who gave birth multiple times during the timeframe, had a PSE birth and a non-exposed birth. **Table 5.8** shows data on mothers who had at least one child exposed to substances and others who had none exposed during the study period. Among the mothers studied, **14.3% of those with at least one PSE birth had two or more children.** In contrast, **only 8.4% of mothers without any PSE births had two or more children within the same three-year timeframe.** This comparison suggests that mothers with at least 1 PSE pregnancy either have more children or have less time between their births (or some combination of both).

**Table 5.8: Distribution of Mothers by Number of Children Born During 2018-2020**

Number of Children	Mothers with at Least 1 PSE Birth*		Mothers with No PSE Births	
	N	%	N	%
1	10,151	85.75%	76,275	91.61%
2	1,581	13.36%	6,759	8.12%
3	102	0.86%	220	0.26%
4	4	0.03%	6	0.01%
5	0	0%	1	<0.01%
Total	11,838	100%	83,261	100%

*\*Tested for significance with a Chi-square Test of Independence at the  $\alpha = 0.01$  level and yielded a p-value of less than 0.001.*

This data provides a foundation for understanding the familial contexts in which substance exposure occurs and may guide targeted interventions to support families with multiple children at higher risk of recurrent substance exposure issues. This can provide insights into the prevalence and potential patterns of substance-exposure relative to the number of children born to a mother.

Next this analysis examines historical involvement of mothers of the cohorts with CPS from 2000-2020. The study focuses on their interactions as children and the time elapsed between their CPS involvement and the birth of their own children.

**Table 5.9** presents the number of mothers from both the PSE and non-exposed cohorts who were indicated to be alleged victims of abuse or neglect on screened-in CPS reports as children. These screened-in CPS reports may have been dispositioned to Investigation, Institutional Investigation, Agency Assessment, or Differential Response. This table reveals significant disparities between cohorts in terms of this involvement. Among mothers in the PSE cohort, 16% were alleged victims of abuse or neglect as children, a notably higher proportion compared to just 4.7% in the No-PSE cohort. This indicates a higher incidence of documented child welfare-related concerns among mothers of PSE infants, suggesting a potential cycle of familial and social challenges.

**Table 5.9: Mothers Impacted by Childhood Abuse or Neglect in Nevada**

	PSE Cohort		No-PSE Cohort	
	N	%	N	%
Mothers who were alleged victims of abuse or neglect on at least one screened-in CPS Report	1,905*	16.1%	4,490	4.7%
Total Number of Mothers	11,838	100%	83,261	100%

*\*Tested for significance using a one-sided Z-test and yielded a p-value less than 0.0001.*

**Table 5.10** illustrates the time elapsed between the mothers' involvement with CPS as an alleged child victim of abuse or neglect on a screened-in CPS report to the birth of their own children in the cohort examined in this report, providing possible insights into the generational timeline of CPS involvement. If a mother was involved as a child in multiple screened-in CPS reports, the most recent report was used in this time-based analysis.

**Table 5.10: Time from Mother's Childhood CPS Involvement to Cohort Childbirth**

Years Prior to Birth	PSE Cohort		No-PSE Cohort	
	N	%	N	%
After childbirth (mother < age 18 at time of CPS report)	17	0.9%	65	1.5%
Less than 5 years	332	17.4%	857	19.1%
5-9 years	533	28.0%	1,242	27.7%
10-14 years	640	33.6%	1,463	32.6%
15-19 years	371	19.5%	842	18.8%
20 or more years	12	0.6%	21	0.5%
Total	1,905	100%	4,490	100%

The majority of mothers with CPS involvement as a child in both cohorts experienced this involvement more than five years before the birth of their own children (81.7% in the PSE cohort and 79.6% in the No-PSE cohort). These findings underscore the importance of early and consistent interventions to support at-risk families and prevent the perpetuation of adverse outcomes across generations. A chi-square test of independence revealed no significant difference between the two cohorts ( $\chi^2$  (5, 6,395) = 6.71, p-value

= 0.24), indicating that the distribution of time elapsed between CPS involvement and childbirth is similar for both groups.

### Touchpoints of Care

The purpose of this section is to understand how frequently the interventions outlined in [Section 3.4](#) for substance-affected infants are being utilized within the PSE cohort.

**Table 5.11** below provides a clear overview of the distribution of touchpoints among the PSE infants, highlighting the different points of contact for potential intervention and care.

**Table 5.11: Distribution of Interventions for PSE Infants (2018-2020)**

Touchpoints	N	%
CARA Plan of Care and CPS Report*	1,191	9.2%
CARA Plan of Care only	1,064	8.2%
CPS Report* only	2,218	17.2%
No CARA Plan of Care or CPS Report*	8,428	65.3%
Total	12,901	100%

*\*A CPS referral is the initial notification of a substance-affected infant to a child welfare agency; as noted in section 3.4 of this report, after a CPS referral is reviewed by a supervisor and a screening decision and disposition is made, the notification becomes known as a report. In this table, the CPS Report category captures the referral of the substance-affected infant to the child welfare agency. This table displays how many PSE infants had a CPS report, regardless of screening decision or disposition, from a medical provider involved with their care within 6 months of birth.*

Substance-affected infants (infants showing signs of adverse effects from substance-exposure at birth) should have a CARA Plan of Care created and referral to CPS as required by NRS 432B. These interventions are targeted at substance-affected infants who show signs of impact of exposure at birth, missing a large portion of the infants known to be substance-exposed. Not all PSE infants show adverse effects from substance exposure at birth. They may experience adverse effects later in life that these touchpoints of care are not designed to address. Two striking findings from this distribution of interventions are:

- 83% of infants identified as substance-exposed had no CARA Plan of Safe Care record.
- 74% of infants identified as substance-exposed had no associated CPS report.

The findings displayed in the flowchart below illustrate the attrition of substance exposures through the structure of possible interventions. **Figure 5.3** highlights how the CARA Plan and a notification to CPS have not occurred for many PSE infants and their families.

**Figure 5.3: Illustration of Attrition of PSE Infants (2018-2020)**



<sup>1</sup> Of the 2,255 mothers whose infants had a CARA Plan of Care developed for them, 1,191 also had an associated CPS report from a medical provider involved in the care of the infant in the UNITY system within 6 months of birth.

The most noteworthy observation from **Table 5.11** and **Figure 5.3** is that a significant majority (65.3%) of substance-exposed infants did not receive either a CARA Plan of Care or a notification to CPS, highlighting a critical gap in the initial interventions and ongoing care for these vulnerable infants. These findings highlight the critical need for continued funding to enhance screening efforts later in childhood and beyond. This will help identify children who experience delayed adverse effects from substance exposure and ensure they receive the necessary interventions. Current interventions miss a substantial portion of substance-exposed infants.

## Conclusion

This study has identified that at least 12% of Nevada's births are gestationally exposed to substance. Mothers to infants who are gestationally exposed to substances are less likely to receive early and adequate prenatal care and more likely to deliver preterm. Substance-exposed infants fare significantly worse than their non-exposed counterparts, with significantly higher rates of low birthweight, abnormal births, and congenital anomalies. They are twice as likely to require NICU admissions after birth and have an increased likelihood of being placed on mechanical ventilation. Substance-exposed infants have CPS reports generated for them at a rate 9.2 times higher than non-exposed infants, are 1.4 times more likely to be admitted to the hospital and are 2.5 times more likely to die before reaching their second birthday.

Further, this study found that when considering a mother whose previous pregnancy involved substance exposure, there is a 70% likelihood that their next pregnancy will also be gestationally exposed to substances, illustrating a need to provide strong addiction support services to all mothers identified as having a substance exposed infant.

While Nevada does have limited strategies in place to identify and assist substance-affected infants and their families, through the CARA Plan of Safe Care and CPS, these services are tailored to only a portion of substance-exposed infants, those who show physical signs of gestational exposure at birth. A large proportion of substance-exposed infants are not identified early, with adverse effects often not visible at birth, leaving 65% of the substance-exposed cohort without either a CARA Plan of Care or a referral to CPS.

## Opportunities for Future Study

Future studies could delve deeper into the experiences of substance-affected infants, aiming to better grasp the frequency and efficacy of interventions detailed in [Section 3.4](#) for those who show adverse effects from substance exposure at birth.

Another promising area for investigation is the comparison of Nevada Early Intervention Services (NEIS) usage between substance-exposed and non-exposed cohorts. NEIS supports families with children under three, offering services in natural settings like homes and community playgroups, guided by an Individualized Family Services Plan. The Office of Analytics is striving to access NEIS data for upcoming research.

A deeper analysis of the effectiveness of the CARA Plan is also necessary. Office of Analytics is working to obtain more recent and ongoing CARA Plan of Care data for exploration.

As the infants in this cohort age (currently 3-6 years old), long-term studies could shed light on the enduring impacts of gestational substance exposure. Future research might explore how many of these

children utilize Medicaid or SNAP benefits and track their interactions with juvenile or adult criminal justice systems.

## Recommendations

Various policy recommendations may be made from the conclusions drawn in this report; subject matter experts in Nevada will no doubt have many ideas to enhance prevention and intervention efforts for substance-exposed infants and their families.

According to the National Center on Substance Abuse and Child Welfare (NCSACW), there are: “five major timeframes when intervention in the life of the substance-exposed infant can reduce the potential harm of prenatal substance exposure” (Young et al.). They are:

- 1. Pre-pregnancy**

This timeframe offers the opportunity to promote awareness of the effects of prenatal substance use among women of child-bearing age and their family members;

- 2. Prenatal**

This intervention point encourages health care providers to screen pregnant women for substance use as part of routine prenatal care and make referrals that facilitate access to treatment and related services for women who need those services;

- 3. Birth**

Interventions during this timeframe incorporate testing newborns for substance exposure at the time of delivery;

- 4. Neonatal**

Developmental assessment and the corresponding provision of services for the newborn as well as the family at this intervention point, immediately after the birth event, are the emphasis; and

- 5. Throughout Childhood and Adolescence**

This timeframe calls for ongoing provision of coordinated services for both child and Family

Important work has already been undertaken in Nevada by various groups to establish policies and programs to help children and families impacted by substance use. For instance, the [Nevada Perinatal Health Initiative](#) has been underway since 2018 and is a network of medical professionals, social workers, hospitals, clinics, behavioral health programs, and policymakers, and has been meeting regularly to work to improve health outcomes for pregnant individuals and individuals of childbearing age impacted by substance use.

As previously noted, some interventions mentioned in this report were designed to address the needs at some of these stages, such as the CARA Plan of Care for the neonatal stage; they may only be designed for substance-affected infants and may miss substance-exposed infants. The effects of substance-exposure may be delayed for many individuals, so there is a need to further develop and fund services for substance-exposed infants throughout later infancy, childhood, and adolescence.

Finally, it may be worth exploring how to expand interagency coordination efforts. As noted in *Substance-Exposed Infants: State Responses to the Problem*, states often have at least four sets of interagency entities covering these areas:

1. A group with a focus on child welfare outcomes who manages a Program Improvement Plan (PIP) under federal Child and Family Services Review (CFSR) requirements;
2. A group of treatment providers who meet to work on policy and planning around a statewide treatment policies;
3. A group focused on early intervention programs for developmentally disabled children or children affected by early mental health issues; and
4. A group focused on perinatal outcomes (Young et al.).

These groups may address policies and programs for substance-exposed infants as a single item under their broader mission, which may result in the work for this group being just one other item in larger strategic plans. There may be room to further develop a focused working group for substance-exposed infants and their families or to specifically develop a statewide, cross-group strategic plan for substance-exposed infants as well as interagency outcomes for substance-exposed infants which could be monitored annually or at some other frequency.

A state self-assessment may be useful to identify further opportunities for policy and program development. Working together, policymakers and stakeholders and families could collaboratively identify further strategies and recommendations to better support substance-exposed infants and their families in achieving optimal health.

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## Appendix A – ICD-10-CM Codes Indicating Maternal Use

ICD-10 Code	Description
F10	Mental and behavioral disorders due to use of alcohol
F11	Mental and behavioral disorders due to use of opioids
F12	Mental and behavioral disorders due to use of cannabinoids
F13	Mental and behavioral disorders due to use of sedatives or hypnotics
F14	Mental and behavioral disorders due to use of cocaine
F15	Mental and behavioral disorders due to use of other stimulants, including caffeine
F16	Mental and behavioral disorders due to use of hallucinogens
T40	Poisoning by narcotics and psychodysleptics [hallucinogens]
T51	Toxic effect of alcohol
O9932	Drug use complicating pregnancy, childbirth, and the puerperium
O9931	Alcohol use complicating pregnancy, childbirth, and the puerperium

## Appendix B – ICD-10-CM Codes Indicating Gestational Exposure

ICD-10 Code	Description
P961	Neonatal withdrawal symptoms from maternal use of drugs of addiction
P044	Newborn affected by maternal use of drugs of addiction
P0414	Newborn affected by maternal use of opiates
P0416	Newborn affected by maternal use of amphetamines
P0440	Newborn affected by maternal use of unspecified drugs of addiction
P0441	Newborn affected by maternal use of cocaine
P0442	Newborn affected by maternal use of hallucinogens
P0449	Newborn affected by maternal use of other drugs of addiction
P0481	Newborn affected by maternal use of cannabis
P043	Newborn affected by maternal use of alcohol
Q860	Fetal alcohol syndrome (dysmorphic)
P042	Newborn affected by maternal use of tobacco
P9681	Newborn affected by maternal use of tobacco

## Appendix C – Definitions of Fetal Anomalies

**Adequate Prenatal Care:** Adequacy of prenatal care is quantified using the Kotelchuck Index. The Kotelchuck Index classifies the adequacy of prenatal care based on two measures: the month of pregnancy in which prenatal care began, and the number of prenatal care visits from initiation to delivery. Healthy People 2030 reports 75.6% of pregnant persons received adequate prenatal care in the United States in 2021, with a target of 80.5%.

**Preterm Births:** Preterm births are defined as live births before 37 weeks of gestation. Healthy People 2030 reports 10.5% of births in the United States in 2021 as preterm, with a target of 9.4%. Note 22.0% of substance-exposed infants from 2016-2020 were preterm.

**Abnormal Births:** Births in which additional care was required. This includes those in need of immediate medical care (utilizing the Infant Abnormal Conditions variables in the birth certificate data) listed below.

- Infant Abnormal Conditions: Assist Ventilation Immediately
- Infant Abnormal Conditions: Assist Ventilation More Than 6 Hours
- Infant Abnormal Conditions: NICU Admission
- Infant Abnormal Conditions: Surfactant Replacement Therapy
- Infant Abnormal Conditions: Antibiotics for Neonatal Sepsis
- Infant Abnormal Conditions: Seizures
- Infant Abnormal Conditions: Anemia (Hct. <39/Hgb.<13)
- Infant Abnormal Conditions: Fetal Alcohol Syndrome
- Infant Abnormal Conditions: Hyaline Membrane Disease/RDS
- Infant Abnormal Conditions: Meconium Aspiration Syndrome
- Infant Abnormal Conditions: Birth Injury
- Infant Abnormal Conditions: Other

**Congenital Anomalies:** A group of structural or functional abnormalities of the body and are prenatal in origin. This includes those in Congenital Anomaly Groups (utilizing the Infant Congenital Anomalies variables in the birth certificate data) listed below.

### Central Nervous System Disorders:

- Infant Congenital Anomalies: Anencephaly
- Infant Congenital Anomalies: Meningomyelocele/Spina Bifida
- Infant Congenital Anomalies: Microcephalus
- Infant Congenital Anomalies: Other Nervous System Anomalies

### Respiratory Disorders:

- Infant Congenital Anomalies: Cyanotic Congenital Heart Disease
- Infant Congenital Anomalies: Heart Malformations
- Infant Congenital Anomalies: Other Circulatory/Respiratory Anomalies

### Gastrointestinal Disorders:

- Infant Congenital Anomalies: Omphalocele
- Infant Congenital Anomalies: Gastroschisis

Infant Congenital Anomalies: Rectal Atresia/Stenosis

Infant Congenital Anomalies: Tracheo-Esophageal Fistula/Esophageal Atresia

Infant Congenital Anomalies: Other Gastrointestinal Anomalies

**Musculoskeletal Disorders:**

Infant Congenital Anomalies: Limb Reduction Defect

Infant Congenital Anomalies: Cleft Lip With or Without Cleft Palate

Infant Congenital Anomalies: Cleft Palate Alone

Infant Congenital Anomalies: Polydactyly/Syndactyly/Adactyly

Infant Congenital Anomalies: Club Foot

Infant Congenital Anomalies: Congenital Diaphragmatic Hernia

Infant Congenital Anomalies: Other Musculoskeletal/Integumental Anomalies

**Urogenital Disorders:**

Infant Congenital Anomalies: Malformed Genitalia

Infant Congenital Anomalies: Renal Agenesis

Infant Congenital Anomalies: Hypospadias

Infant Congenital Anomalies: Other Urogenital Anomalies

**Chromosomal Disorders:**

Infant Congenital Anomalies: Downs Syndrome- Karyotype

Infant Congenital Anomalies: Suspected Chromosomal Disorder- Karyotype

Infant Congenital Anomalies: Other Chromosomal Anomalies

**Other Disorders:**

Infant Congenital Anomalies: Other (none of the above disorders)

## Appendix D – Health Outcomes in Six Month Intervals

Counts represent the number of distinct reports/visits/admissions not number of distinct individuals. For example, there were 4,688 CPS reports total report for the 12,901 infants in the PSE Cohort. An interesting conclusion from this breakdown of outcomes into six-month intervals, is that differences in outcomes between the two cohorts becomes less significant the older the infants get. There is a statistically significant difference between fewer categories of health outcomes for 18-24 month year olds than for infants in their first 6 months of life.

**Table D.1: Health and Outcomes: First Six Months of Life**

Birth – 6 Months				
	PSE Cohort		No-PSE Cohort	
Cohort Size	12,901		91,216	
	Count	Crude Rate	Count	Crude Rate
<b>CPS Reports</b>	<b>4,688</b>	<b>238.4*</b>	<b>2,116</b>	<b>23.2</b>
<b>Emergency Department Visits</b>	<b>4,836</b>	<b>374.9*</b>	<b>20,276</b>	<b>222.9</b>
<i>J00-J99: Diseases of the respiratory system</i>	1,258	97.5*	4,753	52.1
<i>R00-R99: Symptoms, signs, and abnormal clinical and laboratory findings</i>	1,235	95.7*	5,298	58.0
<i>S00-T88: Injury, poisoning and certain other consequences of external causes</i>	413	32.0*	2,114	23.2
<b>Inpatient Admissions</b>	<b>9018</b>	<b>70.0*</b>	<b>4,887</b>	<b>53.6</b>
<i>J00-J99: Diseases of the respiratory system</i>	269	20.9*	960	10.5
<i>P00-P69: Certain conditions originating in the perinatal period</i>	231	17.9*	1,935	21.2
<i>R00-R99: Symptoms, signs, and abnormal clinical and laboratory findings</i>	78	6.0*	302	3.3
<b>Mortality</b>	<b>120</b>	<b>10.2*</b>	<b>329</b>	<b>3.6</b>
Premature birth-related	44	3.7*	136	1.5

\*Tested for significance using a one-sided Z-test and yielded a p-value less than 0.01.

**Table D.2: Health and Outcomes: 6 - 12 Months**

6 – 12 Months				
	PSE Cohort		No-PSE Cohort	
Cohort Size	12,769		90,829	
	Count	Crude Rate	Count	Crude Rate
<b>CPS Reports</b>	<b>1,350</b>	<b>105.7*</b>	<b>1,728</b>	<b>19.0</b>
<b>Emergency Department Visits</b>	<b>4,782</b>	<b>374.5*</b>	<b>21,552</b>	<b>237.3</b>
<i>J00-J99: Diseases of the respiratory system</i>	1,627	127.4*	6,393	70.4
<i>R00-R99: Symptoms, signs, and abnormal clinical and laboratory findings</i>	962	75.3*	4,782	52.6
<i>S00-T88: Injury, poisoning and certain other consequences of external causes</i>	565	44.2*	2,761	30.4
<b>Inpatient Admissions</b>	<b>358</b>	<b>28.0*</b>	<b>1,627</b>	<b>17.9</b>
<i>J00-J99: Diseases of the respiratory system</i>	160	12.5*	598	6.6
<i>P00-P69: Certain conditions originating in the perinatal period</i>	32	2.5*	116	1.3
<i>R00-R99: Symptoms, signs, and abnormal clinical and laboratory findings</i>	30	2.3*	130	1.4
<b>Mortality</b>	<b>11</b>	<b>0.9*</b>	<b>30</b>	<b>0.4</b>
Premature birth-related	2	0.2	5	0.1

*\*Tested for significance using a one-sided Z-test and yielded a p-value less than 0.01.*



**Table D.3: Health and Outcomes: 12 - 18 Months**

12 – 18 Months				
	PSE Cohort		No-PSE Cohort	
Cohort Size	12,758		90,794	
	Count	Crude Rate	Count	Crude Rate
<b>CPS Reports</b>	<b>1,392</b>	<b>109.1*</b>	<b>1,739</b>	<b>19.2</b>
<b>Emergency Department Visits</b>	<b>4,089</b>	<b>320.5*</b>	<b>19,299</b>	<b>212.6</b>
<i>J00-J99: Diseases of the respiratory system</i>	1,113	87.2*	4,870	53.6
<i>R00-R99: Symptoms, signs, and abnormal clinical and laboratory findings</i>	802	62.9*	4,118	45.4
<i>S00-T88: Injury, poisoning and certain other consequences of external causes</i>	597	46.8*	3,350	36.9
<b>Inpatient Admissions</b>	<b>301</b>	<b>23.6*</b>	<b>1,377</b>	<b>15.2</b>
<i>J00-J99: Diseases of the respiratory system</i>	130	10.2*	508	5.6
<i>P00-P69: Certain conditions originating in the perinatal period</i>	30	2.4*	131	1.4
<i>R00-R99: Symptoms, signs, and abnormal clinical and laboratory findings</i>	30	2.4	155	1.7
<b>Mortality</b>	<b>1</b>	<b>0.2</b>	<b>17</b>	<b>0.2</b>
Premature birth-related	0	0.0	1	<0.1

\*Tested for significance using a one-sided Z-test and yielded a p-value less than 0.01.

**Table D.4: Health and Outcomes: 18 - 24 Months**

<b>18 – 24 Months</b>				
	<b>PSE Cohort</b>		<b>No-PSE Cohort</b>	
<b>Cohort Size</b>	<b>12,756</b>		<b>90,775</b>	
	<b>Count</b>	<b>Crude Rate</b>	<b>Count</b>	<b>Crude Rate</b>
<b>CPS Reports</b>	<b>1,143</b>	<b>89.6*</b>	<b>1,819</b>	<b>20.0</b>
<b>Emergency Department Visits</b>	<b>3,369</b>	<b>264.1*</b>	<b>16,238</b>	<b>178.9</b>
<i>J00-J99: Diseases of the respiratory system</i>	927	72.7*	3,926	43.2
<i>R00-R99: Symptoms, signs, and abnormal clinical and laboratory findings</i>	632	49.5*	3,178	35.0
<i>S00-T88: Injury, poisoning and certain other consequences of external causes</i>	610	47.8*	3,738	41.2
<b>Inpatient Admissions</b>	<b>186</b>	<b>14.6</b>	<b>1,199</b>	<b>13.2</b>
<i>J00-J99: Diseases of the respiratory system</i>	84	6.6	461	5.1
<i>P00-P69: Certain conditions originating in the perinatal period</i>	20	1.6	141	1.6
<i>R00-R99: Symptoms, signs, and abnormal clinical and laboratory findings</i>	14	1.1	69	0.7
<b>Mortality</b>	<b>4</b>	<b>0.3</b>	<b>11</b>	<b>0.1</b>
Premature birth-related	0	0.0	0	0.0

*\*Tested for significance using a one-sided Z-test and yielded a p-value less than 0.01.*

## Appendix E – Causes of Mortality

**Table E.1: Causes of Mortality, PSE Cohort, Birth to 24 Months**

Causes of Mortality		
Primary Diagnosis	PSE Cohort	
	N	%
Perinatal period conditions	51	38.1%
Symptoms, signs, not elsewhere classified	25	18.7%
Congenital malformations abnormalities	19	14.2%
Nontransport accidents	18	13.4%
Assault (homicide)	3	2.2%
Events of undetermined intent	3	2.2%
Influenza and pneumonia	3	2.2%
Other diseases of respiratory system	2	1.5%
Other infectious and parasitic diseases	2	1.5%
All other diseases (residual)	1	0.8%
Benign neoplasms	1	0.8%
COVID-19	1	0.8%
Cerebrovascular diseases (stroke)	1	0.8%
Certain other intestinal infections	1	0.8%
Complications of medical/surgical care	1	0.8%
Diseases of the heart	1	0.8%
System Missing or Undefined	1	0.8%

**Table E.2: Causes of Mortality, No-PSE Cohort, Birth to 24 Months**

<b>Causes of Mortality</b>		
<b>Primary Diagnosis</b>	<b>PSE Cohort</b>	
	<b>N</b>	<b>%</b>
Perinatal period conditions	163	38.4%
Congenital malformations abnormalities	84	19.8%
Symptoms, signs, not elsewhere classified	51	12.0%
Nontransport accidents	47	11.0%
All other diseases (residual)	21	5.0%
Diseases of the heart	11	2.6%
Assault (homicide)	6	1.4%
Malignant neoplasms	6	1.4%
Other diseases of respiratory system	6	1.4%
Certain other intestinal infections	4	0.9%
Influenza and pneumonia	4	0.9%
Events of undetermined intent	3	0.7%
Septicemia	3	0.7%
Transport accidents	3	0.7%
COVID-19	2	0.5%
Chronic liver disease and cirrhosis	2	0.5%
Other acute lower respiratory infections	2	0.5%
Hernia	1	0.2%
Intentional self-harm (suicide)	1	0.2%
Other diseases of circulatory system	1	0.2%
Other disorders of circulatory system	1	0.2%
Other infectious and parasitic diseases	1	0.2%
System Missing or Undefined	1	0.2%

## Appendix F – Hospitalizations

**Table F.1: Emergency Department Visits, PSE Cohort, Birth to 24 Months**

Primary Diagnosis	PSE Cohort	
	N	%
10 - Diseases Of The Respiratory System (J00-J99)	7248	28.8%
18 - Symptoms, Signs And Abnormal Clinical And Laboratory Findings, Not Elsewhere Classified (R)	4955	19.7%
19 - Injury, Poisoning And Certain Other Consequences Of External Causes (S00-T88)	3618	14.3%
01 - Certain Infectious And Parasitic Diseases (A00-B99)	2620	10.4%
08 - Diseases Of The Ear And Mastoid Process (H60-H95)	1396	5.6%
11 - Diseases Of The Digestive System (K00-K95)	1128	4.5%
12 - Diseases Of The Skin And Subcutaneous Tissue (L00-L99)	988	3.9%
21 - External Causes Of Morbidity (V00-Y99)	634	2.5%
07 - Diseases Of The Eye And Adnexa (H00-H59)	491	2.0%
16 - Certain Conditions Originating In The Perinatal Period (P00-P96)	416	1.7%
14 - Diseases Of The Genitourinary System (N00-N99)	385	1.5%
00 - Invalid/Unknown Diagnosis Code	323	1.3%
22 - Factors Influencing Health Status And Contact With Health Services (Z00-Z99)	267	1.0%
20 - Codes For Special Purposes (U00-U99)	213	0.9%
13 - Diseases Of The Musculoskeletal System And Connective Tissue (M00-M99)	188	0.8%
04 - Endocrine, Nutritional And Metabolic Diseases (E00-E89)	84	0.3%
06 - Diseases Of The Nervous System (G00-G99)	58	0.2%
09 - Diseases Of The Circulatory System (I00-I99)	50	0.2%
17 - Congenital Malformations, Deformations And Chromosomal Abnormalities (Q00-Q99)	42	0.2%
03 - Diseases Of The Blood And Blood-Forming Organs And Certain Disorders Involving The Immune	26	0.1%
05 - Mental, Behavioral And Neurodevelopmental Disorders (F01-F99)	26	0.1%
02 - Neoplasms (C00-D49)	4	0.02%

**Table F.2: Emergency Department Visits, No-PSE Cohort, Birth to 24 Months**

Primary Diagnosis	No-PSE Cohort	
	N	%
10 - Diseases Of The Respiratory System (J00-J99)	30,751	25.8%
18 - Symptoms, Signs And Abnormal Clinical And Laboratory Findings, Not Elsewhere Classified (R)	24,915	20.9%
19 - Injury, Poisoning And Certain Other Consequences Of External Causes (S00-T88)	20,477	17.2%
01 - Certain Infectious And Parasitic Diseases (A00-B99)	12,688	10.7%
08 - Diseases Of The Ear And Mastoid Process (H60-H95)	6,092	5.1%
11 - Diseases Of The Digestive System (K00-K95)	5,527	4.6%
12 - Diseases Of The Skin And Subcutaneous Tissue (L00-L99)	3,738	3.1%
21 - External Causes Of Morbidity (V00-Y99)	2,573	2.2%
14 - Diseases Of The Genitourinary System (N00-N99)	2,252	1.9%
16 - Certain Conditions Originating In The Perinatal Period (P00-P96)	2,120	1.8%
07 - Diseases Of The Eye And Adnexa (H00-H59)	1,706	1.4%
00 - Invalid/Unknown Diagnosis Code	1,555	1.3%
20 - Codes For Special Purposes (U00-U99)	1,117	0.9%
13 - Diseases Of The Musculoskeletal System And Connective Tissue (M00-M99)	1,079	0.9%
22 - Factors Influencing Health Status And Contact With Health Services (Z00-Z99)	1,071	0.9%
04 - Endocrine, Nutritional And Metabolic Diseases (E00-E89)	481	0.4%
06 - Diseases Of The Nervous System (G00-G99)	318	0.3%
09 - Diseases Of The Circulatory System (I00-I99)	182	0.2%
17 - Congenital Malformations, Deformations And Chromosomal Abnormalities (Q00-Q99)	147	0.1%
03 - Diseases Of The Blood And Blood-Forming Organs And Certain Disorders Involving The Immune	144	0.1%
05 - Mental, Behavioral And Neurodevelopmental Disorders (F01-F99)	79	0.1%
02 - Neoplasms (C00-D49)	48	0.04%

**Table F.3: Inpatient Admissions, PSE Cohort, Birth to 24 Months**

Primary Diagnosis	PSE Cohort	
	N	%
10 - Diseases Of The Respiratory System (J00-J99)	846	39.3%
16 - Certain Conditions Originating In The Perinatal Period (P00-P96)	234	10.9%
18 - Symptoms, Signs And Abnormal Clinical And Laboratory Findings, Not Elsewhere Classified (R	175	8.1%
19 - Injury, Poisoning And Certain Other Consequences Of External Causes (S00-T88)	173	8.0%
11 - Diseases Of The Digestive System (K00-K95)	126	5.9%
01 - Certain Infectious And Parasitic Diseases (A00-B99)	123	5.7%
17 - Congenital Malformations, Deformations And Chromosomal Abnormalities (Q00-Q99)	116	5.4%
14 - Diseases Of The Genitourinary System (N00-N99)	62	2.9%
04 - Endocrine, Nutritional And Metabolic Diseases (E00-E89)	57	2.7%
06 - Diseases Of The Nervous System (G00-G99)	50	2.3%
12 - Diseases Of The Skin And Subcutaneous Tissue (L00-L99)	47	2.2%
00 - Invalid/Unknown Diagnosis Code	30	1.4%
03 - Diseases Of The Blood And Blood-Forming Organs And Certain Disorders Involving The Immune Mechanism (D50-D89)	25	1.3%
13 - Diseases Of The Musculoskeletal System And Connective Tissue (M00-M99)	20	0.9%
21 - External Causes Of Morbidity (V00-Y99)	17	0.8%
09 - Diseases Of The Circulatory System (I00-I99)	14	0.7%
20 - Codes For Special Purposes (U00-U99)	13	0.6%
08 - Diseases Of The Ear And Mastoid Process (H60-H95)	9	0.4%
22 - Factors Influencing Health Status And Contact With Health Services (Z00-Z99)	6	0.3%
07 - Diseases Of The Eye And Adnexa (H00-H59)	4	0.2%
05 - Mental, Behavioral And Neurodevelopmental Disorders (F01-F99)	3	0.1%
02 - Neoplasms (C00-D49)	2	0.1%

**Table F.4: Inpatient Admissions, No-PSE Cohort, Birth to 24 Months**

Primary Diagnosis	No-PSE Cohort	
	N	%
10 - Diseases Of The Respiratory System (J00-J99)	3,725	31.5%
16 - Certain Conditions Originating In The Perinatal Period (P00-P96)	1,939	16.4%
19 - Injury, Poisoning And Certain Other Consequences Of External Causes (S00-T88)	849	7.2%
01 - Certain Infectious And Parasitic Diseases (A00-B99)	812	6.9%
18 - Symptoms, Signs And Abnormal Clinical And Laboratory Findings, Not Elsewhere Classified (R	742	6.3%
11 - Diseases Of The Digestive System (K00-K95)	644	5.4%
17 - Congenital Malformations, Deformations And Chromosomal Abnormalities (Q00-Q99)	622	5.3%
14 - Diseases Of The Genitourinary System (N00-N99)	594	5.0%
04 - Endocrine, Nutritional And Metabolic Diseases (E00-E89)	377	3.2%
06 - Diseases Of The Nervous System (G00-G99)	297	2.5%
12 - Diseases Of The Skin And Subcutaneous Tissue (L00-L99)	241	2.0%
00 - Invalid/Unknown Diagnosis Code	164	1.4%
03 - Diseases Of The Blood And Blood-Forming Organs And Certain Disorders Involving The Immune Mechanism (D50-D89)	145	1.2%
21 - External Causes Of Morbidity (V00-Y99)	132	1.1%
20 - Codes For Special Purposes (U00-U99)	122	1.0%
09 - Diseases Of The Circulatory System (I00-I99)	120	1.0%
13 - Diseases Of The Musculoskeletal System And Connective Tissue (M00-M99)	106	0.9%
02 - Neoplasms (C00-D49)	63	0.5%
08 - Diseases Of The Ear And Mastoid Process (H60-H95)	56	0.5%
22 - Factors Influencing Health Status And Contact With Health Services (Z00-Z99)	54	0.5%
07 - Diseases Of The Eye And Adnexa (H00-H59)	28	0.2%
05 - Mental, Behavioral And Neurodevelopmental Disorders (F01-F99)	11	0.1%