



Collaborating Across Service Systems

How to Develop a Comprehensive
Data Approach for Families Affected by
Prenatal Substance Exposure

A TWO-PART SERIES

BRIEF 1: State Data Collection and Reporting Approaches for
Infants and Families Affected by Prenatal Substance Exposure



National Center on
Substance Abuse
and Child Welfare



Introduction

The National Center on Substance Abuse and Child Welfare (NCSACW) created this series for state child welfare and partner agencies (e.g., public health, maternal and child health, substance use services, mental health services) seeking to understand the scope of prenatal substance exposure (PSE) in a state or other jurisdiction. Understanding the scope to ensure child safety requires a multiagency approach for strategic planning and efficient resource allocation to prevent and mitigate the effects on children and families.

Brief 1: State Data Collection and Reporting Approaches for Infants and Families Affected by Prenatal Substance Exposure

- ◆ Explores the need for a multiagency data approach to understand the scope of PSE in a state or other jurisdiction
- ◆ Explains how states collect and report data on families affected by PSE (includes state responses to the Child Abuse and Prevention Treatment Act/Comprehensive Addiction and Recovery Act (CAPTA/CARA))

Brief 2: Implementation Guidance for Developing a Comprehensive Data Approach for Infants and Families Affected by Prenatal Substance Exposure

Offers three key steps to overcome common challenges in a multiagency data approach:

- ◆ Build cross-system workgroups
- ◆ Reduce barriers to cross-sector data collection and analyses
- ◆ Identify and access to key data sources



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Introduction

This document describes why a comprehensive data approach—across service systems—remains critical to ensure that systems respond to the various challenges faced by families affected by prenatal substance exposure (PSE). Also included are examples of state data collection approaches.

Background

Each year, an estimated 340,000 infants are born prenatally exposed to a tobacco or vaping product, 300,000 infants are born prenatally exposed to alcohol, and 180,000 are born prenatally exposed to illicit drugs.*^{1,2} Picture **over 10,000 classrooms**[†] filled with children needing early intervention, special education, and other services to mitigate potential effects. PSE may result in a variety of physical, cognitive, and social-emotional consequences—each of which requires different interventions. Effects vary depending on several factors, including exposure to multiple substances, the type of substance and timing of exposure, and the mother's access to substance use disorder (SUD) treatment.^{3,4,5}

The opioid epidemic and increasing numbers of overdose deaths serve as a “call to action” for states and other jurisdictions to ensure services remain available for families affected by PSE. The rate of opioid use disorders (OUD) among women giving birth in the U.S. *increased 131%* from 2010 through 2017 while the rate of infants with neonatal abstinence syndrome (NAS) increased 82%.^{†6} NAS rates vary among regions, states, and counties.^{6,7}

A 2018 Tennessee study found elementary school children with a NAS diagnosis had an increased need for special education services—including assessment services and in-classroom interventions—compared to children without a NAS diagnosis.⁸ Children with a NAS diagnosis were also more likely to meet criteria for an education disability. Specifically, 19.3% of children with a NAS diagnosis received referrals to a special education assessment while 15% met criteria for an educational disability.

Adolescents affected by PSE remain at an increased risk for mental health disorders and other concerns. Recent findings from the Adolescent Brain Cognitive Development (ABCD) study show adolescents with prenatal exposure to cannabis have an increased risk of cognitive, mental health, and

* Based on percentage of pregnant women who report use of tobacco or vaping products (9.4%); alcohol (8.4%); illicit drugs (4.9%) and the number of births in 2023 (n=3,596,017). Illicit drugs include marijuana, cocaine, heroin, hallucinogens, inhalants, methamphetamine, misuse of prescription psychotherapeutics, opioids (excluding illegally made fentanyl), central nervous system stimulants, and illicit drugs other than marijuana.

† Based on average number of infants born prenatally exposed to tobacco or vaping products, alcohol, or illicit drugs and an average class size of 24 students.

‡ Prenatal exposure to opioids can lead to neonatal abstinence syndrome (NAS). “NAS” is the conventional terminology and more recently “NOWS” (neonatal opioid withdrawal syndrome) is also used. For more information see The American Academy of Pediatrics Clinical Report, November 2020, *Neonatal Opioid Withdrawal Syndrome*.

other challenges—thereby increasing their risk of developing SUDs or psychiatric disorders.⁹ Further, studies show adolescents affected by *parental SUD* are at increased risk of developing their own SUD.^{10,11} Adolescents affected by parental substance use and who have experienced out-of-home care (particularly those that *age-out* of care) have an even higher risk of developing their own SUD as well as other concerns.¹²

Increases in drug-related hospitalizations and overdose deaths of parents or caregivers positively correlate with an increase in reports of child maltreatment, substantiated reports of maltreatment, and children entering out-of-home care.¹³ These data underscore a need for comprehensive services for infants, children, and adolescents with PSE—as well as their parents. Comprehensive services across systems include

- ◆ Family-centered SUD services and treatment (e.g., screening and assessment, medication for opioid use disorders (MOUD) for pregnant/postpartum women and others (e.g., fathers, other caregivers))
- ◆ Residential SUD treatment for pregnant/postpartum women, fathers, and other caregivers along with their infants and children
- ◆ Early intervention for infants and children 0-3 for assessment and other services to mitigate the cognitive, physical, and other effects of PSE
- ◆ Child welfare risk and safety assessment services when necessary, as well as case management services to ensure engagement into comprehensive care
- ◆ Maternal and child health, home visiting, and peer recovery support services for care coordination
- ◆ Special education and other supports to ensure ongoing help for children, adolescents, and young adults
- ◆ Developmentally appropriate SUD prevention and treatment for children, adolescents, and young adults

A Data-Driven Approach to Developing a Comprehensive Service Array for Families Affected by PSE

Data-driven approaches remain essential to identifying: 1) the scope of service need, 2) those most affected, and 3) how to implement services where they are most needed. Each system understands the nuances of how their system functions. Collaboration across sectors allows staff to consider each system's knowledge and experiences in the context of data collection and sharing.

Data, when implemented as a tool across systems, prompt a feedback loop that allows for both the ongoing improvement of services and outcomes, as well as the continuous refinement of data collection and sharing mechanisms. A data-driven approach helps answer several important questions:

- ◆ How many infants are affected by PSE in the community, state, region?
- ◆ What are the key systems involved and how can collaborative relationships among systems be built?
- ◆ Which data are currently available and useful?
- ◆ How can data be collected and shared across systems?
- ◆ How can data be used to understand the scope of unmet need?
- ◆ How can data be used to implement policy and programmatic changes?
- ◆ What structures and efforts encourage ongoing data and information sharing among systems?



State Reporting of Prenatal Substance Exposure

Plans of Safe Care (POSC), or Family Care Plans (FCP)—as a few states have named them—offer an opportunity for states, Tribal communities, and other jurisdictions to bring various service providers together in a collaborative approach. Key service providers include maternal and infant health care, child welfare, SUD treatment, mental health, early childhood development, and others.

CAPTA (2003) required POSC for infants born and identified as being affected by illegal substance use or withdrawal symptoms.¹⁴ It also directed health care providers involved in the delivery or care of such infants to notify child protective services (CPS). An amended CAPTA in 2010 included identification and development of POSC for infants affected by fetal alcohol spectrum disorder (FASD).¹⁵ More recently, CARA (2016) made several amendments to CAPTA, including: 1) removal of the term “illegal” regarding infants affected by substance abuse or withdrawal symptoms, and 2) a requirement that POSC meet the needs of the infant and affected family or caregiver.¹⁶ Other amendments include development and implementation of POSC monitoring systems and revisions to POSC data that state child welfare systems are to report. States and other jurisdictions have implemented POSC statutes, policies, and protocols based on their unique needs.

CAPTA requires states to report specific data elements annually to the maximum extent practicable.¹⁶ These data elements (hereinafter referenced as the “CAPTA PSE” data elements) include:

- ◆ Number of infants born and identified as being affected by substance abuse or withdrawal symptoms resulting from prenatal drug exposure or a fetal alcohol spectrum disorder
- ◆ Number of such infants for whom a Plan of Safe Care was developed
- ◆ Number of such infants for whom a referral was made for appropriate services, including services for the affected family or caregiver

For more information on POSC, see [About CAPTA: A Legislative History, POSC Learning Modules, PI-17-02 | The Administration for Children and Families](#), and [ACYF-CB-PI-23-01](#).

State child welfare systems report a variety of data including the CAPTA PSE data elements to Children's Bureau (CB). The data is submitted via the [National Child Abuse and Neglect Data System](#) (NCANDS) and published in the annual [Child Maltreatment Report](#).¹⁷ The number of states reporting on the CAPTA PSE data elements in 2023 has increased since 2018 (when reporting requirements were first required). Thirty-five states reported on the number of infants with POSC in 2023 compared to 13 in 2018.^{18,19}

An increasing number of states and other jurisdictions have adopted the term **“Family Care Plan”** as an alternative to **Plan of Safe Care**. Some states have determined the use of Family Care Plan is the preferred term as it is less stigmatizing and may enhance engagement of families into services. States now implementing the term include [Oklahoma](#) and [Connecticut](#). Certain states have adopted other terminology such as Family Wellness and Support Plans. See [Model Substance Use During Pregnancy and Family Care Plans Act](#).

Despite significant improvements, states report a wide range in the number of families affected by PSE. States in 2023 reported a range of 13- 7, 503 infants with PSE whom health care providers referred to CPS.^{20,21}

State Data Collection Approaches to Prenatal Substance Exposure

For a more comprehensive data approach, child welfare can partner with various service systems to explore data sources in addition to the PSE data reported under CAPTA. Additional data sources include Medicaid and other insurance claims data which includes information on ICD diagnostic codes.[§] There are ICD codes specific to infants with PSE, such as those with exposure to alcohol, tobacco, opioids, or other substances; infants who exhibit symptoms of NAS; and those with FASD.

Estimates on the number of infants with PSE in a state or other jurisdiction based solely on ICD codes may fall short—potentially excluding those with exposure who either did not receive an assessment or did not meet diagnostic criteria. Other sources of information include data regarding certificates of live birth, pregnant women with a SUD diagnosis, or pregnant women entering SUD treatment. For detailed information on certificates of live birth and other data sources pertinent to PSE, see

[Brief 2: Implementation Guidance for Developing a Comprehensive Data Approach for Infants and Families Affected by Prenatal Substance Exposure.](#)

Some states have implemented PSE data collection systems in addition to (or outside of) the CAPTA PSE data elements reported to NCANDS (see above for detail):

CONNECTICUT

Connecticut birth hospitals enter information (e.g., potential risks) on infants with PSE into an online portal. Based on the provided information, the portal determines one of two different pathways:

- ◆ A child maltreatment report should go to the Connecticut Department of Children and Families (DCF). In this pathway, the portal system first directs the user to complete a form with information on the family before submitting the report. DCF develops the POSC; data from the child maltreatment report and POSC are available in the DCF child welfare data system.
- ◆ A notification, as mandated by CAPTA, should go to the Connecticut DCF. In this pathway, the birth hospital develops a POSC with the family. Staff enter information such as “recommended family services” into the portal system.

Staff make a DCF report amid concerns about the safety of the infant and when prenatal exposure is a result of maternal substance use. Exposure includes prescribed medications, as clinically indicated, such as those used to treat OUD.

Connecticut DCF uses de-identified data from both pathways, including maternal and infant information, the type of exposure, and community type (e.g., urban, rural, suburban) to determine the total estimated number of families affected by PSE as well as how to allocate resources.

There are various points, including prior to the birth (or hospital discharge), when staff can develop POSC. The POSC must include a lead provider, and the birth hospital must verify (with the developer) upon notification. Absent verification, the portal will direct the case to the child maltreatment report track. View further details at the [Connecticut State Department of Children and Families Newborn Notification Portal](#).

[§] ICD codes are international standards developed by the World Health Organization and are used for a variety of purposes including medical billing. See [International Classification of Diseases, Ninth Revision \(ICD-9\)](#).

NEBRASKA

In Nebraska, all infants with PSE receive POSC documented in maternal or neonatal medical records, such as the discharge summary. Hospitals are to send the POSC to the infant's pediatric care provider. The development of the plan should involve the family who will then receive a final copy at discharge.

The state has implemented different pathways for families affected by PSE. A child maltreatment report goes to the Nebraska Child Abuse/Neglect Hotline when there's a concern for child safety (e.g., parents with SUD are not engaged in treatment). Absent child safety concerns, a CARA Notification Form goes to the state Department of Health and Human Services. Examples of when a notification is applicable include when parents are stable and engaged in MOUD with a licensed physician.

The CARA notification form collects de-identified information, including type of substance to which the infant was exposed, maternal and infant information, reason for the notification, existence of a POSC, and whether staff referred the family to services. See [Nebraska Department of Health and Human Services Comprehensive Addiction and Recovery Act \(CARA\)](#). See also [Infants born affected by substance use or misuse and an update on Nebraska's response to the CARA letter](#).

NEW HAMPSHIRE

New Hampshire modified its certificate of live birth, known as the birth certificate worksheet, to include items such as prenatal exposure to opioids, stimulants, and other substances. Upon birth, the birthing center or hospital completes the worksheet. Staff de-identify and aggregate the data on prenatal exposure before submitting to CB to fulfill the CAPTA data reporting requirements on an annual basis.

All infants with PSE receive POSC in New Hampshire. The health care provider develops the POSC with the mother. Staff must complete the Plan before the family leaves the hospital. State law requires attaching a copy of the POSC to the hospital discharge instructions provided to the family. New Hampshire encourages providers to send the POSC to the infant's pediatrician at the time of discharge. State law requires providers to send a copy to the Department of Children, Youth and Families in cases of suspected child maltreatment. See [New Hampshire's POSC Guidance Document](#).

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