



Substance-Exposed Infants:
A Report on Progress in Practice and
Policy Development in States Participating in
A Program of In-Depth Technical Assistance
September 2014 to September 2016

Executive Summary

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Executive Summary

Data from the Substance Abuse and Mental Health Services Administration's (SAMHSA) National Survey on Drug Use and Health show that between 2007 and 2014 the numbers of persons who misuse prescription drugs, new users of heroin, and people with heroin dependence increased significantly (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). As the rates of opioid use and addiction increased among individuals of all ages and backgrounds, it is not surprising that the rates also increased among pregnant women and women of child-bearing age. States also began reporting significant increases in neonatal abstinence syndrome (NAS) and infants manifesting withdrawal symptoms as a result of opioid exposure in utero with higher concentrations in some regions such as the northeast corridor, the Appalachia bordering states, and mid-southeast (Patrick et al., 2015).

In September 2014, the National Center on Substance Abuse and Child Welfare (NCSACW) began a special initiative, building on its past program of In-Depth Technical Assistance (IDTA), to help states respond to growing concerns about opioid use during pregnancy, the increasing number of infants with prenatal exposure, particularly those with NAS, and the lack of coordinated and ongoing services needed to support infants, families, and caregivers during the critical postpartum and infancy period. The NCSACW is a technical assistance (TA) resource center that is jointly funded by the Department of Health and Human Services' SAMHSA and the Administration on Children, Youth and Families' (ACYF), Children's Bureau's Office on Child Abuse and Neglect (OCAN).

The Substance-Exposed Infant (SEI) Initiative provided IDTA for 18 months for six states. The initiative focused on strengthening collaboration and linkages among child welfare, mental health and substance use disorder treatment, public health and medical communities, home visiting and early intervention systems, and other key stakeholders to improve outcomes for infants with prenatal exposure, their mothers and families. An application, scoring, and selection process was implemented and Connecticut, Kentucky, Minnesota (with a focus on tribal communities), New Jersey, Virginia, and West Virginia were selected to participate. In March 2016, Connecticut, Kentucky, Minnesota, New Jersey, and Virginia received an additional six months of TA to continue their work. This summary highlights the efforts of these five states.

A senior change leader (CL) was assigned to work with each site providing a range of TA including bimonthly calls, research, materials development and review, and site visits. Monthly webinars provided sites with opportunities to participate in peer-to-peer networking and to dialogue with experts on this issue. TA provided to the sites was informed by the SAMHSA publication, [*A Collaborative Approach to the Treatment of Pregnant Women with Opioid Use Disorders: Practice and Policy Considerations for Child Welfare, Collaborating Medical, and Service Providers*](#) (SAMHSA, 2016), along with other tools developed by the NCSACW.

During the latter part of the TA engagement with these states, *P.L. 114-198, "Comprehensive Addiction and Recovery Act of 2016" (CARA)*, went into effect, including Title V, Section 503,

“Infant plan of safe care.” The legislation, signed into law on July 22, 2016, made several changes to the Child Abuse Prevention and Treatment Act (CAPTA), including:

- Removing the term, “illegal” in regard to substance abuse;
- Requiring that the plan of safe care address the needs of both the infant and the affected family or caregiver;
- Specifying data to be reported by states, to the maximum extent practicable on the affected infants and the plans of safe care:
 - The number of infants identified as being affected by substance abuse, withdrawal symptoms resulting from prenatal drug exposure, or fetal alcohol spectrum disorder (FASD);
 - The number of infants for whom a plan of safe care was developed; and,
 - The number of infants for whom referrals were made for appropriate services—including services for the affected family or caregiver.
- Requiring that states develop and implement monitoring systems on the implementation of such plans to determine whether and in what manner local entities are providing, in accordance with state requirements, referrals to and delivery of appropriate services for the infant and affected family or caregiver.

As a result of these changes in CAPTA, states were provided an additional year of TA to understand the critical components of the statute and actions needed to comply with the legislation. States have either amended existing legislation or are in the process of proposing new legislation to comply with the new CAPTA requirements. All five states continued to work with the NCSACW on the development of a statewide plan of safe care for these infants, their families, and caregivers.

This Executive Summary highlights the lessons learned, challenges and barriers, state strategies, and progress made toward improving the safety, health, permanency, and well-being of infants affected by prenatal substance exposure, primarily opioids, and the recovery of pregnant and parenting women and their families.

Lessons Learned

Synthesis of key lessons was generated by reviews of site visit and TA reports, site surveys, peer-to-peer webinars and presentations, CL engagement with sites, and evaluation of the TA efforts. These reviews yielded many lessons related to partnerships and collaboration as well as practices and policies that affect outcomes for this population.

State teams identified a number of barriers to services for pregnant and parenting women with substance use disorders and their infants. They also identified policies and practices that may inadvertently discourage women from seeking the care they need, resulting in poor outcomes for both mothers and infants. The following list is not all inclusive, but contains the most commonly reported barriers across the states.

State Reported Service Barriers

- Despite the American Congress of Obstetricians and Gynecologists (2012) recommendation that screening for substance use be a standard part of prenatal care, most healthcare providers screen selectively—if at all. Providers cited several reasons for not screening: not knowing how to discuss substance use, depression, and domestic violence; lack of time or reimbursement barriers; challenges with connecting to substance use disorder treatment services; and fear of pregnant women being penalized for substance use.
- States reported concerns that pregnant women with substance use disorders (SUDs) may avoid prenatal care or substance use disorder treatment for fear of prosecution or losing custody of their child at birth. States also reported concern that the threat of punitive measures would limit women’s disclosure of critical information about their substance use to their physician and others.
- Resistance to the use of medication-assisted treatment (MAT), the accepted standard of care for pregnant women with opioid use disorders, is limiting access to this level of care (American Society of Addiction Medicine, 2015).
- Pregnant women have difficulty accessing MAT, as some opioid treatment providers (OTPs) will not admit pregnant women. Those who do may not understand or address the multiple and often complex needs of pregnant women and their families. OTPs who only prescribe medication often do not connect women to therapeutic and other recovery support services or have the capacity to provide more comprehensive services.
- Inconsistent hospital protocols, within and across states, limited access to the full array of service options for treating infants with prenatal substance exposure, such as the use of non-pharmacological as well as pharmacological methods for treating infants with NAS and promoting mother-infant bonding such as rooming-in and breastfeeding.
- There were several actions lacking at the time of birth that should have been taken:
 - Hospitals often failed to notify or delayed notification to Child Protective Services (CPS) for infants that meet CAPTA requirements for notifying CPS when an infant is “born with and identified as being affected by substance abuse or withdrawal symptoms resulting from prenatal drug exposure, or a Fetal Alcohol Spectrum Disorder (FASD)”;
 - Inconsistent responses by CPS to hospital notifications;
 - Hospital discharge plans that do not address mother’s substance use, or involve other caregivers when the infant is not released in the mother’s care; and
 - No plans of safe care developed for the infant, family, or other caregivers.
- There were multiple challenges with the availability of or eligibility for other essential services: infants not being referred to or not found eligible for early intervention services under Part C of the Individuals with Disabilities Education Act (IDEA); Home Visiting providers not being equipped to work with pregnant and parenting women with substance use disorders; and Home Visiting programs, which are voluntary, having providers who report difficulty engaging women in services.

- There is great variation or lack of consistent medical coverage for continuing care and follow-up for postpartum women and their infants.
- There was a lack of culturally appropriate and evidence-informed services for American Indian women with opioid use disorders.

Collaboration Barriers

State teams also identified a number of challenges with collaboration and development of the cross-systems approaches needed for identifying and serving this population of women, their children, and families. Examples of such challenges include:

- Stigma and differences in values and perceptions about pregnant and parenting women with substance use disorders emerged during team discussions.
- Identifying, engaging, and retaining the array of partners needed to meet the needs of this population of women, their infants, and other family and caregivers at each stage of pregnancy, birth, and ongoing care was challenging for several reasons. These included workload, changes in staff assigned to the project, competing priorities, and differing opinions related to roles, responsibilities, and effective strategies.
- The process of collecting, sharing, and reporting data was new to many groups. Data challenges included a lack of baseline data to define the needs within and across systems to demonstrate cost savings and show improved outcomes (e.g., number of pregnant women with SUDs needing treatment or the number of infants identified as being born with and affected by prenatal drug exposure or FASD); obtaining data from private providers (e.g., obstetricians [OBs], MAT providers); and uncertainty about how to collect and report data for CAPTA reporting requirements.
- States needed to clearly define state policies and protocols and provide guidance on consistent and appropriate responses from child welfare, hospitals, and other partners. Overall, there was a lack of understanding and clarity about compliance with federal CAPTA requirements (e.g., identification of infants born with and affected by prenatal drug exposure, notification of child protective services, developing a plan of safe care, and data collection and reporting).
- As different confidentiality regulations governed child welfare, substance use disorder treatment, and healthcare systems, these regulations were viewed as a barrier to sharing client information. Ensuring that all partners understand confidentiality regulations, the use of informed consent, and the need to fully engage women and their families in the development of plans of safe care was needed.

State Strategies

With the support of NCSACW staff and consultants, states began developing strategies to improve outcomes for women with substance use disorders and their families from pre-pregnancy through the postpartum and parenting period. These strategies include:

- Developing statewide hospital protocols to promote consistent identification of and services for infants with NAS;
- Conducting hospital assessments to inform implementing plans of safe care for infants, their families, and caregivers;

- Creating systems of care or wraparound models of care that address the comprehensive needs of pregnant and parenting women and their children;
- Drafting guidance documents for OTPs and other treatment providers that delineate best practices for serving pregnant and postpartum women;
- Using consistent and non-stigmatizing language when referring to pregnant and parenting women with substance use disorders and their infants or children. “*Language matters*” became a common mantra among NCSACW staff and partners in all sites;
- Providing outreach and engagement in tribal communities of American Indian women in prenatal care and the development of treatment models that do not conflict with tribal beliefs; and,
- Developing state policies and procedures for hospital notifications of infants and the development of a plan of safe care model.

State Accomplishments

Connecticut

- The Department of Children and Families (DCF) and the Department of Mental Health and Addiction Services (DMHAS) jointly funded the Connecticut Keeping Infants Drug Free (K.I.D.) Project, a statewide initiative to coordinate interagency efforts to address FASD and NAS. Funding supports a statewide FASD/NAS coordinator, whose job includes facilitating interagency coordination, overseeing the development of the strategic plan, and ensuring activities are implemented.
- The state’s strategic plan was expanded to address the prevention, early intervention, and treatment needs of pregnant and postpartum women as well as their infants and children. The 5-Year Plan was approved by state commissioners for DCF, DMHAS, the Department of Public Health (DPH), and the Office of Early Childhood.
- DPH created a NAS fact sheet as part of the public education and awareness campaign. Hospital discharge data provided baseline data needed for a workgroup studying economic impact of NAS.
- The Connecticut Hospital Association administered a survey of birthing hospitals to assess current screening, identification, and treatment practices for infants with prenatal substance exposure. The survey identified inconsistencies in practices across hospital settings and provided baseline data against which they can demonstrate improvements.
- The Connecticut Certification Board, in partnership with The Connecticut Women’s Consortium, developed training for their child welfare workers on the “ABCs of MAT.” DCF workers throughout the state are being trained.
- A multi-agency workgroup is developing a protocol for consistent identification and notification of child protection services of infants with prenatal substance exposure and a Connecticut model for plan of safe care for infants and their families.

- Connecticut hospitals are beginning to implement new standards of care for infants with NAS and their mothers, including more opportunities for rooming-in and increased focus on care that promotes mother-infant bonding such as skin-to-skin contact and breastfeeding.

Kentucky

- The Department of Behavioral Health, Developmental and Intellectual Disabilities (DBHDID) increased availability of MAT for pregnant and postpartum women with opioid use disorders through three MAT expansion sites—two funded through the SAMHSA Expansion Grant and one through funding from DBHDID and Medicaid.
- The KIDS NOW Plus Program, supporting pregnant women at risk for using substances during and after pregnancy, was expanded to all 14 community mental health and substance abuse regions.
- As part of the IDTA Team, the Kentucky Department of Public Health (DPH) led the state's efforts to improve outcomes for infants with NAS. Legislation passed in 2014 [KRS 211.676] made NAS a reportable health condition. All hospitals now use the same criteria for reporting NAS cases to DPH, with the first annual NAS report issued in December 2015. The department is also working with hospitals on guidelines and protocols for treatment of NAS infants and their mothers and guidelines for multidisciplinary assessments and discharge planning for such infants and their mothers.
- In 2015 and 2016, the Kentucky School of Alcohol and Other Drug Studies presented workshops focused on issues related to pregnant and postpartum women and opioid use disorders, including MAT for pregnant women, understanding adverse childhood experiences, NAS, MAT, and challenges with MAT. Treatment agencies have expressed greater acceptance of MAT, with several working towards becoming MAT providers.
- The Department of Community Based Services (DCBS) and their partners are working with local hospitals to pilot the infant/mother assessments and discharge planning into a plan of safe care. The goal is to integrate this information into any DCBS prevention plan, case plan, or aftercare plan.

Minnesota

- The Department of Human Services initiated a request for applications process and awarded funding—with the goal of improving birth, health, and recovery outcomes—to five northern Minnesota Tribes to develop collaborative, community-driven approaches to serving American Indian families affected by substance use disorders.
- The leadership team submitted a formal set of recommendations for American Indian women with opioid use disorders, their infants, and families to the Governor's task force in the fall of 2016. These recommendations were incorporated into a comprehensive substance abuse system reform package, which is under legislative review for passage. Some of the recommendations were also integrated into the action planning and work of a statewide workgroup on developing best practice guidance for child welfare staff on working with families affected by maternal substance use disorders.

- A resource guide was developed providing information about programs and services available for American Indian pregnant women with substance use disorders and their families in the metro area and in each tribal community.

New Jersey

- The Department of Mental Health and Addiction Services issued a request for proposals to develop intensive case management and recovery support services for opioid-dependent pregnant and postpartum women and their families. Three regions of the state will receive funding to implement this program, which combines intensive case management, wraparound services, and recovery supports for opioid-dependent pregnant/postpartum women and their families for up to one year following birth.
- The core team administered a comprehensive survey for birthing hospitals, OBs/gynecologists and pediatricians to understand how pregnant women with substance use disorders and substance-exposed infants are identified, treated, and triaged with partners at discharge.
- As a compliment to the hospital survey, the core team is working on a white paper on the costs associated with NAS across the state. During the initiative, the team was able to analyze 2013 and 2014 Medicaid data to establish prevalence and costs of treatment for NAS.
- With a broad group of cross-system partners, the Camden County Perinatal Substance Use Partnership (CCPSUP) is developing a continuum of care, including increasing shared communication about pregnant women with substance use disorders and their infants. The CCPSUP completed a walkthrough of their county's system (medical, substance use, child welfare) for pregnant women and identified initial goals for building collaborative practice.
- The core team provided progress reports and developments to the state opioid workgroup. Members of the core team jointly served as co-directors of the state opioid workgroup, which further increased integration with other state initiatives and oversight.

Virginia

- The team's legislative workgroup developed and disseminated a survey to community services boards (CSBs) across the state, which are a single point of entry to substance use and mental health services in Virginia. The surveys asked about identification, referral, and triage practices between OTPs, CSBs, and medical professionals for pregnant women and infants. Results were used to inform practice guidelines for CSBs working with pregnant and postpartum women and their infants, including their role in implementing plans of safe care. The draft guidelines were presented at a statewide conference in June 2016 and are being finalized to include information about plan of safe care development and implementation.
- The prenatal workgroup developed and disseminated a survey to 30 OTPs across the state, the majority of whom are private providers. Results showed that many OTPs inconsistently address infant/family concerns, do not provide or connect patients to other therapeutic services, and some do not admit pregnant women. OTPs connected with CSBs were much more likely to share information and coordinate with other systems to

address the range of other needs for women and their families. Survey results are being used to develop guidelines for OTPs for serving pregnant and postpartum women. The state opioid authority is working on incorporating some of the guidelines into state regulations.

- The infant workgroup developed a draft guidance document for implementing plans of safe care in Virginia, which includes a draft universal discharge summary for use by birthing hospitals. The team will continue to work on the development of the Virginia plans of safe care model.
- Core team members provided extensive input into Virginia's 1115 Medicaid Waiver Application, particularly as it relates to pregnant and postpartum women with opiate use disorders. The application was approved in December 2016, and proposed a comprehensive transformation of the current service delivery system, with full integration of physical health, mental health, and addiction and recovery treatment services in Virginia's Managed Care Organizations.
- The Virginia General Assembly passed three bills that support substance-exposed infants and their families. These included marking the first week of July as substance-exposed infant awareness week; designating NAS as a reportable health condition to the board of health; and empanelling a committee to identify barriers to treatment for substance-exposed infants and their families. The committee included several members of the Virginia IDTA collaborative.

These states are continuing to develop and implement policy and practice changes in response to the increasing numbers of infants with prenatal exposure, the impact of the opioid epidemic on the child welfare system, and the need for expanded substance use disorder treatment for affected caregivers and their families. A long-term commitment from the multiple partner agencies is essential to continuing this work and responding effectively to the safety, well-being, and healthcare needs of these infants and their families or caregivers. TA from the NCSACW is available to assist states with implementing plans of safe care for infants and their families or caregivers, and develop collaborative practices to expand access to family-centered treatment services on a system-wide basis. SAMHSA and the Children's Bureau are committed to supporting states' efforts to improve outcomes for infants and families affected by prenatal substance exposure.

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