



Collaborating Across Service Systems

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

A TWO-PART SERIES

BRIEF 2: Implementation Guidance for Developing a Comprehensive Data Approach 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 requires a multiagency approach allowing for strategic planning and efficient allocation of resources to prevent and mitigate the effects on 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 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 key data sources

Table of Contents

Section I: Key Opportunities for States and Other Jurisdictions to Improve Outcomes for Infants and Families Affected by Prenatal Substance Exposure 4

- Establish a Population Estimate** 4
 - Use Existing Data to Assess Infant Prenatal Substance Exposure..... 4
 - Develop Proxy Estimates to Explore and Identify State- and Other Jurisdiction-Specific Data..... 5
- Determine Key Systems Involved and Build a Collaborative Infrastructure** 6
 - Identify all Key Sectors..... 6
 - Convene a Data Workgroup and Understand the Data Landscape.....7
 - Develop Memoranda of Understanding and Data Sharing Agreements..... 8
- Employ Strategies to Collect and Share Data Collaboratively** 8
 - Establish Shared Outcomes 9
 - Collect Data With an Equity Lens..... 9
 - Develop and Monitor Data Systems Across State Departments and Within the Community..... 10
 - Reduce Barriers to Data Sharing Across Systems Via Data Aggregation 10
- Use Data to Assess Unmet Need**12
 - Examine Data With an Equity Lens.....12
- Recommend Data-Driven Policy and Practice Changes**.....13
 - Use Data Visualization as a Tool for Monitoring and Change.....13
 - Engage in an Ongoing Data and Practice Feedback Loop14

Section II: Common Challenges Encountered in Cross-Sector Data-Driven Approaches.....15

- Variation Across Data Systems**15
- Missing and Incomplete Data**..... 16
- Variation Across Practices** 16

Appendices:

- Appendix A: Key Populations Affected by PSE - Data Points**17
- Appendix B: Sample Data Sources**18
- Appendix C: Sample Data Template**.....23
- Appendix D: PSE Data Disproportionality Worksheet**.....27
- Appendix E: Sample Cross-Sector Data Landscaping Tool** 35

Sources 36

This document provides an approach for cross-system collaboratives to conduct data-driven strategic planning for families affected by PSE. The sections are **not** intended to be completed consecutively as data collection and sharing, system-wide collaboration, and service improvement all remain ongoing and concurrent efforts.



SECTION I: Key Opportunities for States and Other Jurisdictions to Improve Outcomes for Infants and Families Affected by PSE

Establish a Population Estimate

It is critical to identify the number of pregnant and postpartum people with substance use disorders (SUD)—as well as infants, children, and adolescents with PSE—to clearly understand both the scope of the problem and each state's needs.

Suggestions to better understand how PSE affects families

- ▶ Use examples to show how states developed protocols to collect and report data
- ▶ Develop proxy estimates utilizing available data
- ▶ Ask follow-up questions to guide the process

Use Existing Data to Assess Infant PSE

Publicly available secondary public health and International Classification of Disease (ICD)-10, Medicaid, and other insurance claims data exist that

can help identify the total number of affected infants. Plan of Safe Care (POSC) data, which state child welfare systems report to the maximum extent practicable,¹ offer a helpful yet incomplete population estimate. These data are typically available in state child welfare data systems and appear in the federally published [Child Maltreatment Report](#) on an annual basis. The report includes useful data, such as the number of infants with PSE referred to state child welfare agencies, and the number determined in need of an investigation or assessment. These data help state child welfare agencies determine capacity to respond to cases involving PSE. However, in some states, the data may represent only infants identified with PSE *in cases where a health care professional determines the infant requires child welfare interventions.*

For additional information see [Brief 1: State Data Collection and Reporting Approaches for Infants and Families Affected by PSE](#)

There are potentially a larger number of infants with PSE who are **not** referred to child welfare agencies, but receive a notification. Thus, state child welfare data pertaining to infants with PSE are just one step toward understanding the total number of infants and families affected by PSE in a state or other jurisdiction. Pathways to collect notification data are not in place in all states; thus it's essential to conduct a review of collected data.

A comprehensive estimate of the number of infants with PSE informs service planning and capacity across child welfare, early intervention, health care, and other systems, as well as an evaluation of policy and practice changes focused on reducing PSE.

A variety of ICD diagnostic codes exist for infants with PSE, such as those who exhibit symptoms of NAS and those with fetal alcohol syndrome. Estimates based solely on these diagnostic codes would likely be an **undercount**—excluding infants with prenatal exposure who do not meet diagnostic criteria or did not receive an assessment for prenatal exposure. Including other relevant ICD codes, such as infants affected by maternal use

of substances and people with a SUD diagnosis (at the birth of their infant), results in a more complete estimate. See *Appendix B* for ICD codes pertinent to PSE.

Additional data sources, such as hospital birth and other medical records, provide other key pieces of information critical to determining the number of infants, children, adolescents, and parents affected by PSE. See *Appendix B* for these data sources in addition to practical tips on using the data to establish population estimates.

Secondary data can be examined in conjunction with available state-level administrative data. Establishing an estimate of the number of families affected by PSE does not require individual-level data. Instead, de-identified data can be used. Typically, sharing de-identified data, such as aggregated data in summary tables, or administrative level data, does not require a large infrastructure and can be incorporated into existing data sharing agreements.² See [Administrative Data in Child Welfare Evaluations: Using Administrative Data to Understand Populations and Measure Outcomes](#) for information on how to identify and use administrative data.

“ State child welfare data pertaining to infants with PSE are just one step toward understanding the total number of infants and families affected by PSE in a state or other jurisdiction.



Develop Proxy Estimates to Explore and Identify State- and Other Jurisdiction-Specific Data

State- and other jurisdiction-specific data may not be readily available, or there may be incomplete data. In the absence of data, proxy data and estimates based on national or state data can help explore and identify additional data sources.

For example, the Substance Abuse and Mental Health Services Administration's (SAMHSA) Treatment Episode Data Set (TEDS) contains state SUD treatment agency information on publicly funded treatment programs. TEDS data include pregnancy admissions/discharges from treatment and helps establish an approximation of the population of pregnant people with SUDs. The TEDS data could be applied to jurisdictions' annual number of births. States' annual number of births are accessible through a variety of sources, including [The Annie E. Casey Foundation: Kids Count Data Center](#). The resulting calculation based on TEDS data would be an **undercount**, however, since it relies on the number of admissions for pregnant people who enter SUD treatment and does not provide information on those who did **not** enter or remained unable to access treatment.

Exploratory questions include

- ▶ **How representative are the TEDS data?** Does the data represent pregnant people who can access and enter SUD treatment or the total number of pregnant people with a SUD in a state? Data on pregnant people with a SUD could be informed by a variety of sources, including the Pregnancy Risk Assessment

Monitoring System (PRAMS). See *Appendix B* for more details.

- ▶ **Are there factors, such as stigma, which would prevent a pregnant person from accessing SUD treatment?**
- ▶ **How does the TEDS-based estimate compare to the total estimated number of infants with PSE?** A much larger number of infants with PSE—compared to the number of pregnant and postpartum people entering SUD treatment—indicates an issue with treatment access and engagement. There are a variety of data sources to estimate the number of infants with PSE, including ICD codes. ICD codes are used for a variety of purposes, including medical records and billing. See *Appendix B* for more detail.

Similarly, national estimates of the percentage of pregnant people who have used substances, based on the National Survey on Drug Use and Health (NSDUH), are applicable to state or other jurisdictions' annual birth data to develop a baseline estimate. Exploratory questions include

- ▶ **This estimate is based on national data, so how representative is that of our state or community?**
- ▶ **What data sources are available that contain data specific to our state or community?** For example, which partner on the collaborative initiative could access data based on ICD codes pertaining to PSE?

Additional Considerations

After completing an assessment of key populations and a review available data, follow-up questions may include

- ▶ **For which population are the most comprehensive data available?**
- ▶ **What is the intent of establishing the estimate?** For example, if the primary purpose is to use it to explore and identify additional data sources, proxy estimates—such as those based on readily available national data or partial state data—could help. An approach based on proxy data requires fewer resources since staff would not need to allocate time to data queries.
- ▶ **Is there a known scarcity of services and support for one of the populations?** Prioritizing populations for development of an estimate based on a known need, such as waitlists for SUD treatment or early intervention services, is practicable.
- ▶ **What strategies are available to fill data gaps?** Examples include mapping or linking child welfare

data to public health, SUD, or other relevant data; and modification of child welfare information systems. These strategies can help identify infants affected by prenatal exposure, type of exposure, and including PSE in data collected by state public health departments.

Determine Key Sectors Involved and Build a Collaborative Infrastructure

Identify All Key Sectors

A multiagency effort is necessary to understand what the population estimate means in the context of the need, and to fill in gaps in data and knowledge. Existing data from the sources highlighted previously may provide an incomplete picture of the number of families affected by PSE. Multiple systems are the gatekeepers of different data elements that, when combined, can paint a more comprehensive picture.

Data are often collected in different systems, within different units of measurement, and across varying points in time. Many challenges inherent in analyses of data from numerous systems require a collaborative approach. This effort cannot be undertaken without recognizing which systems intersect and interact with pregnant and postpartum people with SUDs and their families. A key question to ask is: Are there service sectors missing, and how do we know?

Representatives from all relevant state departments and divisions, the substance use treatment system, the child welfare system, the court system, public health, community peer recovery agencies, the medical community, and others should be involved in the planning and building of the infrastructure. Feedback and active participation from individuals with lived experience are also critical throughout the process.

A strong infrastructure supports cross-sector approaches and includes the following

- ▶ **Oversight committee:** Executive leadership (with convening authority across systems) who ensure the collaborative effort remains a priority for partners

“Multiple systems are the gatekeepers of different data elements that, when combined, can paint a more comprehensive picture.”



- ▶ **State leadership core team:** State system representatives with the authority to allocate resources and assume responsibility for leading the initiative
- ▶ **Topic area workgroups and implementation teams:** Wide variety of state system representatives, including individuals with lived expertise, who develop and pilot practice changes

For more information on building collaborative infrastructures see NCSACW's [Building Collaborative Capacity Series: How to Develop Cross-Systems Collaborative Teams and Implement Collaborative Practice](#). Another pertinent resource from the NCSACW is the [Key Considerations for Applying an Equity Lens to Collaborative Practice](#). See also the Regional Partnership Grant's [Practice-Level Strategies to Create Systems-Level Change: Results](#).

Convene a Data Workgroup and Understanding the Data Landscape

The state leadership core team can convene a data workgroup whose role is to gather, summarize, and analyze data across service systems to develop an understanding of the number of families affected by PSE. Workgroup members ideally include knowledgeable individuals with access to the pertinent state data systems. Members can also include individuals who understand the procedures and practices that could affect the data. A child welfare administrator or manager could explain how staff enter information on cases involving PSE into data systems. There may be different data systems within a single state agency. For example, there may be one system to collect data on child maltreatment reports made to child welfare, and a separate system, such as case

management, containing data on child welfare services provided to families.

Various techniques, such as logic modeling, exist to identify the goals of the project and anticipate outcomes in the context of the available resources. It may also be useful as a preliminary activity to develop a client flow chart to understand how individuals intersect with multiple systems to assess how and when systems collect data elements. See the Robert Wood Johnson Foundation's report, [A Practical Guide for Engaging Stakeholders in Developing Evaluation Questions](#), for additional tips and techniques.

Establishing trust and building relationships among workgroup members are key to a successful data initiative. The larger collaborative's efforts to develop a shared mission and statement of principles can help since they serve as a foundation for collaborative practice within each of the project's workgroups. Defining expectations, roles, and responsibilities of participating members remains equally important to the success of collaborative workgroups. These essential components—a shared mission, a shared statement of principles, and clearly defined expectations and roles—would appear in a memorandum of understanding (MOU).

Data is collected and analyzed for many purposes: to explore concepts or systems to understand how they function, to describe a population, to explain the relationship between concepts or systems, or to evaluate an existing program. Conducting a data inventory or using a data landscaping tool helps the data workgroup identify what data are available, in what form, how they can be shared among the workgroup, and for what purpose. See [Appendix E](#) and the [Urban Institute's Understanding Community Resources: A Tool for Data Landscaping](#).

Exploratory questions to guide data landscaping

- ▶ What is the overall purpose of the data workgroup?
- ▶ How can all systems develop a shared mission for the workgroup?
- ▶ What data elements do each of the representatives collect?
- ▶ What are the institutional and other barriers to data sharing and how can they be overcome?

Establishing trust and building relationships among workgroup members are key to a successful data initiative.

Develop Memoranda of Understanding and Data Sharing Agreements

Central to the successful implementation of a memorandum of understanding or data sharing agreement is the use of rigorous ethical and technical standards for data storage, sharing, and protection of information. Clearly defining how the data will be de-identified, shared, and examined helps to bring teams together and support collaboration outside of silos. The development of the workgroup is a significant part of the process by which representatives buy into the shared mission and work collectively to overcome data sharing barriers.

State departments and divisions may have existing MOU and data sharing agreement templates, as well as processes that require review and approval at multiple levels of government. Some states may also utilize internal or external Institutional Review Boards; this process may require an ethical review board to determine that the data sharing falls within research study standards and to ensure the protection of confidential information. Political and departmental concerns may exist since priorities may change as social, political, and economic environments shift. Ongoing communication and collaboration are necessary to







determine how to approach the workgroup recognizing potential constraints in the environment, such as staff capacity or funding. The development and subsequent approval of the MOU or data sharing agreement may be a long process and require the input of representatives from all relevant state leadership, pointing again to the necessity of collaboration.

See *Appendix E* and the [Urban Institute's Understanding Community Resources: A Tool for Data Landscaping](#).

Employ Strategies to Collect and Share Data Cross-Collaboratively

This section provides information on how to collect and share data across sectors and within an equity lens. Also included are critical data elements for assessing the incidence and effect of infant PSE. If opportunities exist to collect data from programs or systems to support pregnant and postpartum people affected by substance use, it is important to choose outcome variables that reflect the current literature on what matters.^{3,4,5,6,7}

Strategies that help collect data related to both Five R outcomes and PSE do exist. The quality of the data determines the ability to make sound decisions; this process requires comprehensive, complete, and timely data.

<p>Focus on data literacy: </p> <p>What do the concepts mean? For example, how is recovery defined? Is there a shared and collective understanding among partners of how the variables are defined?</p>	<p>Focus on the prenatal period: </p> <p>Which community agencies are collecting data during the prenatal and postpartum periods? What data are currently being collected?</p>	<p>Examine methodology: </p> <p>How can qualitative data increase understanding? What contextual and nuanced information is not currently available? Beyond examining what service elements and features help children remain at home, qualitative data can allow for a deeper understanding of the mechanism (e.g., the relationship between the case worker and the pregnant person). What are the potential benefits and challenges of mixed-methods data collection?</p>
<p>Unit of measurement: </p> <p>On what level are data collected? Collecting data at the state or community level is recommended so that data better reflect local challenges.</p>	<p>Timeframe matters: </p> <p>How can data across different time intervals be shared and compared?</p>	
<p>Linkages: </p> <p>How can data across systems link to measure the Five Rs? What technical challenges exist?</p>		

These questions can be explored further with the use of a data landscaping tool, as described previously. See *Appendix E* for more information.



Establish Shared Outcomes

Children and Family Futures' Five Rs outline the shared outcomes that affect families at the intersection of SUD treatment and child welfare. These identified outcomes include

- ▶ **Recovery:** Is timely access to treatment available for all in need? How long do they engage in treatment? Are they able to successfully complete treatment?
- ▶ **Remain at Home:** Are children able to remain at home rather than be placed in out-of-home care?
- ▶ **Reunification:** Are children reunited with their parents in a timely manner if removal is necessary?
- ▶ **Repeat Maltreatment:** Do children experience repeat maltreatment?
- ▶ **Re-entry:** Do reunified children experience reentry into out-of-home care?

For more information on the Five Rs and how they have been implemented in programming, see the [Comprehensive Framework to Improve Outcomes for Families Affected by Substance Use Disorders and Child Welfare Involvement](#).

The **Social Determinants of Health** (SDOH) is another helpful frame to examine when considering what variables to collect to understand the scope of service need for families affected by PSE and to conduct program evaluation. The U.S. Department of Health and Human Services (HHS) defines SDOH as “the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning and quality-of-life outcomes and risks.” The SDOH greatly affect family outcomes,

particularly those of families who interact with multiple systems.

When collecting or examining data, consider incorporating elements that reflect the SDOH framework and acknowledge the connection between the reality of what families affected by PSE experience and the support and resources they need to recover. Some demographic and outcome variables to consider within the SDOH domains may include

- ▶ **Economic Stability:** Employment, Stable Housing, Food Security, Transportation
- ▶ **Education Access and Quality:** Education, Childcare, Early Education Services
- ▶ **Health Care Access and Quality:** Health Insurance, SUD Treatment, Mental and Medical Health, Prenatal Care, Family Planning, Dental Care
- ▶ **Neighborhood and Built Environment:** Access to Technology, Safe Living Places
- ▶ **Social and Community Context:** Community Support, Self-Help Groups, Well-Being

Collect Data Within an Equity Lens

State departments, community agencies, and other partners may already collect much of the outcome and demographic data outlined in the previous section. Collecting data within an equity lens, however, requires a concerted effort to consider the procedures by which data are gathered and the use of inclusive language and practices. Equity can encompass a broad range of factors beyond race and ethnicity to include gender and gender expression, language of origin, household income, medical insurance, and sexual orientation, among others. An equity lens encourages the reflection of intersectionality in data collection, where possible, through the recognition of the interconnected identities of individuals. Simply put, every family affected by PSE has a set of factors or characteristics that are interconnected and represent the experiences of the person. Data collection through an equity lens includes all these identities and the data collection instruments reflect that idea.

How to incorporate inclusive language in data collection

- ▶ Use gender-inclusive language
- ▶ Understand the difference between race and ethnicity
- ▶ Include Tribal affiliation
- ▶ Refrain from using the term “other” when collecting race data

- ▶ Use translated data collection tools and trained bilingual research staff, when possible
- ▶ Understand that words matter and avoid use of stigmatizing language by using person-centered language

An additional tip is to collect “self-report” data while avoiding provider or systems assumptions, when possible. This process will help reduce instances of individuals being mislabeled or misgendered by well-meaning systems and community partners who collect and report data.

For additional information, see Child Trend’s [How to Embed a Racial and Ethnic Equity Perspective Throughout the Research Process](#) and the Robert Wood Johnson Foundation’s [Charting a Course for an Equity-Centered Data System](#). Other helpful resources include the Center for Study of Social Policy’s [Guide to Anti-Racist Data Collection for System Leaders and Data Administrators](#) and the Center for Culturally Responsive Engagement’s [Considerations for Conducting Evaluation Using a Culturally Responsive and Racial Equity Lens](#).

Develop Data Systems Across State Departments and Within the Community for Monitoring

When publicly available data and separate state department administrative data are limited in both their ability to provide an accurate population estimate—and do not capture the necessary community-specific data elements—there exists an opportunity to develop a data system. This integrated system could be outlined as a primary goal of the data workgroup and the details could be described in the MOU or in data sharing agreements.

The development of the system is a step beyond the sharing of data, where the emphasis is on partnering with the other state departments and the community to create a depository. SUD treatment, child welfare, mental health service, and other community-based data can be combined to aid in service delivery and for analysis purposes. Of particular significance is POSC data that may be available from community-based agencies. Linking available data on pregnant and postpartum people is useful on both the individual and aggregate level for service improvement and to obtain better estimates of families affected by PSE.

See *Appendix C* for a template to assist in data collection, organization, and analyses across systems.



Use Data Aggregation to Reduce Barriers to Sharing Data Across Systems

Prohibitions in sharing health records, such as federally mandated by 42 CFR Part 2 and the Health Insurance Portability and Accountability Act (HIPAA), are often cited as a major barrier to sharing data across systems. 42 CFR Part 2 applies to SUD treatment programs that receive federal assistance and seeks to prohibit the inappropriate disclosure of SUD service and treatment records. The statute specifically prohibits sharing of information, referenced as “patient identifying information,” that identifies an individual...

“...as directly or indirectly having a current or past drug or alcohol problem, or as a participant in a Part 2 program.”⁸

Patient identifying information includes names, addresses, social security numbers, fingerprints, and photographs. For more information see [Frequently Asked Questions](#), prepared by the Legal Action Center for SAMHSA and SAMHSA’s [Fact Sheet: SAMHSA 42 CFR Part 2 Revised Rule](#).

HIPAA regulations govern health care providers, health plans, and others.^{9,10} The regulations guard “protected health information” that would either identify an individual or provide a reasonable basis to believe that the information could be used to identify an individual. Protected health information under HIPAA also includes an individual’s physical or mental health condition as well as services provided to the individual.

For more information see The Office of the National Coordinator for Health Information Technology’s [Guide to Privacy and Security of Electronic Health Information](#).

Hence, 42 CFR Part 2 and HIPAA protect information that would identify an individual. As previously noted, developing estimates of families affected by PSE do not require data containing identifying information. Instead, data from health records can be aggregated, *with all identifying information removed*. 42 CFR Part 2, HIPAA, and related state regulations should be considered when developing MOUs and data sharing agreements. A commitment to guarding client identifying information

is fundamental. Collaboratives can include this commitment in documents such as the interagency MOU or data sharing agreement as discussed previously.

Some states have developed policies to facilitate interagency data sharing while ensuring protection of personal information. For example, New Hampshire instituted [Chapter 5-C Vital Records Administration](#),

Integrated Data Systems

Washington State Department of Social and Health Services (DSHS), Research and Data Analysis (RDA) division, Office of Data Analysis (ODA) conducts data analyses across DSHS services and programs. DSHS includes the Behavioral Health Administration that oversees services for adults and children with SUD and mental health conditions, and the Developmental Disabilities Administration that oversees child development services.

The ODA conducts cross-program analyses of data from across DSHS program databases. On a monthly basis, a database of unduplicated individuals served across DSHS programs is developed. The database includes services provided to each individual as well as direct costs associated with the services. ODA also maintains the client registry which is updated daily to coordinate service delivery across DSHS programs. The registry shows which DSHS offices are providing services to each individual.

RDA's Program Research and Evaluation Section (PRES) conducts analyses of administrative data from the various DSHS program databases. The analyses are used for a variety of purposes, including assessment of service usage and gaps and cost-analysis.

RDA collaborates with other state departments including the Washington State Department of Children, Youth and Families (DCYF). Some examples include

- Integrated Client Databases: Contains longitudinal data from over 20 years spanning three state agencies—DSHS, DCYF, and Health Care Authority. The databases help with program evaluation as well as cost-benefit and offset analyses.
- Substance Use Disorder Treatment Penetration among Child Welfare-Involved Caregivers
- Child Welfare and Health Service Trends in Washington State
- Behavioral Health Treatment Needs and Outcomes among Medicaid Enrolled Children in Washington State among Medicaid Enrolled Children in Washington State
- The Allegheny County (PA) Data Warehouse integrates data from a variety of publicly funded services, including child welfare, SUD treatment, mental health, and developmental disability. The warehouse serves a variety of purposes. For example, child welfare staff look up information, such as participation in SUD treatment services, in the warehouse prior to responding to child maltreatment reports. For more information see
- Allegheny County's Data Warehouse: Leveraging Data to Enhance Human Service Programs and Policies
- Allegheny County Data Warehouse

Section 5-C:9 in 2021. The policy pertains to vital records that include birth certificates and other related information. Section 5-C9 includes parameters on disclosure of vital records as well as sharing of statistical data. New Hampshire also modified its certificate of live birth to include items such as prenatal exposure to opioids, stimulants, and other substances.

For more information on the use of vital records as a data source, see [Brief 1: State Data Collection and Reporting Approaches for Infants and Families Affected by PSE](#).



Use Data to Assess Unmet Need

The data collection and sharing process is only purposeful when data are used to understand and assess unmet need. The building of partnerships, data workgroups, and data systems—and the breakdown of barriers across these systems—allows for more precise population estimates and better understanding of how PSE affects families. How can collaboratives examine these data to uncover patterns and trends across systems regarding service delivery and need? What does it mean to examine these data within an equity lens?

Examine Data Within an Equity Lens

Documented disparities in access to critical services, differential treatment of pregnant people, and systemwide structural barriers exist that affect prenatal

screening practice, access to prenatal care, and child welfare outcomes. For example, studies show Native American and Black women admitted to hospitals for childbirth are more likely to receive a drug test.¹¹ In a study of approximately 8,500 births, Black women were 1½ times more likely to be tested for substance use despite equivalent rates of positive toxicology results among Black women and those of other racial/ethnic background.

Factors contributing to disproportionate administration of toxicology testing include risk-based protocols in which

pregnant and postpartum women are selected for SUD screening or testing based on a set of risk factors,

such as inconsistent (or lack of) prenatal care.¹² Various structural barriers, such as English-only services, impede access to prenatal care for racial, ethnic, and other groups.¹³ Black and Latinx individuals experience more barriers to prenatal care, including difficulty taking time off from work, and a lack of insurance, when compared to White women.¹⁴ These findings highlight the complex interplay of factors that underpin structural inequities—and call for a commitment to reducing these inequities—particularly due to the serious consequences. Black children are more likely to be removed from parental care while both Native American and African American families experience the highest rates of parental termination among all racial and ethnic groups.^{15,16} A data-driven approach remains critical to ending these disparities.

These documented disparities require an examination of key data points—service access, entry, engagement, and outcome—disaggregated by race, ethnicity, medical insurance, household income, and other factors. The disaggregation of data allows leaders from all key sectors to understand how inequity and disproportionality affects the families in their state or community. Inequity may include differential treatment in drug testing, structural barriers to accessing services, and differences in child removal rates among racial and ethnic groups.

- ▶ Understand disproportionality and inequity through data analysis and interpretation
- ▶ Reduce analysis bias by examining implicit bias among data analysts and systems partners
- ▶ Disaggregate data by: 1) multiple demographics, and 2) individual and community-level factors at all stages of interaction



Inequity may include differential treatment in drug testing, structural barriers to accessing services, and differences in child removal rates among racial and ethnic groups.

- ▶ Use discretion in the interpretation of racial and ethnic differences within the data and understand that data may not truly reflect the population affected
- ▶ Visualize data using statistical infographics to identify trends: What are we seeing and what does it mean?
- ▶ Assess the unintended consequences of POSC implementation that could result in disproportionate reporting and separation of families of color: What are the real-world consequences of differential treatment and differential pathways for pregnant and parenting people of color?

For tips on examining implicit bias, see the Children's Bureau's [Language Bias in Child Welfare: Approaches to Identifying and Studying Biased Language to Advance Equitable Child Welfare Practice](#).

Recommend Data-Driven Policy and Practice Changes

Cross-system data sharing is key to understanding the scope of need, but how do partners use the data to institute policy and practice changes? Once trends and patterns are established with the examination of available data, this information can implement policy and practice changes that will help increase: 1) equitable treatment within systems, and 2) access to care for pregnant and postpartum people with SUDs and their families. Below are selected Annie E. Casey Foundation tips on the use of data in decision-making.

Tips for using disaggregated data to inform decision-making

- 1. Convene partners and community members for honest discussion about what the data means**
 - a. Understand how systems and policies maintain structural racism and how families of color are harmed
 - b. Include partners and community members in the discussion and disseminate findings
 - c. Ensure concepts are defined and understood across systems and partners
- 2. Let the disaggregated data speak for themselves**
 - a. Use data as a tool for uncovering inequity
 - b. Focus on specific data elements that will guide decision-making

- c. Identify the specific differences and unintended consequences

3. Use Racial Equity Impact Assessments (REIA)

REIAs are tools to examine how policy and practice decisions will affect individuals within different racial and ethnic groups. The purpose of the REIA is to ensure data-driven decision-making, incorporate the perspectives of all affected, understand the potential unintended consequences of policy or practice changes, and examine all possible options for policy or practice change.

- a. Continue using REIA tools and focus on ongoing examination
- b. Implement a cross-system collaborative approach that engages advocates
- c. Consider all data sources with particular emphasis on the role of qualitative data

4. Determine what policy and practice changes can be implemented

- a. Make decisions on how to adjust and shift existing ways of operating that are harmful
- b. Consider all system interactions and where changes can be made (universal screening practices, outreach to underserved communities, training, collection of POSC data)

See the [Casey Foundation Report: It's Time to Talk: How to Start Conversations about Racial Inequities](#) for more information on engaging in honest conversations. See the [Casey Foundation Report: By the Numbers: Using Disaggregated Data to Inform Policies, Practices, and Decision-Making](#) for more information.

For more information and for sample REIA tools, see the [Casey Foundation Report: Tools for Thought: Using Racial Equity Impact Assessments for Effective Policymaking](#) and [The Center for Racial Innovation Report: Race Equity Impact Assessment](#).

Use Data Visualization as a Tool for Ongoing Monitoring and Change

A data dashboard is one tool by which partners can engage in ongoing service coordination, monitor family well-being and outcomes across systems, and identify disparities to fill gaps in service. Outcomes to continuously monitor and track across time may include SUD treatment entry, engagement and recovery,

maternal and infant health, and rates of infant removal and reunification. The 5 Rs, as described previously, can serve as a useful guide for what outcomes to include when examining the effect of PSE on children and families.

The data dashboard allows for monitoring of data disaggregated by race, ethnicity, community, and any other variables that are identified as demographic or service variables related to disproportionality or inequity. Knowing the community—and including individuals with lived experience in the process from initial development—helps partners identify what data to include. A feature of the data dashboard is its availability and accessibility

to partners from the community and across systems, government, and the general public. Sharing the data widely allows for better coordination of services, the breakdown of silos in treatment and community agencies, and the opportunity for data informed discussion on implementing practical policy and practice changes. Government agencies, elected officials, and others may also use the dashboard to assess the need for specific program funding allocation and the sustainability of existing programs and services.

The data workgroup, or similarly organized committee, may work to develop and release the dashboard collaboratively. The development of a data dashboard may require concerted time

and effort, as well as dedicated human and financial resources to develop and maintain. It is not necessary for the data workgroup to wait until the completion of a data dashboard to make recommendations for policy and practice changes. Other forms of storytelling and data visualization are powerful tools to identify gaps in service and facilitate discussion.

For information on developing a data dashboard, see [Data science empowering the public: Data-driven dashboards for transparent and accountable decision-making in smart cities](#). For a state-level data dashboard example, see the [Massachusetts State Neonatal Abstinence Syndrome Data Dashboard](#).



Engage in an Ongoing Data and Practice Feedback Loop

The continuous monitoring of data and the implementation of process evaluation practices that treat data collection and analysis as ongoing are necessary to remain aware of what is happening in communities and states regarding PSE. Policy and practice changes over time may require revisions to data collection tools, open new mechanisms for data sharing, and introduce new partners. The implementation of an ongoing process of data monitoring and sharing allows for: 1) more accurate estimates of the number of families affected by PSE, and 2) a better understanding of the effect of existing services on family outcomes.



Sharing the data widely allows for better coordination of services, the breakdown of silos in treatment and community agencies, and the opportunity for data informed discussion on implementing practical policy and practice changes.



SECTION II: Common Challenges Encountered in Cross-Sector Data-Driven Approaches

Various challenges can impede establishment of estimates of need. Identifying the common challenges to implementing a data-driven approach allows cross-system partners to discuss and discover potential solutions to increase data sharing and monitoring efforts.

Variations Across Data Systems

Systems that house data are often independent of each other and remain generally inaccessible across service sectors.

- ▶ Child welfare data are typically collected in a state **Comprehensive Child Welfare Information System** (CCWIS) and subsequently reported to a federal system. Data on child maltreatment reports and investigations are reported to the federally sponsored **National Child Abuse and Neglect Data System** (NCANDS).¹⁷ Information on children placed in out-of-home care is reported to the **Adoption and Foster Care Analysis and Reporting System** (AFCARS), which is also a federally sponsored initiative.¹⁸ There is variability of data reported across states—often due to the differences between what information is collected and how it is recorded in state child welfare information systems.
- ▶ Child welfare data collected at the local level, such as in the CCWIS, may be more complete and provide more detail compared to data available from the federal systems. For example, states are required to include the primary reason for child removal to AFCARS. Secondary reasons and other factors contributing to removal may be available in state CCWIS or other systems. For instance, states may collect data on PSE and parental substance use in their CCWIS and may map this information to NCANDS and AFCARS in the maltreatment categories of neglect or physical abuse.
- ▶ SUD treatment agencies report information on admissions and discharges from publicly funded SUD treatment programs to the federally administered **TEDS**.¹⁹
- ▶ Data based on standardized surveys administered to pregnant and postpartum people are available in the **PRAMS**, an initiative of the Centers for Disease

Control and Prevention (CDC) and state health departments. Nearly four dozen participating states and other jurisdictions administer a core survey that includes items on alcohol and cigarette use. Some states participate in supplementary surveys that specifically inquire about the use of prescription opioids or cannabis.

- ▶ **Alliance for Innovation on Maternal Health (AIM) Safety Bundle for Opioid Use Disorder:** Many hospitals are implementing this set of strategies to improve care for families affected by PSE. Performance measures include length of stay for opioid-exposed newborns, parent engagement in treatment, reporting to child welfare agencies, and infants discharged home with parent(s).

Missing or Incomplete Data

Some of the key data elements necessary to establish estimates are missing or incomplete due to absence of, or variation in, data collection requirements and protocols. For example, parental substance use as a factor in child maltreatment cases is not a federally required data element. More recently, CARA amended CAPTA so that states must report annually, to the maximum extent practicable, the number of infants with PSE who received a notification from a health care provider to child welfare, the number of infants for whom

POSC was developed, and the number of infants (and affected family or caregivers) who received a referral for appropriate services.²⁰ As the amendments were issued fairly recently, states may still be developing or modifying data systems and data collection protocols. Currently available data may not accurately represent the number of infants with PSE in a state or jurisdiction.

See [Brief 1: State Data Collection and Reporting Approaches for Infants and Families Affected by PSE](#) for discussion on state child welfare systems data.

Variation in Practices

Variation in screening and other service delivery protocols contribute to challenges in establishing population estimates. The [American College of Obstetricians and the American Society of Addiction Medicine](#) recommends unbiased universal screening for SUDs and engagement into services and treatment as components of comprehensive obstetric care. However, maternal health providers often report challenges determining how and where to refer pregnant people for substance use services. As a result, data based on prenatal screening may be sparse. Other data sources can help establish a baseline estimate of pregnant people with SUDs. These include the previously noted CDC [PRAMS](#) data.²¹

Appendix A: Key Populations Affected by PSE: Data Points

Key Data Points by Population In each of the populations, incorporate demographic and outcome variables, such as those based on the Social Determinants of Health (SDOH).	
Population	Key Data Points
Population 1: Pregnant and Postpartum People with a SUD	Pregnant and postpartum people <ul style="list-style-type: none"> • With a SUD • With a POSC or prenatal POSC • Engaged into SUD assessment and treatment services, including medication-assisted treatment and residential family-centered treatment (children reside with parents) Maternal mortality data during pregnancy and 6 months postpartum
Population 2: Infants	The number of infants with PSE, and their length of hospital stay, as well as <ul style="list-style-type: none"> • The number received pharmacological or non-pharmacological interventions for PSE • The number have a POSC • The number referred to early intervention services • The number engaged in early intervention services • The number referred to child welfare; received a child welfare response; remain in or have been removed from parental care; and have reunified or received other permanent placement, have experienced repeat maltreatment
Population 3: Children in Primary or Middle School	The estimated number of these children with PSE and those referred for early intervention screening and assessment services.
Population 4 and 5: Adolescents and Young Adults	An estimated number of adolescents and young adults with PSE who have received SUD prevention or treatment services.

Appendix B: Sample Data Sources

This appendix includes three tables:

Table 1: Data Sources for *Population 1: Pregnant and Postpartum People with SUDs*

Table 2: Data Sources for *Population 2: Infants with PSE*

Table 3: Data Sources for *Populations 3, 4, and 5: Children, Adolescents, and Young Adults*

Table 1: Data Sources for Population 1: Pregnant and Postpartum People with SUDs*		
NATIONAL DATA SOURCES		
Source	Description	Pertinent Data and How to Access
National Survey on Drug Use and Health (NSDUH)	Administered annually to a representative sample of persons 12+ in the civilian noninstitutionalized population in all 50 states and the District of Columbia under the umbrella of SAMHSA	National 2016-2019 data on past month substance use by pregnant women: SAMHSA, 2019 National Survey on Drug Use and Health: Women
Treatment Episode Data Set (TEDS)	A national data system that annually compiles information from states on publicly funded SUD treatment programs for persons 12+	Data includes national and state pregnancy admissions and treatment outcomes of pregnant admissions (e.g., program completion). These data are typically housed in state SUD treatment data systems and are also available from SAMHSA .
STATE DATA SOURCES		
TEDS	See above	See above
Pregnancy Risk Assessment Monitoring System (PRAMS)	A CDC initiative. Data are from questionnaires administered to pregnant and postpartum people. Forty-six states, the District of Columbia, New York City, Northern Mariana Islands, and Puerto Rico participate in PRAMS. The core questionnaire administered by all participating jurisdictions includes items on alcohol and cigarette use.	Some participating jurisdictions administer supplemental questionnaires, including Marijuana & Prescription Drug Supplement and Prescription Opioid Use. PRAMS data are typically available in state public health agency data systems. Data from the 2019 Prescription Opioid Use Supplement is available in a 2021 CDC study. The data, based on 32 states and jurisdictions, found 6.6% of women reported opioid use during pregnancy. Of those, almost 30% indicated wanting or needing to decrease or stop their use of prescription opioids, while approximately 20% reported misuse. These data may help develop baseline estimates on pregnant people with opioid and other SUDs.
ADDITIONAL DATA SOURCES TO EXPLORE		
TEDS	See above	See above
PRAMS	See above	See above
International Classification of Diseases (ICD) Codes	International standards developed by the World Health Organization. ICD codes serve a variety of purposes, including coding of diagnoses in patient records.	ICD data is typically available in Medicaid or other insurance systems. Key ICD codes pertaining to pregnant people with SUDs: ICD-9-CM Codes <ul style="list-style-type: none"> ▪ Opioid Dependence: 304.00-304.02, 304.70-304.72 ▪ Non-Dependent Opioid Abuse: 305.50-305.52 ICD-10-CM Codes* <ul style="list-style-type: none"> ▪ Opioid Dependence: F11.20, F11.22-F11.29 ▪ Non-Dependent Opioid Abuse: F11.10, F11.12-F11.19 ▪ Long-Term Use of Opioid Analgesics: Z79.891 ▪ Unspecified Opioid Use: F11.90-F11.99 * <i>The ICD codes have been revised to reflect developments in the medical field, with the most recent revisions reflected in ICD-10-CM.</i>
Certificate of Live Birth	A nationally standardized CDC form completed by birth hospitals and submitted to Vital Records	The Certificate of Live Birthform includes demographic information on the parents and infant, prenatal health history, prenatal risk factors, and prenatal exposure to smoking. Some states have incorporated prenatal exposure to other substances in the form (e.g., “known or self-reported non-prescribed or illicit drug use during pregnancy”). Aggregated data are typically available in state health data systems and may help establish baseline estimates of pregnant people with SUDs.

*See also [Centers for Disease Control and Prevention Maternal Mortality Rates in the United States, 2020](#) and [Alliance for Innovation on Maternal Health \(AIM\) Safety Plan, Care for Pregnant and Postpartum People with Substance Use Disorder](#).

Table 2: Data Sources for Population 2, Infants with PSE

NATIONAL DATA SOURCES		
Source	Description	Pertinent Data and How to Access
National Survey on Drug Use and Health (NSDUH)	Administered annually to a representative sample of persons 12+ in the civilian noninstitutionalized population in all 50 states and the District of Columbia under the SAMHSA umbrella	National 2016-2019 data on past month substance use by pregnant women is available at SAMHSA, 2019 National Survey on Drug Use and Health: Women and could help estimate the number of infants with PSE.
STATE DATA SOURCES		
Pregnancy Risk Assessment Management System (PRAMS)	A CDC initiative. Data are from questionnaires administered to pregnant and postpartum people. Forty-six states, the District of Columbia, New York City, Northern Mariana Islands, and Puerto Rico participate in PRAMS. The core questionnaire administered by all participating jurisdictions includes items on alcohol and cigarette use.	PRAMS data are typically available in state public health agency data systems. Some participating jurisdictions administer supplemental questionnaires, including Marijuana & Prescription Drug Supplement and Prescription Opioid Use . Data from the 2019 Prescription Opioid Use Supplement is available in a 2021 CDC study . The data, based on 32 states and other jurisdictions, found 6.6% of women reported opioid use during pregnancy. Of those, almost 30% indicated wanting or needing to decrease or stop their use of prescription opioids, and approximately 20% reported misuse. These data could be informative in developing baseline estimates on infants with prenatal opioid and other substance exposure.
Child Maltreatment Report (2021)	Based on National Child Abuse and Neglect Data System (NCANDS) data and published annually by the Administration for Children and Families, Administration on Children, Youth and Families, Children's Bureau.	The report includes state-specific information on a variety of topics, including POSC as reported by state child welfare agencies. It also includes the number of infants with PSE reported to child welfare, those that received a child welfare assessment or investigation, those who have POSC, and those who received a referral to services. The previously described information may be available in state child welfare data systems; NCANDS data is available by request from the National Data Archive on Child Abuse and Neglect .
Rate of NAS per 1,000 Newborn Hospitalizations	2010-2020 state rates of infants with a NAS diagnosis, based on ICD codes. Data maintained by the Agency for Health Care Research and Quality, Healthcare Cost and Utilization Project (AHCRO, HCUP)	Click here to access: State rates of NAS per 1,000 newborn hospitalizations, 2010-2020

ADDITIONAL DATA SOURCES TO EXPLORE		
NCANDS child welfare data	See above Child Maltreatment Report 2021.	Typically available in state child welfare data systems
International Classification of Diseases (ICD) Codes	<p>International standards developed by the World Health Organization</p> <p>ICD codes serve a variety of purposes, including coding of diagnoses in patient records.</p>	<p>ICD data is typically available in Medicaid or other insurance systems. Key ICD codes pertaining to infants with PSE:</p> <p>ICD-10-CM* Codes</p> <ul style="list-style-type: none"> ▪ P04.14: Newborn affected by maternal use of opiates ▪ P04.13: Newborn affected by maternal use of anticonvulsants ▪ P04.15: Newborn affected by maternal use of antidepressants ▪ P04.16: Newborn affected by maternal use of amphetamines ▪ P04.17: Newborn affected by maternal use of sedative-hypnotics ▪ P04.2: Newborn affected by maternal use of tobacco ▪ P04.3: Newborn affected by maternal use of alcohol ▪ P04.41: Newborn affected by maternal use of cocaine ▪ P04.42: Newborn affected by maternal use of hallucinogens ▪ P04.49: Newborn affected by maternal use of other drugs of addiction ▪ P04.81: Newborn affected by maternal use of cannabis ▪ P96.1: Neonatal Withdrawal symptoms from maternal use of drugs of addiction ▪ Q86.0: Fetal alcohol syndrome (dysmorphic) <p><i>* The ICD codes have been revised to reflect developments in the medical field, with the most recent revisions reflected in ICD-10-CM.</i></p>
Certificate of Live Birth	A nationally standardized CDC form completed by birth hospitals and submitted to Vital Records	<p>The Certificate of Live Birth form includes demographic information on the parents and infant, prenatal health history, prenatal risk factors, and prenatal exposure to smoking. Some states have incorporated prenatal exposure to other substances into the form (e.g., "known or self-reported non-prescribed or illicit drug use during pregnancy").</p> <p>Aggregate data are typically available in state health data systems and may help establish baseline estimates of pregnant people with a SUD.</p>

Table 3: Data Sources for Populations 3,4,5 Children, Adolescents, and Young Adults

NATIONAL DATA SOURCES		
Source	Description	Pertinent Data and How to Access
National Survey on Drug Use and Health (NSDUH)	Administered annually to a representative sample of persons 12+ in the civilian noninstitutionalized population in all 50 states and the District of Columbia under the SAMHSA umbrella	National 2017-2020 data on alcohol and substance use by adolescents (12-17) and young adults (18-25) are available here . National 2016-2019 data on past month substance use by pregnant women is available at SAMHSA, 2019 National Survey on Drug Use and Health: Women and could be used to develop a <i>broad</i> baseline estimates of children, adolescents, and young adults with PSE.
STATE DATA SOURCES		
Youth Risk Behavior Surveillance System (YRBSS)	A CDC initiative that includes a national school-based survey and local surveys	State data from 2019, including children and adolescent substance use, are available from the Middle School Youth Risk Behavior Survey and High School Youth Risk Behavior Survey . Data from other jurisdictions, including some tribal communities, U.S. Territories, and large metropolitan areas are also available. See YRBSS Current Participation Maps and Participation History .
Pregnancy Risk Assessment Management System (PRAMS)	A CDC initiative. Data come from questionnaires administered to pregnant and postpartum people. Forty-six states, the District of Columbia, New York City, Northern Mariana Islands, and Puerto Rico participate in PRAMS. The core questionnaire administered by all participating jurisdictions includes items on alcohol and cigarette use.	Similar to the NSDUH data, PRAMS data could be used to develop estimates of children, adolescents, and young adults with PSE. Some participating jurisdictions administer supplemental questionnaires, including Marijuana & Prescription Drug Supplement and Prescription Opioid Use. PRAMS data are typically available in state public health agency data systems. Data from the 2019 Prescription Opioid Use Supplement is available in a 2021 CDC study. The data, based on 32 states and other jurisdictions, found 6.6% of women reported opioid use during pregnancy. Of those, almost 30% indicated wanting or needing to decrease or stop their use of prescription opioids while approximately 20% reported misuse. These data could be informative in developing baseline estimates on children, adolescents and young adults with prenatal opioid and other substance exposure.
Rate of NAS per 1,000 Newborn Hospitalizations	2010-2020 state rates of infants with a NAS diagnosis, based on ICD codes. Data maintained by the Agency for Health Care Research and Quality, Healthcare Cost and Utilization Project (AHCQR, HCUP)	Similar to the NSDUH and PRAMS data, state NAS rates could be used to develop a broad estimate of children, adolescents, and young adults with PSE. Click here to access: State rates of NAS per 1,000 newborn hospitalizations, 2010-2020

ADDITIONAL DATA SOURCES TO EXPLORE		
<p>International Classification of Diseases (ICD) Codes</p>	<p>International standards developed by the World Health Organization. ICD codes serve a variety of purposes, including coding of diagnoses in patient records.</p>	<p>Similar to the NSDUH, PRAMS, and state NAS rates, data based on ICD codes could be used to develop a broad baseline estimate of children, adolescents, and young adults with PSE.</p> <p>ICD data is typically available in Medicaid or other insurance systems. Key ICD codes pertaining to infants with PSE</p> <p>ICD-10-CM* Codes</p> <ul style="list-style-type: none"> • P04.14: Newborn affected by maternal use of opiates • P04.13: Newborn affected by maternal use of anticonvulsants • P04.15: Newborn affected by maternal use of antidepressants • P04.16: Newborn affected by maternal use of amphetamines • P04.17: Newborn affected by maternal use of sedative-hypnotics • P04.2: Newborn affected by maternal use of tobacco • P04.3: Newborn affected by maternal use of alcohol • P04.41: Newborn affected by maternal use of cocaine • P04.42: Newborn affected by maternal use of hallucinogens • P04.49: Newborn affected by maternal use of other drugs of addiction • P04.81: Newborn affected by maternal use of cannabis • P96.1: Neonatal Withdrawal symptoms from maternal use of drugs of addiction • Q86.0: Fetal alcohol syndrome (dysmorphic) <p><i>* The ICD codes have been revised to reflect developments in the medical field, with the most recent revisions reflected in ICD-10-CM.</i></p>
<p>Certificate of Live Birth</p>	<p>A nationally standardized CDC form completed by birth hospitals and submitted to Vital Records.</p>	<p>Similar to the above data sources, information from Certificates of Live Birth could be used to understand the number of children, adolescents, and young adults with PSE.</p> <p>The Certificate of Live Birth form includes demographic information on the parents and infant, prenatal health history, prenatal risk factors, and prenatal exposure to smoking. Some states have incorporated prenatal exposure to other substances into the form (e.g., “known or self-reported non-prescribed or illicit drug use during pregnancy”).</p> <p>Aggregate data are typically available in state health data systems and may help establish estimates of pregnant people with an SUD.</p>

Appendix C: Sample Data Template

This appendix includes sample data templates for the five populations affected by PSE.

- ▶ Data Template 1: *Population 1: Pregnant and Postpartum People with SUDs*
- ▶ Data Template 2: *Population 2: Infants with PSE (Tables A, B, and C)*
 - Table A: *Estimated Infants with PSE*
 - Table B: *Estimated Infants with PSE Who Received Services*
 - Table C: *Estimated Infants with PSE, Removed From or Remained in Parental Care, and Reunified or Other Permanent Placement*
- ▶ Data Template 3: *Populations 4 and 5: Adolescents and Young Adults with PSE and in Need of Special Education and SUD Treatment Services*

Data Template 1, Population 1: *Pregnant and Post-partum People with SUDs*

Column A	Column B	Column C	Column D	Column E
Number of Annual Births^a Insert state or other jurisdiction annual births.	Percent of Pregnant People with SUDs^b	Estimated Number of Pregnant People with SUDs	Number of Pregnant People Who Enter SUD Treatment^c	Estimated Percent of Pregnant People with SUD and Treatment
	Insert the percentage of affected people, based on the data source.	Insert the result of Column B multiplied by Column A.	Insert number based on data source.	Insert the result of Column D divided by Column C.
	Insert additional rows for each data source. ^d	Insert additional rows for each data source.	Insert additional rows for each data source.	Insert additional rows for each data source.

Table Notes

- a: Sample data sources include the Annie E. Casey Foundation Kids Count Data Center. See above for more information.
- b: Sample data sources include the NSDUH, PRAMS, and ICD Codes. See above for more information.
- c: Sample data sources include TEDS. See above for more information.
- d: Data analyses based on different sources can help understand the SUD treatment needs of pregnant people. For instance, analyses of pregnant people who enter treatment based on ICD diagnostic codes will highlight the rate of those with a diagnosis who were able to access treatment. It does not include the number of pregnant people who have a SUD and were unable to access services for a clinical assessment, or the number of pregnant people unable to enter treatment due to barriers such as lack of residential facilities for parents and children.

Data Template 2, Population 2: Infants with PSE (Tables, A, B, and C)

Table A: Estimated Infants with PSE		
Column A	Column B	Column C
Number of Annual Births^a Insert state or other jurisdiction annual births.	Percent of Infants with PSE^b	Estimated Number of Infants with PSE
	Insert the percentage of infants with PSE, based on the data source.	Insert the result of Column B multiplied by Column A.
	Insert additional rows for each data source.	Insert additional rows for each data source.

Table Notes

a: Sample data sources include the Annie E. Casey Foundation Kids Count Data Center. See above for more information.

b: Sample data sources include AHCRO, HCUP; NSDUH; and data based on ICD codes. See above for more information.

Table B: Estimated Infants with PSE and Received Services								
Column A	Column B	Column C	Column D	Column E	Column F	Column G	Column H	Column I
Estimated Number of Infants with PSE	Number of Infants Who Received a CAPTA Notification to Child Welfare^a	Estimated Percent of Infants with PSE Who Received a CAPTA Notification	Number of Infants Who Received a POSC^a	Estimated Percent of Infants Who Received a POSC	Number of Infants Referred to IDEA, Part C^a or Other Referral Source for Early Intervention	Estimated Percent of Infants Referred to IDEA, Part C, or other referral source for Early Intervention	Number of Infants Received Early Intervention Service	Estimated Percent of Infants Received Early Intervention Services
Insert results from Table A.	Insert based on data source.	Insert the result of Column B divided by Column A	Insert based on data source.	Insert result of Column D divided by Column A.	Insert based on data source.	Insert result of Column F divided by Column A.	Insert based on data source.	Insert result of Column H divided by Column A.
Insert additional rows for each additional data source. ^b								

Table Notes

a: Sample data sources include the federally published Child Maltreatment Report. See above for details.

b: For instance, each row in the table would detail the different rates of infants who received Plan of Safe Care, based on the different estimated total number of infants with PSE, such as those with a diagnosis and those with exposure and without a diagnosis. This information could help understand gaps in available service for infants with PSE.

Table C: Estimated Infants with PSE, Removed or Remained in Parental Care, and Reunified or Other Permanent Placement										
Column A	Column B	Column C	Column D	Column E	Column F	Column G	Column H	Column I	Column J	Column K
Estimated Number of Infants with PSE ^a	Number of Infants Screened in for Child Welfare Assessment ^b	Estimated Percent of Infants Screened in for Child Welfare Assessment	Number of Infants Who Received Child Welfare Assessment ^b	Estimated Percent of Infants Who Received Child Welfare Assessment	Number of Infants Removed from Parental Care ^c	Estimated Percent of Infants Removed from Parental Care	Number of Infants Reunified or other Permanent Placement ^c	Estimated Percent of Infants Reunified or Other Permanent Placement	Number of Infants with Recurrence of Maltreatment ^c	Estimated Percent of Infants with Recurrence of Maltreatment
Insert results from Table A.	Insert based on data source.	Insert result of Column B divided by Column A.	Insert based on data source.	Insert result of Column D divided by Column B.	Insert based on data source.	Insert result of Column F divided by Column D.	Insert based on data source.	Insert result of Column G divided by Column F.	Insert based on data source.	Insert result of Column J divided by Column H.
Insert additional rows for each additional data source.										

Table Notes

a: The population base (total estimated infants with PSE) is suggested as a first step in this table and serves as an example. Analyses using all infants with PSE can be helpful in identifying gaps in services. For example, states and other jurisdictions may want to explore pertinent practices and protocols if the analyses indicate a small percentage of the state's total estimated population of infants with PSE receive a child welfare investigation or assessment. Exploratory questions include: Was a family assessment conducted to determine whether a notification or report should be made to child welfare services? When families are not reported, or notification is not made to child welfare, are they connected to services? Particularly, early intervention services for screening of developmental delays among infants.

The suggested population base in the subsequent steps in the table is based on key service points in the child welfare investigation/assessment and case management process. Analyses based on this information would also help identify service gaps. For example, if there is a large percentage of infants with PSE who removed from parental care, exploratory questions include: What factors determine removal of infants from parental care? What are the permanency outcomes for infants removed from parental care?

b: Data sources include NCANDS and the federally published Child Maltreatment Report. See above for details.

c: Data sources in AFCARS and state child welfare data systems

Population 3: Children with PSE and In Need of Early Intervention and Special Education Services

Column A	Column B	Column C	Column D	Column E
Number of Children^a Insert state or other jurisdiction number of children.	Percent of Children with PSE ^b	Estimated Number of Children with PSE	Percent of Children with PSE Who Need Early Intervention and Special Education Services^c	Estimated Number Children with PSE Who Need Early Intervention and Special Education Services
	Insert the percentage of children with PSE, based on the data source.	Insert the result of Column B multiplied by Column A.	Insert the percentage, based on data source.	Insert the result of Column D multiplied by Column A.
	Insert additional rows for each data source.			

Table Notes

- a: Data sources include the Missouri Census Data Center that provides data child population data. The data can be customized by different age groups. See above for details.
- b: Proxy data sources include NSDUH, which provides estimates of the percentage of pregnant women who report substance use. See above for details.
- c: Proxy data can be based on research literature. See above for details.

Data Template 3, Populations 4 and 5: Adolescents and Young Adults with PSE and in Need of Special Education and SUD Treatment Services

Column A	Column B	Column C	Column D	Column E	Column F	Column G	Column H	Column I
Number of Adolescents and Young Adults ^a Insert state or other jurisdiction number of children.	Percent of Adolescents and Young Adults with PSE ^b	Estimated Number of Adolescents and Young Adults with PSE	Percent of Adolescents and Young Adults with PSE Who Need Special Education Services ^c	Estimated Number Adolescents and Young Adults with PSE Who Need Special Education Services	Percent of Adolescents and Young Adults Who Need SUD Treatment ^d	Estimated Number of Adolescents and Young Adults Who Need SUD Treatment	Percent of Adolescents and Young Adults Entering SUD Treatment ^e	Estimated Number of Adolescents and Young Adults Entering SUD Treatment
	Insert the percentage of children with PSE, based on the data source.	Insert the result of Column B multiplied by Column A.	Insert the percentage, based on data source.	Insert the result of Column D multiplied by Column A.	Insert the percentage, based on data source.	Insert the result of Column F multiplied by Column A.	Insert the percentage, based on data source.	Insert the result of Column H multiplied by Column A.
	Insert additional rows for each data source.							

Table Notes

- a: Data sources include the Missouri Census Data Center that provides child population data. The data can be customized by different age groups. See above for detail.
- b: Proxy data sources include NSDUH which provides estimates of the percentage of pregnant women who report substance use. See above for detail.
- c: Proxy data can be based on research literature. See above for detail.
- d: Data sources include YRBSS and NSDUH. See above for detail.
- e: Data sources include TEDS. See above for detail.

Appendix D: PSE Data Disproportionality Worksheet

DATA ELEMENT	DATA						
	Metric	Race/ Ethnicity		%	Source	Time Period*	Explanation (if data not avail.)
POPULATION-LEVEL DATA							
Number of children in STATE**	Total	Ethnicity					
		Hispanic/Latino					
		Non Hispanic/Latino					
		TOTAL					
		Race					
		African American					
		Asian American					
		Caucasian					
		Hispanic					
		Hispanic Non-Latino					
		Native American-Alaska Native					
		Native Hawaiian or Other Pacific Islander					
		Two or more races					
		TOTAL					

(Continued)

DATA ELEMENT	DATA						
	Metric	Race/ Ethnicity		%	Source	Time Period*	Explanation (if data not avail.)
CHILD WELFARE DATA							
1. Total number of notifications and total number of reports of infants to Child Welfare	Notifications	<i>Ethnicity</i>					
		Hispanic/Latino					
		Non Hispanic/Latino					
		TOTAL					
		<i>Race</i>					
		African American					
		Asian American					
		Caucasian					
		Hispanic					
		Hispanic Non-Latino					
		Native American-Alaska Native					
		Native Hawaiian or Other Pacific Islander					
		Two or more races					
	TOTAL						
	Reports	<i>Ethnicity</i>					
		Hispanic/Latino					
		Non Hispanic/Latino					
		TOTAL					
		<i>Race</i>					
		African American					
		Asian American					
		Caucasian					
Hispanic							
Hispanic Non-Latino							
Native American-Alaska Native							
Native Hawaiian or Other Pacific Islander							
Two or more races							
TOTAL							
TOTAL							

(Continued)

DATA ELEMENT	DATA						
	Metric	Race/ Ethnicity		%	Source	Time Period*	Explanation (if data not avail.)
2. Type of Maltreatment	<i>Ethnicity</i>						
		Hispanic/Latino					
		Non Hispanic/Latino					
		TOTAL					
	<i>Race</i>						
		African American					
		Asian American					
		Caucasian					
		Hispanic					
		Hispanic Non-Latino					
		Native American-Alaska Native					
		Native Hawaiian or Other Pacific Islander					
		Two or more races					
		TOTAL					
		TOTAL					
3. Type of Substance	<i>Ethnicity</i>						
		Hispanic/Latino					
		Non Hispanic/Latino					
		TOTAL					
	<i>Race</i>						
		African American					
		Asian American					
		Caucasian					
		Hispanic					
		Hispanic Non-Latino					
		Native American-Alaska Native					
		Native Hawaiian or Other Pacific Islander					
		Two or more races					
		TOTAL					
		TOTAL					

(Continued)

DATA ELEMENT	DATA							
	Metric	Race/ Ethnicity		%	Source	Time Period*	Explanation (if data not avail.)	
4. Number screened in/ out (for infants identified as born affected by prenatal exposure to substances)	Screened IN	<i>Ethnicity</i>						
		Hispanic/Latino						
		Non Hispanic/Latino						
		TOTAL						
		<i>Race</i>						
		African American						
		Asian American						
		Caucasian						
		Hispanic						
		Hispanic Non-Latino						
		Native American-Alaska Native						
		Native Hawaiian or Other Pacific Islander						
	Two or more races							
	TOTAL							
	Screened OUT	<i>Ethnicity</i>						
		Hispanic/Latino						
		Non Hispanic/Latino						
		TOTAL						
		<i>Race</i>						
		African American						
		Asian American						
		Caucasian						
		Hispanic						
Hispanic Non-Latino								
Native American-Alaska Native								
Native Hawaiian or Other Pacific Islander								
Two or more races								
TOTAL								
TOTAL								

(Continued)

DATA ELEMENT	DATA						
	Metric	Race/ Ethnicity		%	Source	Time Period*	Explanation (if data not avail.)
5. Disposition (for infants identified as born affected by prenatal exposure to substances)	Substantiated	Ethnicity					
		Hispanic/Latino					
		Non Hispanic/Latino					
		TOTAL					
		Race					
		African American					
		Asian American					
		Caucasian					
		Hispanic					
		Hispanic Non-Latino					
		Native American-Alaska Native					
		Native Hawaiian or Other Pacific Islander					
		Two or more races					
	TOTAL						
	Unsubstantiated	Ethnicity					
		Hispanic/Latino					
		Non Hispanic/Latino					
		TOTAL					
		Race					
		African American					
		Asian American					
		Caucasian					
		Hispanic					
		Hispanic Non-Latino					
		Native American-Alaska Native					
		Native Hawaiian or Other Pacific Islander					
Two or more races							
TOTAL							
TOTAL							

(Continued)

DATA ELEMENT	DATA							
	Metric	Race/ Ethnicity		%	Source	Time Period*	Explanation (if data not avail.)	
6. Number removed, remaining with family (for infants identified as born affected by prenatal exposure to substances)	Removed	<i>Ethnicity</i>						
		Hispanic/Latino						
		Non Hispanic/Latino						
		TOTAL						
		<i>Race</i>						
		African American						
		Asian American						
		Caucasian						
		Hispanic						
		Hispanic Non-Latino						
		Native American-Alaska Native						
		Native Hawaiian or Other Pacific Islander						
		Two or more races						
	TOTAL							
	Remaining w/ Family	<i>Ethnicity</i>						
		Hispanic/Latino						
		Non Hispanic/Latino						
		TOTAL						
		<i>Race</i>						
		African American						
		Asian American						
		Caucasian						
		Hispanic						
Hispanic Non-Latino								
Native American-Alaska Native								
Native Hawaiian or Other Pacific Islander								
Two or more races								
TOTAL								
TOTAL								

(Continued)

DATA ELEMENT	DATA						
	Metric	Race/ Ethnicity		%	Source	Time Period*	Explanation (if data not avail.)
7. Number of infants with Plan of Safe Care	Ethnicity						
		Hispanic/Latino					
		Non Hispanic/Latino					
		TOTAL					
	Race						
		African American					
		Asian American					
		Caucasian					
		Hispanic					
		Hispanic Non-Latino					
		Native American-Alaska Native					
		Native Hawaiian or Other Pacific Islander					
		Two or more races					
		TOTAL					
	TOTAL						
8. Number of infants referred for services (who were identified as being born affected by prenatal exposure to substances)	Ethnicity						
		Hispanic/Latino					
		Non Hispanic/Latino					
		TOTAL					
	Race						
		African American					
		Asian American					
		Caucasian					
		Hispanic					
		Hispanic Non-Latino					
		Native American-Alaska Native					
		Native Hawaiian or Other Pacific Islander					
		Two or more races					
		TOTAL					
	TOTAL						

(Continued)

DATA ELEMENT	DATA						
	Metric	Race/ Ethnicity		%	Source	Time Period*	Explanation (if data not avail.)
9. Number of parents/ caregivers accessing SUD Tx		Ethnicity					
		Hispanic/Latino					
		Non Hispanic/Latino					
		TOTAL					
		Race					
		African American					
		Asian American					
		Caucasian					
		Hispanic					
		Hispanic Non-Latino					
		Native American-Alaska Native					
		Native Hawaiian or Other Pacific Islander					
		Two or more races					
		TOTAL					
TOTAL							
ANNUAL HEALTH DATA ELEMENTS							
10. Number of infants born prenatally exposed to substances as defined by and reported to the state's Department of Health or the state Medicaid office		Ethnicity					
		Hispanic/Latino					
		Non Hispanic/Latino					
		TOTAL					
		Race					
		African American					
		Asian American					
		Caucasian					
		Hispanic					
		Hispanic Non-Latino					
		Native American-Alaska Native					
		Native Hawaiian or Other Pacific Islander					
		Two or more races					
		TOTAL					
TOTAL							
* Please use the same calendar or fiscal year for the data elements							
** Population-level data element is dependent on what makes the most sense for the state (i.e. # of children in state, # in child welfare, # born substance exposed)							

Appendix E: Sample Cross-Sector Data Landscaping Tool

The Urban Institute's *Understanding Community Resources: A Tool for Data Landscaping* provides a data landscaping worksheet to help data workgroups organize and understand what data are available and what can be shared.

Data Landscaping Worksheet

Organization name of data provider or manager	
Staff name, title, and e-mail	
Dataset or datasets managed	Enter the name of the databases/systems your organization is responsible for managing related to the topic above
Description of data	Describe the data you collect. If possible, list summary types of information that might be relevant to the project. Examples include demographic information, entry/exit dates, arrest/booking information (if working in criminal justice), or diagnosis information (if working in health).
Frequency of update	Describe how and when data are entered or updated (e.g., during intake, at arrest, or during client meetings.)
Years of data available	Describe the total time frame of data available.
Unit of analysis	Describe how data appear in the system (e.g., individual)
Identifiers in dataset	Describe what data field provide information for a person's identify that you can link across systems (e.g., name or date of birth)
Individuals responsible for data entry	List the types of people who are responsible for inputting the data, such as caseworkers, police officers, or emergency medical technicians.

Sources

- Administration on Children, Youth and Families, Children's Bureau. (2017). Program instruction ACYF-CB-PI-10-02. U.S. Department of Health and Human Services. <https://www.acf.hhs.gov/sites/default/files/documents/cb/pi1702.pdf>
- Bieretz, B., & Brown, M. (2019). *Understanding Community resources: A tool for data landscaping*. Urban Institute. https://www.urban.org/sites/default/files/publication/101110/understanding_community_resources_a_tool_for_data_landscaping_2.pdf
- Children and Family Futures. (2013). *Regional Partnership Grant (RPG) Program: Final synthesis and summary report*. Prepared for Administration on Children, Youth and Families, Children's Bureau. https://ncsacw.samhsa.gov/files/Final_SSR.pdf
- Children and Family Futures. (2016). *Children affected by methamphetamine program: Implementation progress and performance measurement report*. Prepared for Substance Abuse and Mental Health Services Administration. https://ncsacw.acf.hhs.gov/files/CAM_Final_Report_508.pdf
- Huebner, R. A., Young, N. K., Hall, M. T, Posze, L., & Willauer, T. (2017). Serving families with child maltreatment and substance use disorders: A decade of learning. *Journal of Family Social Work, 4*, 288-305. <https://doi.org/10.1080/10522158.2017.1348110>
- Huebner, R. A., Willauer, T., & Posze, L. (2012). The impact of Sobriety Treatment and Recovery Teams (START) on family outcomes. *Families in Society: The Journal of Contemporary Social Services, 93*(3), 196-203. <https://doi.org/10.1606/1044-3894.4223>
- Huebner, R. A., Posze, L., Willauer, T., & Hall, M. (2015). Sobriety treatment and recovery teams: Implementation fidelity and related outcomes. *Substance Use & Misuse, 50*(10), 1341-1350. <https://doi.org/10.3109/10826084.2015.1013131>
- Legal Action Center for the Substance Abuse and Mental Health Services Administration. (n.d.). *Frequently asked questions: Applying the substance abuse confidentiality regulations to Health Information Exchange (HIE)*. U.S. Department of Health and Human Services. <https://www.samhsa.gov/sites/default/files/faqs-applying-confidentiality-regulations-to-hie.pdf>
- Office for Civil Rights. (2022). *The HIPAA privacy rule*. U.S. Department of Health and Human Services. <https://www.hhs.gov/hipaa/for-professionals/privacy/index.html>
- The Office of the National Coordinator for Health Information Technology. (2015). *Guide to privacy and security of electronic health information. 2.0*. U.S. Department of Health and Human Services. <https://www.healthit.gov/sites/default/files/pdf/privacy/privacy-and-security-guide.pdf>
- Kunins, H. V., Bellin, E., Chazotte, C., Du, E., & Arnsten, J. H. (2007). The effect of race on provider decisions to test for illicit drug use in the peripartum setting. *Journal of Women's Health, 16*(2), 245-255. <https://doi.org/10.1089/jwh.2006.0070>
- The American College of Obstetricians and Gynecologists, American Society of Addiction Medicine. (2017). *Opioid Use and Opioid Use Disorder in Pregnancy. Committee Opinion 711 (Replaces Committee Opinion Number 524, May 2012. Reaffirmed 2021)*. <https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2017/08/opioid-use-and-opioid-use-disorder-in-pregnancy>
- Lange, E., & Toledo, P. (2021). Peripartum racial/ethnic disparities. *International Anesthesiology Clinics, 59*(3), 1-7. <https://doi.org/10.1097/AIA.0000000000000326>
- Fryer, K., Munoz, M., Rahangdale, L., & Stuebe, A. (2020). Multiparous Black and Latinx women face more barriers to prenatal care than White women. *Journal of Racial and Ethnic Health Disparities, 8*(1), 80-87. <https://doi.org/10.1007/s40615-020-00759-x>
- Needell, B., Brookhart, M. A., & Lee, S. (2003). Black children and foster care placement in California. *Children and Youth Services Review, 25*(5-6), 393-408. [https://doi.org/10.1016/S0190-7409\(03\)00028-8](https://doi.org/10.1016/S0190-7409(03)00028-8)
- Wildeman, C., Edwards, F. R., & Wakefield, S. (2020). The cumulative prevalence of termination of parental rights for U.S. children, 2000-2016. *Child Maltreatment, 25*(1), 32-42. <https://doi.org/10.1177/1077559519848499>
- Children's Bureau. (n.d.). *About NCANDS* [Fact sheet]. U.S. Department of Health and Human Services. <https://www.acf.hhs.gov/cb/fact-sheet/about-ncands>
- Children's Bureau, An Office of the Administration for Children & Families. (2023). *Adoption and Foster Care Analysis and Reporting System (AFCARS)*. U.S. Department of Health and Human Services. <https://www.acf.hhs.gov/cb/data-research/adoption-fostercare>
- Substance Abuse and Mental Health Services Administration. (n.d.). *Treatment episode data set (TEDS)*. Rockville, MD. <https://www.samhsa.gov/data/data-we-collect/teds-treatment-episode-data-set>
- Administration on Children, Youth and Families, Children's Bureau. (2017). Program instruction ACYF-CB-PI-10-02. U.S. Department of Health and Human Services. <https://www.acf.hhs.gov/sites/default/files/documents/cb/pi1702.pdf>
- Centers for Disease Control and Prevention. (2023). *What is PRAMS?*. U.S. Department of Health and Human Services. <https://www.cdc.gov/prams/index.htm#:~:text=PRAMS%2C%20the%20Pregnancy%20Risk%20Assessment,during%2C%20and%20shortly%20after%20pregnancy>



CONTACT US



Email NCSACW at
ncsacw@cffutures.org



Visit the website at
<https://ncsacw.acf.hhs.gov>



Call toll-free at
866.493.2758

This resource is supported by contract number 75S20422C00001 from the Children's Bureau (CB), Administration for Children and Families (ACF), co-funded by the Substance Abuse and Mental Health Services Administration (SAMHSA). The views, opinions, and content of this presentation are those of the presenters and do not necessarily reflect the views, opinions, or policies of ACF, SAMHSA or the U.S. Department of Health and Human Services (HHS).



National Center on
Substance Abuse
and Child Welfare



Substance Abuse and Mental Health
Services Administration