



Infants with Prenatal Substance Exposure Initiative Final Report 2016-2018

Funded by the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Administration on Children and Families (ACF), Children's Bureau under Contract Number: HHSS270201700001C

Executive Summary.....4
 Overview.....4
 Key Findings and Lessons Learned.....5
 Accomplishments.....6
 Conclusions.....8

I. Program Overview.....9

II. Background and Statement of Need.....10
 Adoption and Foster Care Analysis and Reporting System.....11

III. Site Profiles.....15

 Delaware.....15
 Overview.....15
 Program Goals.....15
 Accomplishments.....16
 Governance Structure, Key Partners, and Other Stakeholders.....17
 Data Collection and Reporting.....18
 Products.....20
 Ongoing Implementation.....20

 Minnesota.....21
 Overview.....21
 Program Goals.....23
 Accomplishments.....23
 Governance Structure, Key Partners, and Other Stakeholders.....24
 Data Collection and Reporting.....25
 Products.....26
 Ongoing Implementation.....26

 New York.....27
 Overview.....27
 Involvement of American College of
 Obstetricians and Gynecologists, District II.....28
 Program Goals.....29
 Accomplishments.....29
 Governance Structure, Key Partners, and Other Stakeholders.....30
 Data Collection and Reporting.....32
 Products.....34
 Ongoing Implementation.....34

IV. Collaboration.....35
 Partners and Other Stakeholders.....35
 Governance Structure.....36

V. Stigma and Differences in Values and Perceptions.....37

VI. Barriers to Services for Women and their Families.....39
 Early Identification and Screening.....39
 Engagement and Retention in Treatment.....40
 Services for Infants, Their Families, and Caregivers.....41

VII. Implementation Challenges.....43
 Data Challenges and Needs.....43

VIII. Lessons Learned.....45
 Collaboration.....45
 Governance Structure.....46
 Values and Perceptions.....46
 Services for Women and Their Families.....46
 Implementation Challenges.....47

IX. Conclusions.....48

X. References.....49

XI. Appendix.....51
 Technical Assistance Process.....51
 The Change Liaison.....51
 Technical Assistance Tools and Methods.....52
 Webinars and Peer-to-Peer Networking.....57
 Site Visits.....57

Page Intentionally Left Blank.

Executive Summary

Overview

The National Center on Substance Abuse and Child Welfare (NCSACW) is a national resource center jointly funded by the Substance Abuse and Mental Health Services Administration's (SAMHSA's) Center for Substance Abuse Treatment (CSAT) and the Administration on Children, Youth and Families (ACYF), Children's Bureau's Office on Child Abuse and Neglect (OCAN). In September 2014, NCSACW embarked on an initiative to advance the capacity of states to improve the safety, health, permanency, and well-being of infants born with and affected by prenatal substance exposure, and the recovery outcomes of pregnant and parenting women and their families.

From September 2014–September 2016, NCSACW received funding for the In-Depth Technical Assistance-Infants with Prenatal Substance Exposure (IDTA-IPSE) program to facilitate collaboration and linkages across child welfare, mental health and substance use disorders treatment, medical communities, and early intervention systems, and they included other key stakeholders. The objective was to improve outcomes for infants with prenatal substance exposure, their mothers, and families. Sites from this round of IDTA-IPSE (Round One) included Connecticut, Kentucky, Minnesota, New Jersey, Virginia, and West Virginia.

In September 2016, CSAT approved the selection of Delaware and New York for Round Two of IDTA-IPSE and granted Minnesota an extension to continue working with designated tribal communities until September 2018. This report summarizes the work of these three sites.

The “Comprehensive Addiction and Recovery Act of 2016” (CARA) (P.L. 114-198) went into effect on July 22, 2016. This legislation includes Title V, Section 503, “Infant Plan of Safe Care,” which is

designed to help states address the effects of substance abuse disorders and prenatal substance exposure on infants, children, and families. This legislation amended the Child Abuse and Treatment Act (CAPTA) for infants with prenatal substance exposure by removing the word “illegal” when referring to substance abuse that affects infants, by requiring the Plan of Safe Care to include the needs of both the infant and family/caregiver, by specifying the data to be reported by states, and by increasing the level of monitoring required by states.

In response to these CAPTA amendments, the majority of technical assistance in Delaware and New York focused on developing policies and protocols to successfully implement the CAPTA requirements, especially those that pertain to hospital notifications to Child Protective Services of infants affected by prenatal substance exposure; Plans of Safe Care for the affected infant, the family, and other caregivers; and data collection and reporting. Technical assistance also focused on providing the linkages and services needed to support infants and families.

The Minnesota tribal communities focused primarily on engaging American Indian women in prenatal care and in ensuring that individuals with substance use disorders received culturally competent treatment as early as possible.

This final report submitted to SAMHSA and OCAN summarizes the findings, challenges, and barriers sites identified as they assessed changes made toward improving the safety, health, permanency, and well-being of infants affected by prenatal substance exposure, primarily opioids. This report also summarizes sites' efforts toward improving recovery outcomes of pregnant and parenting women and their families.

Key Findings and Lessons Learned

Syntheses of key findings were generated by reviewing site visit and technical assistance reports, site surveys, peer-to-peer webinars, and presentations, as well as from engaging with change liaisons who are involved with the work at these IDTA-IPSE sites. These reviews yielded many lessons related to partnerships and collaboration as well as to practices and policies that affect outcomes for infants and families. Some of the most salient findings and lessons from this round of IDTA-IPSE are set out below:

- Collaborative teams require an array of committed partners.

Teams should include representatives from:

- | | |
|---|--|
| <ul style="list-style-type: none"> • Child welfare • Substance use disorder treatment • Women’s treatment services and medication-assisted treatment providers • Mental health agencies • State Departments of Health, Maternal and Child Health | <ul style="list-style-type: none"> • Home visiting • Hospital/institution licensing staff • Obstetricians and gynecologists (OB-GYNs), midwives, and other prenatal care providers; • Pediatricians and neonatal staff; and • Early intervention/Individuals with Disabilities Education Act (IDEA) Part C¹ providers. |
|---|--|

NCSACW also highly recommends encouraging the participation of state or regional American College of Obstetricians and Gynecologists (ACOG), hospital associations, Medicaid, and managed care plans.

- Local, community-level implementation relies on identifying and engaging partners and stakeholders to carry out the work that was initiated at the state level. Successful program implementation requires investing the time to engage local team members and foster collaboration. Delaware and New York successfully implemented CAPTA requirements by effectively engaging and fostering collaboration between community hospitals and local treatment providers. In Minnesota, tribal communities created a network of resources for tribal members living in communities as well as on tribal lands.
- Sites with an involved, supportive, and consistent oversight committee were able to break through challenges more quickly and keep issues elevated to the highest level of state government. Core Team members need a significant level of authority and direct access to Agency Commissioners and Secretaries when challenges and barriers arise.
- Statewide practice changes are not successfully implemented simply by issuing a policy brief or guidance document. Dialogue with local partners is critical, whether it occurs through onsite training and meetings, webinars, or phone consultations. Local partners need opportunities to discuss their concerns, communicate their perceptions and ask questions. Implementation of these practice changes on a large, statewide scale takes time. Phasing-in across multiple regions and counties is likely to yield greater success and compliance than implementing changes on a wider scale.

¹This law ensures the delivery of services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education, and related services to more than 6.5 million eligible infants, toddlers, children, and youth with disabilities. Infants and toddlers with disabilities (birth through age 2) and their families receive early intervention services under IDEA Part C.

- Reaching agreement on goals, outcomes, and indicators from the outset is critical. Teams must also be open to adapting, revising, and prioritizing goals and governance structures when needed to achieve outcomes.
- Building on existing structures and initiatives avoids duplication of efforts and allows sites to leverage the support from governors and other key stakeholders. Existing structures and initiatives had a big impact on the progress in all three sites.
- Stigma is still prevalent with regard to how pregnant women with substance use disorders are perceived among many systems. Although none of the states involved in this initiative have laws or policies that penalize women for substance use during pregnancy, most partners agreed that pregnant women still fear that they will be condemned or punished, or that their child will be removed from them at birth. These perceptions often cause them to avoid prenatal care and substance use disorder treatment and to isolate themselves even more from family and friends.
- Screening for substance use in hospital settings is often done selectively or is targeted to certain women, which can result in racial and socioeconomic bias. Adhering to the ACOG recommendation to universally screen patients and using a validated instrument increases the chance that prenatal substance use will be identified, addressed, and potentially reduced.
- Data should be reviewed across multiple systems to understand how achieving outcomes in one system can impact another. When more women are screened for substance use, additional treatment capacity will likely be needed. Medicaid Directors, managed care entities, and hospitals need to engage in discussions about data collection and reporting so that each system understands what outcomes are expected and how to achieve them.
- Mapping community resources and conducting cross-system walkthroughs and local case studies can solidify knowledge of existing programs; client flow processes across systems; the roles of each partner agency; and the gaps and barriers encountered by women, children, and their families and partner agencies.

Accomplishments

Delaware

- Delaware's team developed a Plan of Safe Care template and draft implementation guide. The state fully implemented the Plan of Safe Care at all birthing hospitals across the state after completing a three-hospital pilot and deploying Child Protective Services investigators at hospitals to develop the Plan of Safe Care.
 - The Delaware Legislature passed Aiden's Law during the 2018 legislative session. The legislation formalizes a uniform, collaborative response protocol for developing a Plan of Safe Care for infants affected by prenatal substance exposure and their families or caregivers.
-

- Delaware developed materials that describe the use of screening tools and the legislation that requires prenatal care providers to discuss the dangers of substance use during pregnancy with their patients.

New York

- New York’s Office of Alcoholism and Substance Abuse Services (OASAS) and ACOG District II are working with OB-GYNs and other prenatal care providers to ensure Screening, Brief Intervention, and Referral to Treatment (SBIRT) are standard practice for pregnant women and women of childbearing age. OASAS and ACOG are developing a series of training vignettes to guide OB-GYNs and other prenatal care providers with screening pregnant women for substance use and connecting them to additional assessment and treatment resources, when indicated.
- New York’s Office of Children and Families Services, in collaboration with New York’s OASAS, ACOG District II, the Department of Health, and the Perinatal Quality Collaborative developed and implemented a statewide CAPTA policy related to infants affected by prenatal substance exposure. These practice changes are now implemented in pilot counties.
- Peer support services is an integral part of New York’s wraparound model for serving pregnant and parenting women with substance use disorders and their infants and children. Crouse Hospital is using peer supports prior to and after delivery to engage women in treatment services.

Minnesota

- The Department of Human Services awarded state funding to five northern Minnesota tribes to deliver “Integrated Care for High-Risk Pregnancies” (ICHRP). This program adopts collaborative, community-driven approaches to serve American Indian families affected by substance use disorders and provides wraparound supports for high-risk pregnancies. The IDTA-IPSE supported these grantees with project implementation; the goal was to improve birth, health, and recovery outcomes.
- Minnesota’s leadership team submitted a formal set of recommendations for American Indian women with opioid use disorders, their infants, and families to the Governor’s taskforce in the fall of 2016. These recommendations were integrated into a comprehensive substance abuse system reform package.
- NCSACW conducted a listening tour with five tribes in northern Minnesota in September 2018. The listening tour was summarized in the publication, “Tapping Tribal Wisdom: Providing Collaborative Care for Native Pregnant Women with Substance Use Disorders and Their Infants.” The report delves into the challenges, successes, and lessons learned from developing collaborative care models in tribal communities for women with high-risk pregnancies as it relates to substance use, their children, and family members.

Conclusions

Delaware, Minnesota, and New York continue to develop and implement policy and practice changes in response to the rising numbers of infants with prenatal substance exposure, the associated 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. These IDTA-IPSE sites reinforced that this work is developmental in nature and that the sites' accomplishments can be attributed to multiple factors. Success requires a multi-year commitment to enact, adopt, and implement statewide policy and practice changes in order to expand collaboration and care coordination among health care, child welfare, substance use disorder treatment, public health, mental health, and other family-serving agencies. Building trust and a long-term commitment from multiple partner agencies, and working at various intervention points across the lifespan, is essential to achieving the safety, well-being, and wellbeing of infants and their families or caregivers.

The technical assistance NCSACW provided was deemed to be effective in helping sites build or enhance collaborative relationships, initiate practice changes, and develop systems that are likely to improve specific outcomes for women, their families, and communities. Changes made include those that impact opioid prescribing practices, early engagement in prenatal care, early engagement in appropriate treatment, and increased occurrences of infants with prenatal exposure being discharged with mothers to safe home environments.

Program Overview

The National Center on Substance Abuse and Child Welfare is an initiative of the Department of Health and Human Services and jointly funded by the Substance Abuse and Mental Health Services Administration's (SAMHSA's) Center for Substance Abuse Treatment (CSAT) and the Administration on Children, Youth and Families (ACYF), Children's Bureau's Office on Child Abuse and Neglect (OCAN). In September 2014, the NCSACW embarked on an initiative to advance the capacity of states to improve the safety, health, permanency, and well-being of infants born with and affected by prenatal substance exposure, and the recovery of pregnant and parenting women and their families.

From 2014–2016, NCSACW supported the In-Depth Technical Assistance-Infants with Prenatal Substance Exposure (IDTA-IPSE) program to facilitate collaboration and linkages across child welfare, mental health and substance use disorder treatment, medical communities, early intervention systems, and included other key stakeholders to improve outcomes for infants with prenatal substance exposure, their mothers, and families. Connecticut, Kentucky, Minnesota, New Jersey, Virginia, and West Virginia applied for and were approved as IDTA-IPSE sites. In response to the 2016 amendments to the Child Abuse Prevention and Treatment Act (CAPTA), IDTA-IPSE supported states as they developed and implemented the requirements for infants with prenatal substance exposure, particularly hospital notifications to Child Protective Services and Plans of Safe Care.

In September 2016, NCSACW reviewed applications from states interested in the next round of IDTA-IPSE. SAMHSA CSAT approved the selection of Delaware and New York for Round Two. SAMHSA CSAT also approved an extension period for the ongoing technical assistance work with Minnesota to September 2018.

A senior change liaison from NCSACW was assigned to work with each site. The change liaison provided an array of technical assistance services, which included monthly calls, research, materials development and review, site visits, and the facilitation of connections to content experts and peers from other sites. Several SAMHSA publications and NCSACW documents and tools informed the technical assistance provided to the sites, including the Five Points of Intervention Policy and Practice Framework 2. This framework is one of the tools used to help states identify and develop intervention opportunities across the continuum from pre-pregnancy through childhood and adolescence. For more information on the technical assistance process, refer to *Appendix, Section C: Technical Assistance Process*.

On February 7–8, 2017, NCSACW hosted the Policy Academy entitled “Improving Outcomes for Pregnant and Postpartum Women with Opioid Use Disorders and their Infants, Families, and Caregivers” in Baltimore, Maryland. Delaware, Minnesota, and New York teams participated in this event, along with eight other state teams. The Policy Academy helped state teams develop goals and strategies for improving outcomes for pregnant and postpartum women with substance use disorders, their infants, and their families.

² Young, N. K., Gardner, S., Otero, C., Dennis, K., Chang, R., Earle, K., & Amatetti, S. (2009). Substance-Exposed Infants: State Responses to the Problem. HHS Pub. No. (SMA) 09-4369. Rockville, MD: Substance Abuse and Mental Health Services Administration

Background and Statement of Need

Data from SAMHSA's National Survey on Drug Use and Health show that between 2007 and 2014, the number of people who misuse prescription drugs, new users of heroin, and people with heroin dependence has skyrocketed (SAMHSA, 2014). As the rates of people using opioids and people with substance use disorders increased among individuals of all ages and backgrounds, it is not surprising that the rates of people using substances also increased among pregnant women and women of childbearing age. In addition, several recent studies have shown an increase in prescription opioid use among women of childbearing age and among pregnant women (Patrick, 2017). A 2018 Centers for Disease Control and Prevention (CDC) report indicated that national opioid use disorder rates for women giving birth in hospitals has more than quadrupled between 1999 and 2014.

In January 2019, the Healthcare Cost and Utilization Project (HCUP) released a statistical brief entitled "Opioid-Related Hospital Stays Among Women in the United States." The brief, which presents statistics based on opioid-related hospitalizations among women ages 15 years and older states that women are more likely than men to be prescribed pain relievers, more likely to be prescribed these medications in higher doses, and more likely to become dependent on them more quickly (Weiss et al., 2016). The data also show women had higher opioid-related hospitalization rates than men.

Among the variety of data presented in the HCUP brief, the following statistics are most relevant to the subgroup of women of childbearing age and pregnant and parenting women served in the IDTA-IPSE program (Weiss, 2016):

- Nearly one in five opioid-related hospital stays among women of reproductive age involved co-occurring pregnancy/childbirth.
- Co-occurring pregnancy/childbirth and opioid use was more common among women with Medicaid insurance.

In addition, substance use disorder treatment for pregnant and parenting women is often difficult to access in many areas of the country. Although pregnant women are a designated priority population under the SAMHSA Substance Abuse Prevention and Treatment block grant, an Association of State and Territorial Health Officials (ASTHO) December 2018 report indicated that only 19 states have programs designed for pregnant women, and only 15 percent of treatment centers nationally offer specific services for this population (Terplan, Longinaker, & Appel, 2015). One study estimates that about 80 to 95 percent of women with substance use disorders have unmet treatment needs (ASTHO, 2018).

The problems facing women who are pregnant and using substances or have substance use disorders present a complicated scenario for the professionals striving to help them, particularly because these women are often at the intersection of multiple systems, including child welfare, dependency court, and substance use disorder treatment as well as primary and obstetrical health care.

However, all partners do agree that the issues facing women who use substances in pregnancy are complex and require a comprehensive approach that emphasizes prevention, early identification and engagement, and more family-centered treatment services for women, their children, and their families.

Drug overdoses continue to be a major concern stemming from the opioid epidemic. The CDC reports that in 2016, 66.4 percent of the 63,632 drug overdose deaths involved an opioid. In 2017, among 70,237 drug overdose deaths, 47,600 (67.8 percent) involved opioids, with significant increases across age, racial, and ethnic groups, and in multiple states. From 2016 to 2017, synthetic opioid-involved overdose death rates increased 45.2 percent (Scholl et al., 2019).

States also began reporting significant increases in the number of infants with neonatal abstinence syndrome and infants who manifest withdrawal symptoms from opioid exposure in utero. The higher concentrations of these conditions are in the northeast corridor, the Appalachia bordering states, and midsouth east (Patrick et al, 2015). In the American Academy of Pediatrics publication, A Public Health Response to Opioid Use in Pregnancy, Patrick and colleagues reported the rate of infants experiencing neonatal abstinence syndrome grew nearly fivefold over the past decade (Patrick et al., 2016).

Adoption and Foster Care Analysis and Reporting System

States and tribal agencies collect data on all children in foster care as well as children who have been adopted through a Title IV-E agency. The data are reported to the Adoption and Foster Care Analysis and Reporting System (AFCARS).

According to AFCARS data (AFCARS, 2017), parental drug abuse was reported as a circumstance associated with removal of children in the home in 37.7 percent of cases where children entered foster care during fiscal year 2017.

The prevalence of parental substance use as a contributing factor for children removed from their home varies significantly from state to state, ranging from less than 5 percent in New Hampshire to nearly 70 percent in Alaska. This variation may have more to do with state-specific identification and data entry protocols than actual differences in the prevalence of parental substance use in state child welfare systems. States vary significantly regarding the protocols they use to identify parental substance use, the impact that parental substance use has on decisions to remove children from their homes, and the systems used to collect these data. These state variations have led to a perception that the overall prevalence of children removed from homes due to parental alcohol or other drug use as a contributing factor is substantially undercounted.

Figure 1 on page 12 shows the prevalence of parental alcohol or other drug use as a contributing factor for removing children from their home in the United States for 2000 through 2017.

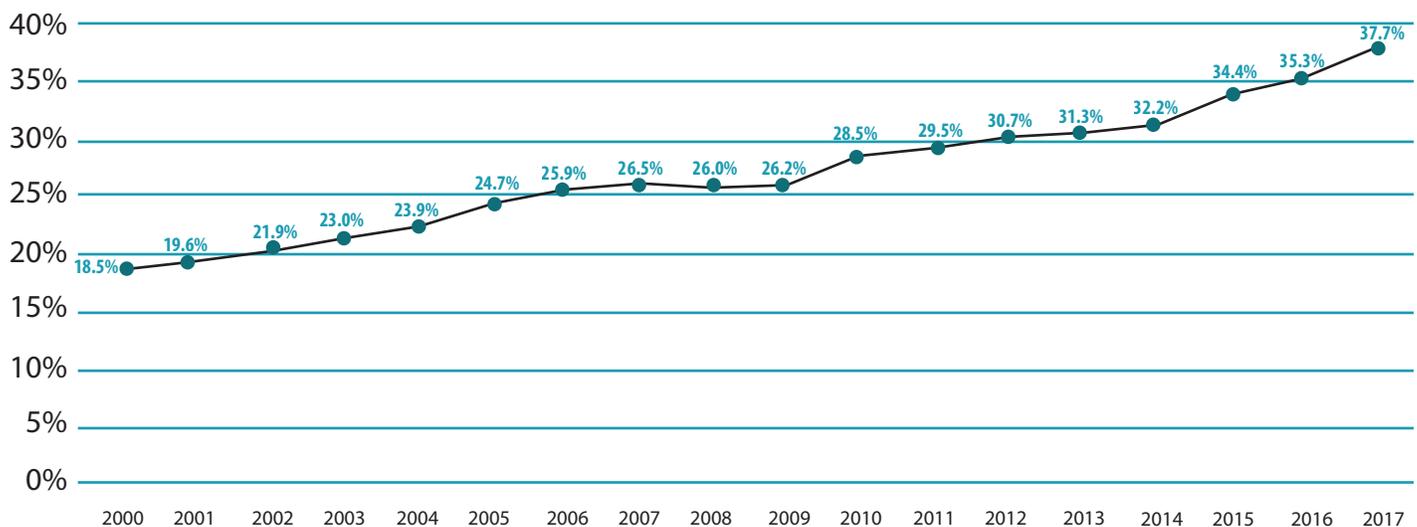
Figure 2 on page 13 shows a state-by-state comparison of the percentage of children removed from their home due to parental alcohol or other drug use by age of children, for the year 2017.

Figure 3 on page 13 shows the percentage of children younger than age 1 with parental alcohol or other drug use, as a reason for removal from the home in the United States, for 2000 through 2017.

Although the relationship is not clear between the rates of neonatal abstinence syndrome and the dramatic increase of infants who are placed in protective custody, the trend of younger children in out-of-home care—and in particular, the number of infants—is alarming. After a decade of seeing decreased numbers of children in out-of-home care, the trend began to reverse in 2012 through 2013, as shown in *Figure 3*.

Note that although states involved in the IDTA-IPSE program were primarily focused on pregnant women with opiate use disorders and infants with neonatal abstinence syndrome, opioid exposure represents only a small percentage of the overall number of infants estimated to be affected by prenatal exposure. *Figure 4* on page 14 shows that among pregnant women, the highest rates of use continue to be the legal substances that have known detrimental effects on the neurodevelopment of the fetus.

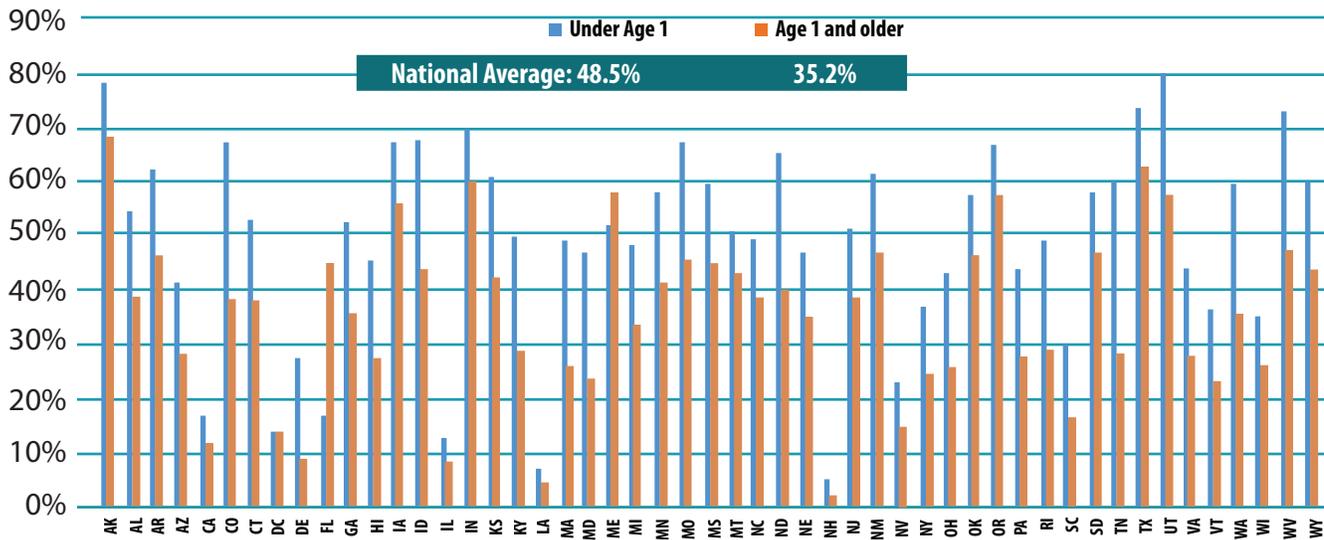
Figure 1. Prevalence of Parental Alcohol or Other Drug Use as a Contributing Factor for Removing Children from the Home in the United States, 2000–2017



Note: Estimates based on all children in out of home care at some point during Fiscal Year

Source: AFCARS Data, 2000-2017

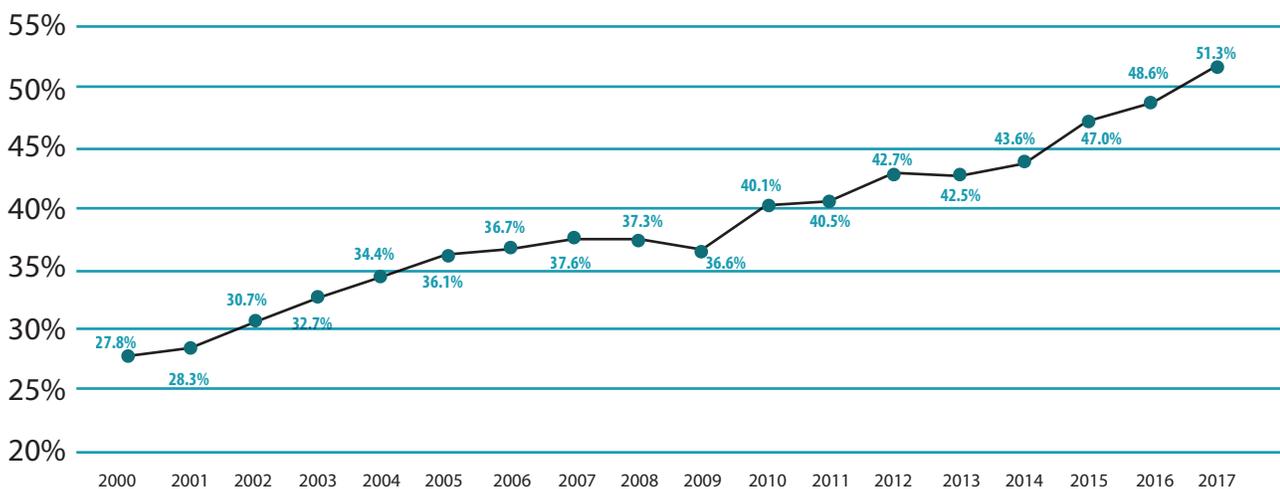
Figure 2. Percentage of Children Removed with Alcohol or Other Drug Use as a Reason for Removing Children from the Home, by Age, 2017



Note: Estimates based on all children in out of home care at some point during Fiscal Year

Source: AFCARS Data, 2000-2017

Figure 3. Percentage of Children Younger than Age 1 with Parental Alcohol and Other Drug Use as a Reason for Removing Children from the Home, United States, 2000–2017

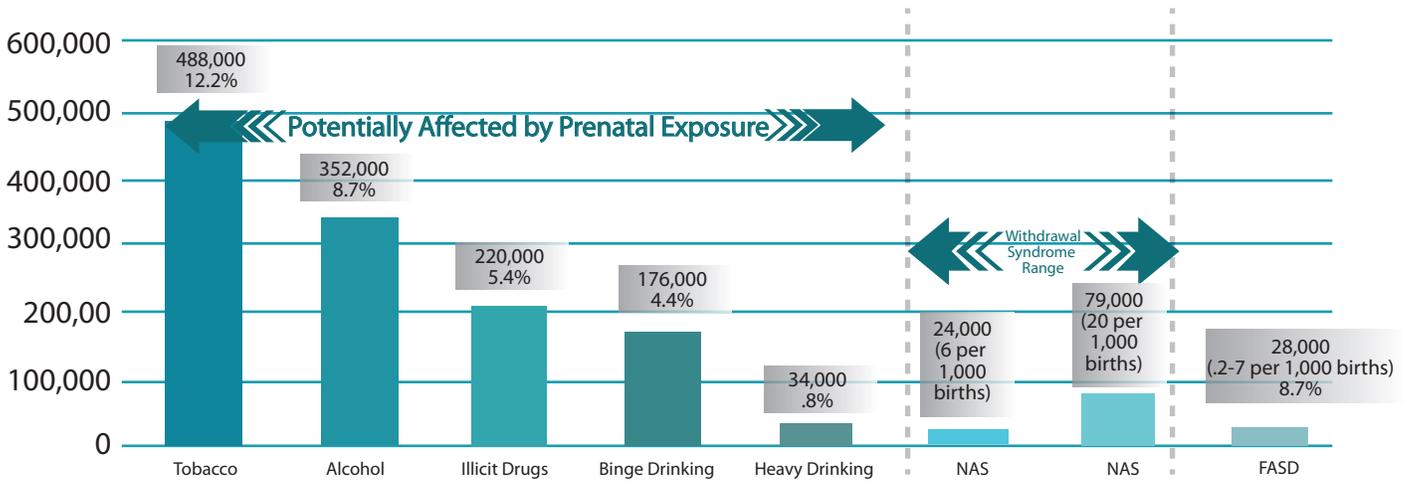


Note: Estimates based on children under age 1 entered out of home care during Fiscal Year

Source: AFCARS Data, 2000-2017

*Approximately 4 million (3,945,875) live births in 2016; National Vital Statistics Report, Vol. 66, No. 1 https://www.cdc.gov/nchs/data/nvsr/nvsr66/nvsr66_01_tables.pdf
 Estimates are based on rates of past month drug use: National Survey on Drug Use and Health, 2016; <https://www.samhsa.gov/data/sites/default/files/NSDUH-DefTabs-2016/NSDUH-DefTabs-2016.pdf>
 ** Includes nine categories of illicit drug use: use of marijuana, cocaine, heroin, hallucinogens, and inhalants, as well as the nonmedical use of prescription-type pain relievers, tranquilizers, stimulants, and sedatives.
 Patrick, et al., (2015). Increasing incidence and geographic distribution of neonatal abstinence syndrome: United States 2009 to 2012. Journal of Perinatology, 35(8), 667
 May, P.A., and Gossage, J.P. (2001). Estimating the prevalence of fetal alcohol syndrome: A summary. Alcohol Research & Health, 25(3): 159–167. Retrieved October 21, 2012 from <http://pubs.niaaa.nih.gov/publications/arh25-3/159-167.htm>

Figure 4. Estimated Number of Infants Affected by Prenatal Exposure, by Type of Substance and Infant Disorder, 2016³



(National Vital Statistics Report, 2017; NSDUH, 2017; Patrick et al., 2015; Milliren et. al, 2017; May & Gossage, 2001)

State partners involved in IDTA-IPSE realize that most of the women they are targeting have co-occurring substance use and mental health disorders, and many are using multiple substances, including tobacco, marijuana, and alcohol.

However, most hospital referrals and notifications are for infants manifesting withdrawal and other neonatal abstinence syndrome symptoms resulting from prenatal opioid exposure.

Site Profiles

This section includes an overview of each IDTA-IPSE site; goals and accomplishments; governance structure, key partners, and stakeholders; data collection and reporting mechanisms; and products developed. The areas that will require ongoing work for each site once the IDTA period is concluded are also described.

States were required to submit an application that included specific data to support their Statement of Need. The data included substance use disorder treatment entry, occurrence of substance use during pregnancy, number of infants with prenatal exposure, increases in Medicaid expenditures for this population, and any other information specific to the opioid epidemic. There was significant variability in the ability of states to provide this information.

The IPSE Committee was created after an escalation of reports to the Division of Family Services involving infants with prenatal exposure (from 145 cases in 2012 to 294 in 2015). Furthermore, in 2015, Delaware experienced 34 cases involving the death or near death of a child due to abuse or neglect. Fifteen of the 34 cases involved infants younger than six months and of those 15, seven involved an infant with prenatal exposure. Tragically, of the infants with prenatal exposure, five died. (Delaware IDTA-IPSE application, 2016)

Delaware

A. Overview

In January 2015, Delaware’s Child Protection Accountability Commission and the Child Death, Near Death and Stillbirth Commission ("Joint Commission") reviewed and prioritized the Child Abuse and Neglect (CAN) Panel Recommendations pertaining to case reviews of deaths and near deaths during the years 2010 through 2014. During this period, the CAN Panel identified approximately 17 system weaknesses or policy failures involving infants with prenatal exposure and medically fragile children. As a result, the Joint Commission recommended the formation of a specialized committee on infants with prenatal exposure and medically fragile children to address the identified areas of concern.

The Committee on Infants with Prenatal Exposure/Medically Fragile Children ("IPSE Committee") was first convened on May 29, 2015. Partners and stakeholders are named in the Governance Structure in Section D.

From September 2016 through September 2018, the State of Delaware received IDTA-IPSE from NCSACW. The 2-year engagement focused on (1) addressing infants with prenatal exposure and their families; and (2) implementing legislation, policies, and protocols to align state practice with federal changes to CAPTA related to Plans of Safe Care.

B. Program Goals

Goal 1: Recommend universal screening of pregnant women for substance use (early identification) and link women and their families to appropriate services, including treatment, prenatal care, home visiting, and other supports as needed.

Goal 2: Build a system of care and provide educational resources to support providers working with pregnant women with substance use disorders and affected children and families. Providers include obstetricians/gynecologists, birthing hospitals, treatment providers, and social services agencies.

Goal 3: Implement a statewide protocol for preparing and monitoring Plans of Safe Care.

Goal 4: Maintain an awareness of the effects of stigma in discouraging pregnant women from treatment or prenatal care, as well as the importance of non-judgmental medical provider support so that women feel safe in discussing substance use.

C. Accomplishments

The change liaison and other NCSACW staff worked with the Delaware site for 24 months to enhance their existing partnerships, establish new relationships, and achieve their stated goals. The Delaware site made significant accomplishments in each of the following goals:

1. Educate providers on universal screening during pregnancy

The site developed materials that explained the use of screening tools and the legislation that requires prenatal care providers to discuss with their patients the dangers of substance use during pregnancy. The site also helped the Division of Public Health develop materials for OB-GYNs that outlined screening practices and tools. In addition, the state rolled out the website “Help is Here DE” (<http://www.HelpIsHereDE.com>), which provided screening tools, information on addiction, and information on accessing substance use disorder treatment.

2. Build a system of care to support providers working with pregnant women with substance use disorders

The core team developed the Delaware Healthy Outcomes with Parent Engagement (DE HOPE) model. The DE HOPE model offers a multidisciplinary team approach for pregnant women who seek medication-assisted treatment for opioid dependency or who become pregnant within the first year of receiving medication-assisted treatment at Connections Community Support Programs and Brandywine Counseling & Community Support clinics across the state. Services are provided throughout pregnancy and after delivery to caregivers and their identified infant up to three years of age. A peer recovery coach and nurse home visitor work as a team to facilitate engagement and maximize learning. Participating families also receive parenting skills training to reinforce positive parenting behaviors while offering families group support to improve family well-being. The DE HOPE initiative implements three evidence-supported models in an integrated fashion to maximize the strengths of each model: (1) Healthy Families America home visiting program; (2) Peer Recovery Coaching; and (3) Nurturing Parenting Program.

3. Implement a statewide protocol for Plans of Safe Care

The core team developed a Plans of Safe Care template and draft implementation guide. The state fully implemented the Plans of Safe Care at all birthing hospitals across the state after completing a three-hospital pilot, which involved co-locating Child Protective Services investigators at hospitals to develop Plans of Safe Care.

The IDTA co-lead, Jen Donahue, in the Office of the Child Advocate, created a database to track Plans of Safe Care elements to align with federal CAPTA mandates and with Delaware's Aiden's Law which aligns state statutes with the CAPTA legislation. The database tracks child welfare data related to fatalities and near fatalities. The database was expanded to include information about notifications and Plans of Safe Care, including referrals for the infant or caregiver.

In addition, the state developed a request for proposal and awarded a contract to a community-based agency to implement Plans of Safe Care for families determined to be low risk through the Department of Family Services screening process. The core team is also working with medication-assisted treatment providers to implement prenatal Plans of Safe Care and to oversee low-risk Plans of Safe Care for mothers on medication-assisted treatment.

4. Maintain an awareness of the effects of stigma

The state has begun working with recovery coaches to build support for Plans of Safe Care and has provided integrated child welfare presentations to medication-assisted treatment providers and clients to discuss Plans of Safe Care. Child welfare investigators have also begun meeting with pregnant clients at their medication-assisted treatment programs to discuss the Plans of Safe Care and the provider's role in supporting families.

5. Passage of House Bill 140: Aiden's Law

House Bill 140 (149th General Assembly 2017–2018) was first introduced on April 13, 2017 and signed into law on June 7, 2018. Known as Aiden's Law, the bill "formalizes a uniform, collaborative response protocol for developing a Plan of Safe Care for infants with prenatal substance exposure and their affected family or caregivers."⁴

6. Regional Partnership Grant

In October 2017, Delaware was awarded a 5-year Regional Partnership Grant, with Children and Families First Delaware as the lead agency. The grant allowed for the expansion of the DE HOPE model described previously. The grant aligns with, and enhances the goals of, the IDTA-IPSE program by providing essential services for women in medication-assisted treatment programs and their infants with prenatal substance exposure.

D. Governance Structure, Key Partners, and Other Stakeholders

Delaware's governance structure was the strongest and most formal of the three IDTA-IPSE sites. *Table 1* on page 18 shows the governance structure. The IPSE Committee and Delaware's Fetal Alcohol Spectrum Disorder (FASD) taskforce became the oversight committee for the IDTA-IPSE program. This oversight committee reported to the Child Protection Accountability Commission on a regular basis.

An IDTA core team was comprised of representatives from the State Opioid Treatment Authority, March of Dimes, Medicaid/managed care, Department of Family Services, the Child Abuse/Neglect investigation coordinator, the FASD coordinator, and various hospital and healthcare systems. The investigation coordinator and the section chief, Office of Health and Risk Communication, Public Health co-chaired the core team and served as the IDTA project liaisons. The co-chairs ensured both a child protection and public health lens focus on Plans of Safe Care implementation.

⁴House Bill 140 (149th General Assembly 2017–2018): <https://legis.delaware.gov/BillDetail/25646>

Throughout the initiative, the team struggled to engage partners from the Division of Substance Abuse and Mental Health. Ultimately, the team did get representatives from this division, but the time lapse in gaining their participation meant that many issues that were resolved became contentious points again, such as staff from the division believing that the Plans of Safe Care would be stigmatizing to women in recovery.

Table 1. Delaware's Governance Structure

Lead Agency <ul style="list-style-type: none"> • Child Protection Accountability Commission 		
Project Liaisons <ul style="list-style-type: none"> • Jennifer Donahue, Esquire, Child Abuse Investigation Coordinator, Office of the Child Advocate • Treenee Parker, Director of the Division of Family Services, Department of Services for Children, Youth and their Families 		
Subcommittee Members	Core Team	Hospital Pilot Locations
<ul style="list-style-type: none"> • Delaware Health and Human Services • Nemours Children’s Hospital • Division of Family Services • Office of the Child Advocate • March of Dimes • Children and Families First • AmeriHealth • Christiana Care Health System • Nanticoke Hospital • St. Francis Hospital • Connections Community Support • Brandywine Counseling and Community Services • Child Death Review Commission • Fetal and Infant Mortality Review • Kent Sussex Counseling • Beebe Healthcare 	<ul style="list-style-type: none"> • Connections Community Services • Health and Human Services • Christiana Care Hospital • Connections Community Support • March of Dimes • Office of the Child Advocate • Division of Family Services • Division of Substance Abuse and Mental Health 	<ul style="list-style-type: none"> • Beebe Healthcare • Nanticoke Hospital • Kent General Hospital • Christiana Care Hospital • St. Francis Hospital

E. Data Collection and Reporting

Delaware provided all requested Census, Medicaid, substance use disorder treatment and child welfare data on IPSEs for 2015, and additional IPSE data for 2016. Delaware also provided data on the types of drugs of exposure for all 142 screened-in cases of infants with prenatal substance exposure.

In 2018, Delaware submitted a final report with 2017 data on IPSEs and their mothers.

Table 2 on page 19 shows a comparison of the 2016 and 2017 data.

Table 2. Comparison of 2016 and 2017 Delaware Data

DELAWARE DATA 2016		
Infants with Prenatal Exposure Reports to Division of Family Services (DFS) ⁵ 2016	Reports of infants with prenatal exposure	226
	• Screened-in for investigation	142
	• Screened out	77
	• Screened-out, linked to active case	7
	• Number of screened-in placed out of the home	17
	• Department of Family Services custody/private adoption	4
	• Guardianship/kinship care	6
	• Safety plan with a relative	7
	Number of screened-in remaining in the home	122
	• Pending	53
• No Safety Plan/No Plan of Safe Care	66	
• Safety Plan	3	
DELAWARE DATA 2017		
Infants with Prenatal Exposure Reports to Division of Family Services (DFS) ⁶ 2017	Reports of infants with prenatal exposure	450
	• Screened-in for investigation	315
	• Screened out	125
	• Linked to active case	10
	Of the total of IPSE cases	450
	• Number remaining in-home	376
	• Department of Family Services custody	34
	• Pending	18
	• Guardianship	12
	• Relative custody	7
• Private adoption	3	
Maternal risk factors	450*	
• History of receiving services from the Department of Family Services as a child	177 (40%)	
• Mental health condition	154 (34%)	
• Prior IPSE birth	126 (28%)	
*Overlap between all three indicators ~		
<p>Thirty eight percent of mothers that received services from the Department of Family Services as a child also have a mental health condition or diagnosis.</p> <p>- Thirty three percent of mothers with a mental health condition or diagnosis also have had a prior IPSE.</p>		

⁵Office of Investigation Coordinator, Analysis of DFS data extracts. Totals exclude coding errors, duplicate and erroneous reports
⁶Ibid.

The report also provides data on the infant's gender; the mother's race, ethnicity and age range; the number of notifications from each hospital; and the types of substances and the extent of the exposure during pregnancy. (See [Substance-Exposed Infants, 2017 Year in Review](#)). The Delaware site continues to excel in data collection and reporting of infants affected by prenatal substance exposure. This state is a role model for other states that want to improve their data collection and reporting methods for this target population.

F. Products

- Delaware Plan of Safe Care
- Delaware Plan of Safe Care Implementation Guide (Draft)
- Delaware Request for Proposals: Oversight of Low-Risk Plans of Safe Care
- Aiden's Law

G. Ongoing Implementation

The Delaware core team was disbanded after the IDTA period was completed. Ongoing work on these issues will continue under the IPSE subcommittee, which reports directly to the Child Protection Accountability Commission. Ongoing efforts include:

- Monitoring the effectiveness of Plans of Safe Care for those people identified as low-risk cases, which are primarily individuals who only use marijuana. An outpatient substance use disorder treatment provider was awarded a contract to work with these families. Initial assessments indicate that some cases may not be as "low-risk" as was anticipated.
- Finalizing a Plan of Safe Care Implementation Guide and ensuring that all hospitals have a Plan of Safe Care for all child-welfare-involved families.
- Working with medication-assisted treatment providers and recovery coaches to increase collaboration with the child welfare system and oversee Plans of Safe Care for non-child-welfare-involved families.
- Monitoring progress with a Regional Partnership Grant in developing Plans of Safe Care with pregnant women in medication-assisted treatment programs.
- Exploring opportunities to work with private buprenorphine providers who serve pregnant women.

Minnesota

A. Overview

Minnesota's IDTA-IPSE engagement began in February 2015. Because Minnesota was approved for an extended IDTA-IPSE engagement through September 2018, this state received 3½ years of in-depth technical assistance.

The Minnesota IDTA-IPSE project initiated from concerns expressed by tribes about the crisis of American Indian babies born dependent on opiates. The state witnessed a surge in the rates of American Indian women admitted to treatment programs for heroin and prescription opioids, as well as increased rates of individuals identified as using these drugs during their pregnancies. Drug use during pregnancy resulted in expanding numbers of babies being born with neonatal abstinence syndrome every year between 2012-2016. An assessment of additional data collected, at the request of tribal partners, showed that many American Indian pregnant women in need of services were not accessing prenatal care; therefore, these women were not identified until the birth of their child. Minnesota provided the following statistics to underscore the problems occurring in tribal communities. These data were taken from Medicaid claims linked to birth records.

- About 33.3 percent of American Indian Medicaid pregnancies have a diagnosis of a substance use disorder, including alcohol (from 10 months prior to 2 months following the delivery). For comparison purposes, about 7.5 percent of all Medicaid pregnancies have this diagnosis. Diagnosed opiate use in pregnancy has risen from 7.7 percent of American Indian births and 0.9 percent of all births in 2009, to 14.8 percent and 1.6 percent, respectively, in 2012.
- Fifty-five percent of mothers with or without diagnosed opiate dependency or misuse received prescription opiates at some time during pregnancy; for American Indians, the percentage is 58 percent. For those with a diagnosed opiate dependency or misuse, 15 percent of all mothers received prescriptions at some point during pregnancy, compared to 31 percent of American Indian mothers.

Twenty six percent of opiate-affected Medicaid newborns are born premature, for all ethnicities, including American Indian births. More than 50 percent of American Indian opiate-affected newborns were born to mothers who received no care or inadequate prenatal care during pregnancy. (Minnesota IDTA-IPSE application, 2014)

With the support of the NCSACW IDTA-IPSE program, the state team worked with its tribal partners to improve coordination across tribes as well as with Minnesota's substance use disorders treatment, child welfare, and maternal and child health agencies. The team employed a unified response to this crisis to achieve better outcomes for these women and their children. Multiple community and planning meetings with tribal partners within state agencies identified several specific needs. They determined that women who use opiates during pregnancy need to be identified earlier, that systems need to be aligned better to address this issue efficiently, women need better access to treatment, and the community needs to reach a consensus regarding the specific types of treatment that are appropriate for this population.

Work focused on integrating fragmented service delivery systems; identifying challenges with information sharing, especially with electronic medical records; developing community/tribal consensus for treatment models; and achieving greater alignment with state and tribal policies, cultural values and beliefs, funding priorities, and legislative proposals.

In 2015, Governor Dayton and the Minnesota Legislature passed legislation that included funding to help five Minnesota tribes provide prenatal care for women with opioid use disorder as well as services for infants, which includes community supports. The Integrated Care for High-Risk Pregnancies (ICHRP) targets opiate use during pregnancy, and supports planning, development and integration of medical and substance use disorder treatment, public health, social services, and child welfare. Additional funds were allocated to hire and train paraprofessionals on the care team with knowledge and skills related to peer recovery support, maternity care, systems navigation, and advocacy.

Tribes receiving funding included:

- Fond du Lac Band of Lake Superior Chippewa
- Leech Lake Band of Ojibwe
- Mille Lacs Band of Ojibwe
- Red Lake Nation
- White Earth Nation

In the first year of IDTA-IPSE, the change liaison focused on ongoing turnover in state and tribal leadership, communication challenges, occasional distrust between state agencies and within and across tribal communities, and differences in values and perceptions about appropriate engagement and treatment strategies for American Indian women.

Knowledge of the state and tribal context of the work in Minnesota is critical to gaining full insight and respect for the challenges and complexities faced by American Indian women, their infants, and families, and for appreciating the progress made. Although a typical IDTA-IPSE site usually involves working with state agencies and other stakeholders, such as hospital associations, and two to three implementation sites, the work in Minnesota involved multiple state agencies, three tribal advisory councils, and nine independent tribes—each with their own government structures, cultures, customs, beliefs, and priorities.

Collaborations between government and tribal entities historically have been fraught with distrust; however local governments that have persisted in establishing meaningful, respectful relationships with neighboring tribal systems have found these relationships to be very rewarding and important in accomplishing mutual public health goals. (MN Department of Health website, American Indian Tribal Governments)

B. Program Goals

Goal 1: Screening and Assessment – Pregnant women, infants with prenatal exposure, and their families will be identified in a consistent, uniform, and timely manner across all systems.

Goal 2: Joint Accountability and Shared Outcomes – Develop a collaborative practice approach to serving infants with prenatal exposure and their families, which intersects each of the systems they use.

Goal 3: Services for pregnant women, infants with prenatal exposure, and their families – Partners will agree upon evidence-based practices and programs that meet the needs of the target populations and have processes in place for monitoring the use and effectiveness of these programs.

C. Accomplishments

1. The Department of Human Services awarded state funding to five northern Minnesota tribes to deliver “Integrated Care for High Risk Pregnancies” through collaborative, community-driven approaches to serving American Indian families affected by substance use disorders and to provide wraparound supports for high-risk pregnancies. The IDTA-IPSE helped these grantees implement projects with the goal of improving birth, health, and recovery outcomes.
 2. The leadership team submitted a formal set of recommendations for responding to American Indian women with opioid use disorders, their infants, and families to the Governor’s taskforce in the fall of 2016. These recommendations were integrated into a comprehensive substance abuse system reform package, which is under legislative review. Some of the recommendations were also integrated into the action planning and work of a statewide workgroup that developed best practice guidance for child welfare staff on working with families affected by maternal substance use disorders.
 3. A [resource guide](#) was developed that provides information about programs and services available in the metropolitan area and in each tribal community for American Indian pregnant women with substance use disorders and their families.
 4. The “[Tapping Tribal Wisdom](#)” report summarizes the findings of the listening tour conducted with five tribes in northern Minnesota in September 2018, when Minnesota’s engagement in IDTA-IPSE concluded. Individual listening sessions with each of the five tribes were designed to capture information about their challenges, successes, and lessons learned as they implemented their collaborative care models. The report also discusses critical issues such as stigma and culture that have an effect on the success of collaborations.
 5. In addition to tangible products, several process changes occurred during IDTA-IPSE, including:
 - Limited buy-in at the initial application period to eventual participation of more than 150 state, tribal, and other stakeholders on a regular basis
 - Increased understanding in tribes in the areas of reimbursements for peer supports, case management, and other recovery support strategies
 - Increased understanding and acceptance of medication-assisted treatment programs
 - Improved screening and engagement practices for pregnant women
-

D. Governance Structure, Key Partners, and Other Stakeholders

Minnesota’s governance structure was the most complicated of the IDTA states, requiring the change liaison to facilitate ongoing communication and trust-building across state agencies, tribes, and local partners. The Department of Human Services Supervisor for the American Indian Section with the Alcohol and Drug Abuse Division served as the project liaison for the IDTA-IPSE program. In the first few months, the change liaison and other NCSACW staff conducted bi-monthly calls with the project liaison and other members of the core team—all of whom represented various state agencies. No tribes were represented on these calls. No oversight committee was established to whom the core team reported, nor from whom they could solicit advice or direction. Moreover, the relationship between the state agencies and the tribes was often tenuous, as tribal sovereignty allows each tribe to manage its own affairs, independent of the governing structure of state and federal governments.

Each tribe in Minnesota is independent and self-regulating. Sovereignty can create complex working relationships, because each nation or tribe is independent of other nations and tribes and should be approached as an independent government entity. (Minnesota Department of Health website, 2018)

The change liaison realized that facilitating cross-tribal involvement required the initiative to be tribal-led; therefore, state agencies had to shift their role and involvement from directing the initiative to becoming a support and resource to the tribes. Local-level work with individual tribes and their county partners was essential to establishing trust and engagement. The high turnover of both state staff and tribal council leaders during the first 18 months presented an additional challenge to building trusting relationships.

Each of the five ICHRP grantees set up their collaborative structures to maximize available resources and to build cross-system partnerships that allow them to streamline tribal resources and improve coordination of services. As ongoing collaboration evolves, tribes are also leveraging new relationships to bring in additional partners (e.g., hospitals, law enforcement, medical providers) which helps to reduce stigma and raise awareness. New partnerships also widen the circle of support that is available for Native women who are pregnant and struggling with addiction. *Table 3* shows the governance structure for Minnesota.

Table 3. Minnesota’s Governance Structure

Lead Agency Minnesota Department of Human Services	
Project Liaisons Don Moore, Department of Human Services Supervisor for the American Indian Section with the Alcohol and Drug Abuse Division	
Partners	
Department of Human Services, Chemical and Mental Health Services <ul style="list-style-type: none"> • Alcohol and Drug Abuse Division – American Indian Section • Legislative Communications • Women’s Treatment Services • State Methadone Authority 	Tribal <ul style="list-style-type: none"> • American Indian Mental Health Advisory Council • American Indian Chemical Dependency Advisory Council • American Indian Child Welfare Advisory Council
Child Welfare <ul style="list-style-type: none"> • American Indian Disparities Consultant • Child Safety and Permanency 	Minnesota Tribes <ul style="list-style-type: none"> • Boise Forte Band of Chippewa • Fond du Lac Band of Chippewa* • Grand Portage Band of Chippewa • Leech Lake Band of Ojibwe* • Lower Sioux Community • Mille Lacs Band of Ojibwe* • Red Lake Nation* • Upper Sioux Community • White Earth Nation* * ICHRP grantee
Department of Health <ul style="list-style-type: none"> • Maternal and Child Health • Home Visiting • Policy Development • American Indian Health 	

E. Data Collection and Reporting

Minnesota provided only limited data about the needs of infants with prenatal substance exposure and pregnant American Indian women with substance use disorders, although some Medicaid claims data were provided (see *Table 4*).

Table 4. Minnesota Data on Medicaid Claims

Minnesota Data	
State or Jurisdiction Overview	
Population size	60,916 American Indians (2010 census), 1.3% of the population
Number of adults	39,230
Number of children younger than 18	21,686
Type of region (urban, rural, frontier)	Fewer than 1/3 of the population living on reservations, greater than 1/3 live in urban areas
Percentage of Births covered by Medicaid	42% of all Minnesota births are covered by Medicaid; 88% of all American Indian births are covered by Medicaid

In 2018, the Department of Human Services provided the following data in a briefing on the opioid epidemic in Minnesota:

- In 2015, American Indian Minnesotans were five times more likely to die from a drug overdose than white Minnesotans; African American Minnesotans were two times more likely to die from a drug overdose than white Minnesotans.
- According to the 2015 Census Bureau data, American Indians made up an estimated 1.1 percent of the state’s population, but they represented 15.8 percent of those who entered treatment facilities for opioid abuse during the state fiscal year 2015.
- American Indian women are 8.7 times more likely to be diagnosed with maternal opiate dependency or abuse during pregnancy compared to non-Hispanic whites; infants are 7.4 times more likely to be born with neonatal abstinence syndrome.
- The number of children entering out-of-home care due to parental drug use has increased from about 1,200 in 2012 to about 2,800 in 2016. This number represents an increase of 128 percent. In 2016, American Indian children were more than 17 times more likely than white children to be removed from their home due to parental substance use.

Fond du Lac reported that 29 of its 32 graduates are now working full time. In White Earth, 100 percent of the mothers engaged in the Maternal Outreach Mood Services (MOMS) program have been able to bring their babies home with them from the hospital.

Data collection and reporting is an ongoing challenge for the tribal communities. The ICHRP grantees will be tracking birth outcomes (including neonatal abstinence syndrome) as required by the grant. They also want to demonstrate success by preventing the need to remove children from their homes, which disrupts families. In addition, their goal is to improve overall health, social, and economic outcomes for the women and children in their care.

F. Products

- [Tribal and Urban Resources for Native Americans in Minnesota](#)
- [Community Asset-Mapping Tool: Optimal Array of Services for Pregnant and Parenting Women with Substance Use Disorders and Their Families](#)
- [“Tapping Tribal Wisdom: Providing Collaborative Care for Native Pregnant Women with Substance Use Disorders and their Infants”](#)

G. Ongoing Implementation

The American Indian Advisory Council meets biannually. This council has created a structure that is most likely to sustain ongoing communication to deal with important issues across tribes. The ICHRP grantees plan to continue sharing knowledge and resources across the five sites. Minnesota will also continue to serve as a mentor for states and tribes who need help addressing the needs of pregnant and parenting American Indian women with substance use disorders, their infants, and families.

New York

A. Overview

In October 2016, the New York State Office of Alcoholism and Substance Abuse Services (OASAS) was awarded IDTA-IPSE to address the needs of pregnant and parenting women with opioid use disorders, their infants with prenatal substance exposure, and their families. The overarching mission of this project was as follows:

To improve prenatal outcomes, help women access substance use disorder treatment, and ensure women, their infants and family members have access to the array of services they need—resulting in healthy women, healthy pregnancies, healthy babies, and healthy families.

The state initially proposed working with Onondaga County in central New York State because they had a motivated cross-systems task force led by staff from Crouse Hospital and the Onondaga County Health Department. OASAS justified their selection of Onondaga County as their initial implementation site, noting that the county was clearly an area of need, and also had a strong service structure and capacity for change.

- In 2013, 140 newborns in Onondaga County received a drug-related diagnosis, out of 6,913 live births. This number represents an increase of almost 18 percent from the previous year, when only 115 newborns in Onondaga County were given a drug-related diagnosis
- In 2013, 197 pregnant women entered substance use disorder treatment; in 2015, 230 pregnant women were admitted to substance use treatment. These numbers only reflect admissions of women into non-crisis services. New York State OASAS does not collect pregnancy indicator data on admissions into crisis services.

The New York team's initial focus was primarily from a substance use disorder treatment perspective; the goals were to improve identification, engagement, and treatment of pregnant women. The oversight committee and core team were comprised of key leaders and stakeholders in Onondaga County and select state leaders from OASAS and the Department of Health, Maternal, Infant and Adolescent Health. The Office of Children and Family Services was only minimally involved at that time.

In 2017, several events occurred resulting in significant changes in the New York IDTA-IPSE program.

- The IDTA-IPSE program director and the change liaison met with staff from the Office of Children and Family Services and OASAS to discuss the 2016 CARA amendments to CAPTA and the opportunities to address the new CAPTA requirements.
 - The initiative was expanded in year two to include Washington, Warren, and Essex Counties. The expansion was due mostly to the work underway at Glens Falls Hospital in collaboration with members of a neonatal abstinence syndrome taskforce.
 - The oversight committee/leadership committee was reconfigured and is now comprised of deputy commissioners and senior directors and managers from OASAS, the Department of Health and the Office of Children and Family Services. Onondaga, Washington, Warren, and Essex counties were designated as implementation sites. Members from the sites also served on subcommittees or ad hoc committees as needed.
-

- The goals and strategies were revised to eliminate duplication of efforts and complement and leverage the work being done in other initiatives (e.g., screening during pregnancy). A goal related to the 2016 amendments to CAPTA requirements for infants affected by prenatal substance exposure and their families was added. The revised goals reinforced the need for greater involvement from the Office of Children and Family Services and continued involvement of each of the state and local partners.

In September 2018, the New York IDTA-IPSE site was approved to receive an additional six months of technical assistance to focus on implementing the strategies developed during their involvement with NCSACW. This work included piloting the New York CAPTA criteria, hospital notification form, and Plans of Safe Care for infants with prenatal substance exposure in the implementation counties.

The leadership committee began developing a training and dissemination plan for hospital staff across the state on CAPTA and the Office of Children and Family Services forms, training vignettes for prenatal care providers, and information briefs for substance use disorders treatment providers on understanding their role in meeting the CAPTA/CARA requirements. Lessons learned in the implementation counties will help inform the type and extent of guidance state partners need to provide to other regions as they roll out CAPTA statewide.

B. Involvement of American College of Obstetricians and Gynecologists, District II

The contextual event that had the most impact on the New York initiative was the involvement of the American College of Obstetricians and Gynecologists (ACOG), District II. In August 2017, the national ACOG Council on Patient Safety in Women's Health Care released a new patient safety bundle focused on obstetric care for women with opioid use disorders. They then formed the Alliance for Innovation on Maternal Health (AIM) National Collaborative on Maternal Opioid Use Disorder. ACOG District II, with funding from the New York State Health Foundation, is participating along with 13 other states.

In 2018, New York ACOG District II released an [Opioid Use Disorder in Pregnancy Provider Education Bundle](#). This educational bundle focuses on preparing for, recognizing, and preventing opioids use disorders in pregnancy. These materials were developed by a multidisciplinary group of women's healthcare providers to improve the quality and safety of care provided to pregnant women with opioid use disorders. OASAS and Department of Health staff have been involved in developing the materials. It addresses one of the primary goals to universally screen women of childbearing age and pregnant women for opioid use disorders. Providers are trained in the use of SBIRT. In addition, OASAS treatment providers are instructed to engage with their local prenatal care providers to help assess and engage women in treatment when indicated.

The New York State Perinatal Quality Collaborative is an initiative led by the New York State Department of Health, Division of Family Health. One of the Perinatal Quality Collaborative goals is to collaborate with ACOG District II and other partners through the AIM Bundle to identify and manage women with opioid use disorder during pregnancy, standardize therapy, and coordinate aftercare for infants with neonatal abstinence syndrome. The Perinatal Quality Collaborative's involvement has allowed additional sites to participate in the initial roll-out of the AIM Bundle training.

As with the ACOG, the Department of Health/Perinatal Quality Collaborative plays a key role in ensuring that women with opioid use disorders are identified early in pregnancy and Plans of Safe Care are developed prior to delivery.

ACOG District II staff have been very involved in the IDTA-IPSE program, participating in regular calls, site visits, and materials development. They are collaborating with OASAS on developing training vignettes that are intended to help healthcare providers better screen and engage women with opioid use disorders. These vignettes will be made available to providers throughout the state. They are also hosting a conference of OB-GYNs, other prenatal care providers, and other key stakeholders to learn more about a multi-partner collaboration in Vermont known as CHARM, or Children and Recovering Mothers, that takes a multidisciplinary approach to serving pregnant and postpartum women with opioid use disorders.

C. Program Goals

Goal 1: Increase universal screening for substance use of all women of childbearing age—with a primary focus on pregnant women.

Goal 2: Increase identification and engagement in substance use treatment of women and infants, including outreach to women in marginalized populations.

Goal 3: Promote the use of peer-recovery support services for pregnant and parenting women with substance use disorders.

Goal 4: Identify and implement policy and practice changes as needed to comply with CAPTA requirements and to promote child and family well-being.

D. Accomplishments

1. Increase universal screening

- In collaboration with the Department of Health and OASAS, ACOG District II is working with OB-GYNs and other prenatal care providers to ensure that SBIRT are standard practice for pregnant women and women of childbearing age.
- OASAS and ACOG are developing a series of vignettes to assist OB-GYNs and other prenatal care providers with screening pregnant women for substance use and connecting them with additional assessments and treatment when indicated. The vignettes are available at <https://www.acog.org/community/districts-and-sections/district-ii/programs-and-resources/medical-education/opioid-use-disorder-in-pregnancy>

2. Increase identification and engagement of women in substance use treatment

- Along with local treatment providers in three SAMHSA grant locations, OASAS is developing a wraparound model for serving pregnant and parenting women with substance use disorders and their infants and children.
- Local implementation teams are developing a multidisciplinary approach for creating and monitoring Plans of Safe Care for pregnant women with substance use disorders prior to delivery and following the birth event.
- OASAS developed a marketing campaign on “Pregnancy and Addiction” with materials placed in prenatal care clinics. Materials are designed to encourage women to talk with their

healthcare providers about any substance use and for healthcare providers to encourage open dialogue with pregnant women and women of childbearing age.

3. Promote the use of peer/recovery support services

- OASAS funded four wraparound models for pregnant and parenting women with opioid use disorder and their families. Providers are required to include peer support services as an integral part of the wraparound model.
- Crouse Hospital is using peers prior to and after delivery with women who are not already engaged in treatment services. Peers will also support women in following through with treatment and other services identified in the Plan of Safe Care.

4. Implement CAPTA policy and practice changes

- In collaboration with other state agencies, the Office of Children and Family Services developed and implemented a CAPTA policy related to infants affected by prenatal substance exposure. Practice changes are being implemented in pilot counties.
- In collaboration with the Office of Children and Family Services, the Department of Health is developing a statewide training for hospital staff on changes in CAPTA requirements related to the New York CAPTA policy, including notifications of infants affected by prenatal substance exposure and the development of Plans of Safe Care for infants, their families, and caregivers.

5. Regional Partnership Grant

- In October 2018, a new Regional Partnership Grant was awarded to Montefiore Medical Center in New York City to improve child welfare outcomes among pregnant women at risk of substance misuse and their newborns. The dual goals of this project are (1) to improve communication and collaboration between substance use treatment providers, obstetricians, and child welfare providers and (2) to enhance child welfare outcomes for pregnant women who are at risk of substance misuse and their babies. The IDTA-IPSE change liaison facilitated connections with members of the state leadership team to ensure the state and local team work together to implement consistent strategies, such as screening pregnant women and following through with the CAPTA notifications requirements.

E. Governance Structure, Key Partners, and Other Stakeholders

New York's initial oversight committee included the Associate Commissioner, Treatment Department for OASAS; the Commissioner for the Onondaga Health Department; a neonatologist for Crouse Hospital, Onondaga County; and the Onondaga County district attorney. Oversight committee members were minimally involved with the core team during the first year.

The core team was comprised of state program directors and senior staff, Onondaga County staff, and community stakeholders. An evaluation staff member in the OASAS, Bureau of Women, Children and Adolescent Health served as the New York project liaison. She conducted monthly calls with the core team but found it difficult to engage them in any meaningful work.

Comprised of core team members, committees were formed to address each of the goal areas. The project liaison chaired each committee and conducted monthly calls. Although each committee had identified activities, the project liaison found it difficult to get work completed.

In October 2017, the governance structure changed as the New York team expanded to other implementation sites and aligned their work with other statewide initiatives. Deputy commissioners, program directors, and senior program managers from OASAS, Office of Children and Family Services, and the Department of Health formed a new leadership team (oversight committee). The team focused on understanding and aligning related initiatives, prioritizing goals, and developing collaborative strategies and products. The ACOG District II Manager, Medical Education, while not an official member of the leadership team, participated in team meetings and ad hoc committees. Her involvement was key to the state’s progress with universal screening of pregnant women for substance use. Implementation counties formed local core teams to work on implementing CAPTA requirements.

This structure proved to be much more effective than the previous one. The New York leadership team is more likely to sustain their cross-system collaboration for any implementation challenges that involve multiple agencies. *Table 5* shows New York’s governance structure.

Table 5. New York's Governance Structure

Lead Agency Office of Alcoholism and Substance Abuse Services (OASAS)	
Project Liaisons Dr. Maggie Taylor, Research Scientist, OASAS, Bureau of Women, Children and Adolescent Health Maria Morris-Groves, Director, OASAS, Bureau of Women, Children and Adolescent Health	
Partners	
OASAS •Bureau of Women, Children and Adolescent Services	Office of Children and Family Services • Division of Child Welfare and Community Services
Department of Health • Division of Family Health -Bureau of Women, Infant and Adolescent Health -AIDS Institute • Division of Hospitals and Diagnostic and Treatment Centers	American College of Obstetricians and Gynecologists, District II
Implementation Counties: • Onondaga • Washington • Warren • Essex	Local implementation teams included: • Crouse Hospital • St. Joseph’s Hospital • Glens Falls Hospital • Medication-assisted treatment and other substance use treatment providers • Local child welfare providers • Prenatal care providers • Pediatricians • Local health departments • Perinatal networks • Neonatal abstinence syndrome taskforces • Healthy Start and Nurse Family Partnership programs, and • Federally Qualified Health Clinics

F. Data Collection and Reporting

Table 6. New York Data on Medicaid Claims

New York Data*	
State or Jurisdiction: Onondaga County	
Substance Use Treatment⁷	
Number of adult substance use treatment entries	11,010
Number of admissions of women entering substance use disorders treatment	3,863
Number of admissions of pregnant women entering substance use disorders treatment	197
Department of Health	
Number of live births ⁸	Crouse Hospital: 3,884 Upstate University Hospital: 1,040 St. Joseph’s Health Center: 1,989 Total for the county: 6,913
Child Welfare	
Number of infants with prenatal exposure reported to Child Protective Services per CAPTA regulations	Data unavailable
Number of IPSEs who are placed in out-of-home care	Data unavailable
Number of IPSEs reported to IDEA Part C	Data unavailable
Medicaid	
Total estimated population	468,387 ⁹
Total number of people enrolled in Medicaid	98,249 ¹⁰
Percentage of people receiving Medicaid assistance in the general population	20.98%

* Data were provided in the 2016 New York IDTA application.

In September 2016, the Department of Health’s Statewide Planning and Research Cooperative System reported the following data by county for 2012–2014 for the neonatal abstinence syndrome rate per 1,000 newborn discharges (any diagnosis) (Department of Health, 2016). *Table 7* on page 33 provides neonatal abstinence syndrome data for the implementation counties only.

⁷ Data from New York State OASAS
⁸ Data retrieved from the New York State Department of Health, Hospital Maternity-Related Procedures and Practices
⁹ Data retrieved from the Onondaga County website, which presents data from the U.S. Census: <http://www.ongov.net/about/populationTrends.html>
¹⁰ Data retrieved from the New York State Department of Health, Medicaid Statistics

Table 7. Neonatal Abstinence Syndrome Rate per 1,000 Newborn Discharges by Implementation County in New York (2012–2014)

Region/County	Discharges				Average Number of Newborns
	2012	2013	2014	Total	2012-2014
Essex	s	s	s	6	220
Warren	8	8	6	22	587
Washington	7	6	s	14	536
Onondaga	39	44	49	132	5,123

“s” means that data do not meet the reporting criteria

In 2018, OASAS reported that 2,000 women were pregnant at the time of admission to any state-funded substance use treatment program. OASAS staff reported this number may represent duplicate clients because clients could have entered more than one program during the year.

ACOG District II is also required to collect data to participate as an AIM Bundle site. The national metrics include, but are not limited to:

- Pregnancy-related opioid deaths
- Average length of stay for newborns with neonatal abstinence syndrome
- Percentage of women with opioid use disorders who received medication-assisted treatment or a behavioral health assessment
- Percentage of prenatal care sites that have implemented a universal screening protocol
- Percentage of newborns diagnosed with neonatal abstinence syndrome

Data collection and reporting was listed as a major challenge in the original application. The team still struggles with collecting and reporting certain data elements, especially the new CAPTA requirements for hospital notifications for substance-affected infants. This is an issue that needs ongoing attention from the leadership committee. The ACOG AIM Bundle sites are likely to produce some of the best data related to both women and infants.

G. Products

- [New York Office of Children and Family Services CAPTA Policy](#)
- [New York Office of Children and Family Services CAPTA Referral/Notification Criteria](#)
- [New York Office of Children and Family Services CAPTA Notification Form](#)
- [New York Office of Children and Family Services Plan of Safe Care Template](#)

- Onondaga County Neonatal Abstinence Syndrome Brochure
- ACOG District II AIM Bundle/Training Guide
- AIM Opioid Metrics
- OASAS training guide CAPTA brief for substance use treatment providers
- ACOG/OASAS vignettes for prenatal care providers
- OASAS media campaign for pregnant women with substance use disorders

H. Ongoing Implementation

The New York leadership committee continues to collaborate on the following:

- Completing a statewide training and dissemination plan for hospitals for CAPTA notifications, development of Plans of Safe Care, and data collection and reporting
- Completing ACOG/OASAS vignettes for prenatal care providers
- Developing guidance for regions and counties to ensure a successful statewide roll-out of CAPTA, which includes developing a Plan of Safe Care at multiple intervention points
- Ensuring ongoing communication between state partners, ACOG District II, and the Montefiore Regional Partnership Grant

Collaboration

A. Partners and Other Stakeholders

The IDTA-IPSE program promotes effective collaboration and partnerships across multiple child- and family-serving agencies and systems. NCSACW recognizes that cross-system linkages between substance use disorder treatment, child welfare, public health, healthcare, early intervention, and other service systems are essential for achieving positive outcomes for pregnant and parenting women with substance use disorders, their infants, family, and other caregivers.

As with Round One of the IDTA-IPSE program, these sites learned the importance of identifying and engaging on an ongoing basis with all the partners that are necessary for meeting the needs of this population of women, their infants, and families.

- For Delaware to accomplish its goals, the state needed to engage community hospitals and local treatment providers to successfully implement CAPTA requirements.
- Minnesota state partners would not have made significant progress toward their goals without the tribal communities and their local partners taking the lead on their initiative.
- In New York, the partnership between OASAS, ACOG District II, the Department of Health, and the Perinatal Quality Collaborative is resulting in a model of early prenatal screening and engagement in substance use treatment that none of these agencies or organizations would have achieved alone.

Local-level implementation requires identifying and engaging a set of partners and stakeholders that carry out the work that was initiated at the state level. Taking time to engage team members and foster collaboration is essential for successful implementation. Partners in all three sites recognized the importance of establishing strong partnerships with hospitals and other medical providers.

Developing good relationships and effective communication with healthcare providers for women, their infants, and families was especially important for these sites.

Sites also recognized that a siloed response to these issues would not produce the outcomes they hoped to achieve. Effectively responding to the opioid epidemic requires strong participation from child welfare agencies as well as health departments and substance use treatment agencies. In addition, child welfare agencies cannot be the only entity responsible for implementing CAPTA and developing Plans of Safe Care. Prenatal care providers, hospitals, pediatricians, public health, substance use treatment providers, the courts, and early intervention agencies must all have a role in supporting families.

To address challenges with collaboration, sites sometimes needed to step back and examine their original goals and expectations. They then needed to assess the issues that might be contributing to the lack of engagement of critical partners. New York struggled initially to get child welfare involved consistently until they realized their goals were primarily focused on women's

substance use disorders and treatment. Similarly, the Office of Children and Family Services was initially focused only on child welfare's responsibilities to comply with CAPTA. The New York team added a goal related to implementing the 2016 CAPTA amendments and spent a significant amount of time discussing how CAPTA/CARA related to and even enhanced other state-level initiatives. Linking CAPTA implementation to the focus on how addressing prenatal substance exposure can prevent or mitigate child welfare involvement, resulted in significant involvement of child welfare staff on the leadership committee, the core team, and at the local level.

Although the governance structure and number of stakeholders varied, sites were very similar with regard to the types of partners they needed and challenges they faced with engaging and retaining these partners.

Although local teams reported having needs and concerns specific to their communities, they also reported the need for support and direction from state team members, especially as it pertains to implementing CAPTA policies.

B. Governance Structure

An effective governance structure, with open and ongoing communication within and across agencies and systems, is necessary for making and sustaining the changes these sites proposed. NCSACW recommends that sites adopt a governance and committee structure to support their work that includes commitment and oversight from the highest level of state leadership, ongoing participation and decision-making authority from senior management and directors, one or more project liaisons who can dedicate the time to manage the initiative, and strong local-level teams for successful implementation. See Appendix, Section C on page 52 for a discussion on developing a governance structure and identifying partners. Each site ultimately adopted a governance structure that was influenced by a number of internal and external factors, but was effective for achieving their goals.

An effective governance structure is also necessary for sustaining the work when the IDTA engagement ends. Building on existing structures and initiatives has proven to be the best method for sustaining this work over time. Examples of these types of structures and initiatives, described in previous sections of this final report, include Delaware's Child Protection and Accountability Commission and Regional Partnership Grant, Minnesota's High-Risk Pregnancy grant program, New York's ACOG AIM Bundle for Pregnant Women with Opioid Use Disorders, and the Perinatal Quality Collaborative.

Stigma and Differences in Values and Perceptions

Stigma and differences in values and perceptions about pregnant and parenting women with substance use disorders were identified as major concerns by each site.

Sites identified substance use during pregnancy and parenting as a public health, child welfare, and criminal justice concern. Sites also found that women facing stigma and fear that they will be punished or that their infant will be removed from them were reluctant to disclose health and social histories and provide critical information for developing an appropriate plan of care.

Addressing stigma was one of Delaware's primary goals. Partners identified the need for increased awareness of the effects of stigma in discouraging pregnant women from seeking treatment or prenatal care. They focused on the importance of ensuring that medical providers give non-judgmental support so women feel safe in discussing substance use or misuse; working with recovery coaches to

build support for Plans of Safe Care; and deploying child welfare investigators to meet with pregnant clients at their medication-assisted treatment facilities to discuss the Plan of Safe Care and their role in supporting families.

Minnesota tribal communities noted that fear stems from the stigmatization associated with addiction, especially in small communities where everyone knows everyone else. This impacts engagement and makes it very difficult to intervene during pregnancy due to the fear, stigma, and shame that inhibits pregnant women in need of treatment and prenatal care from obtaining it (Tapping Tribal Wisdom, 2018). Avoiding prenatal care was cited as one of the greatest concerns for American Indian women in Minnesota. ICHRP grantees are concentrating their attention on working more closely with prenatal providers and Child Protective Services to reduce barriers related to fear. (Tapping Tribal Wisdom, 2018).

The New York Department of Health leaders expressed concern that simply screening pregnant women for substance use disorders further stigmatizes these women and drives them away from care—especially women of color. They advocated for screening all adolescents and adults for substance use disorders, while designating pregnant women and women of childbearing age as priority populations for starting universal screening. The ACOG AIM Bundle training encourages providers to heed the importance of using non-stigmatizing language. As with the Round One IPSE sites, partners advocated for these strategies to addressing stigma and differences in values and perception regarding pregnant women with substance use disorders:

None of the states involved in this initiative have laws or policies that penalize women for substance use during pregnancy. However, most partners agreed that pregnant women still feared they would be condemned, punished, or that their child would be removed from them at birth. These fears often led them to avoid prenatal care and substance use disorder treatment, and to isolate themselves even more from family and friends.

- Use consistent and non-stigmatizing language and definitions when referring to pregnant and parenting women with substance use disorders and their infants or children.
- Increase outreach and engagement efforts to help pregnant and parenting women overcome self-stigma and begin to address their feelings and perceptions of negative self-worth.
- Develop community and cross-systems education to increase understanding of substance use disorders, especially opioid use disorders, as a disease; the history, trends, and treatment of heroin use and prescription pain medication misuse; and the social stigma that arises when groups lack accurate information or perpetuate stereotypes.
- Understand and address existing practices and policies in each system, including negative attitudes and behaviors that inhibit pregnant and parenting women from accessing services.

The White Earth Maternal Outreach Mood Services (MOMS) program has “a huge push to repeat messaging that you won’t get your children removed if you come for help. We’ve held firm to that model, so the community knows it’s true.” These efforts are paying off, as evidenced by an increased number of women who are willing to sign up for voluntary cases to receive extra help and protection for their families.

Barriers to Services for Women and their Families

Barriers to services for women and their families were identified along each intervention point, particularly during pregnancy, the birth event, and during the critical postnatal/postpartum period. Partners used case studies, walkthroughs, focus groups, and surveys to identify and gain insight into barriers and gaps in services.

Prenatal providers in tribal communities expressed concerns about going against what the patient wants. They also have competing requirements. They must maintain client trust while choosing whether to screen for a substance use disorder that, if identified, requires them to notify Child Protective Services.

A. Early Identification and Screening

Screening for substance use in hospital settings is often done selectively or targeted to certain women, which can result in racial and socioeconomic bias. Screening all patients using a validated instrument increases the chance that prenatal substance abuse will be identified, addressed, and potentially reduced. Despite the American College of Obstetricians and Gynecologists 2012 recommendation for universal screening of all pregnant women for substance use disorders, sites reported that screening for substance use is either done without the use of a standardized screening tool or a discussion designed to elicit an honest response, screening is done selectively or targeted to certain women, or screening does not occur. Each of the sites in Round Two included a goal to increase the number of screenings they perform for substance use during pregnancy.

In October 2018, Dr. David Garry, Director of Fetal Medicine at Stony Brook University School of Medicine in New York, facilitated a webinar for IDTA-IPSE sites on the ACOG District II AIM Bundle. During the webinar, he cited several reasons physicians are still reluctant to screen for substance use, including:

- Having the time, place, and appropriate person to conduct screens
- Knowing what tool to use
- Knowing what to do with positive toxicology results, especially how to connect women to appropriate treatment services
- Dealing with patients' fears that if they admit to using substances, it will create problems and could result in punitive measures
- Having restrictions against sharing the results of screening in electronic health records, due to confidentiality regulations

Prenatal care providers generally lack knowledge and understanding about treatment options, the characteristics of quality treatment, and the methods for referring and connecting pregnant women with substance use disorders to appropriate treatment. Although medical and behavioral health care should be integrated, the process for referring and connecting a patient to substance use disorder or mental health treatment is very different from customary referral practices that general practitioners employ. Some providers also fear liability if they suspect the patient has a substance use disorder but does not follow up on a referral or engage in treatment.

B. Engagement and Retention in Treatment

Engaging and retaining pregnant and parenting women, their infants, families, and caregivers in services is a recurring challenge identified by IDTA-IPSE sites. The following are the most frequently cited barriers to treatment for pregnant and parenting women with substance use disorders, particularly opioid use disorder:

- Pregnant and parenting women do not understand or have a resistance to medication-assisted treatment, and they do not understand that women with opioid use disorder who are not on medication-assisted treatment are at greater risk of poor maternal and neonatal outcomes. Although medication-assisted treatment is a well-established, evidence-based treatment approach to opioid use disorder, especially for pregnant and postpartum women, some child welfare, medical, and even other treatment professionals have some resistance to using this treatment.
- In the early stages, most of the tribes in Minnesota involved with the IDTA-IPSE program were reluctant to endorse the use of medication-assisted treatment because of concerns about diversion of the medication and negative health consequences for the unborn child, as well as a fundamental belief in abstinence and the power of traditional healing methods.
- Opioid treatment providers who only prescribe medication (e.g., buprenorphine) lack connections to therapeutic services.
- Many opioid treatment providers and other treatment providers do not accept pregnant women as patients, particularly those in the second or third trimester. Because many pregnant women with opioid use disorder do not access prenatal care or treatment until later in their pregnancy, it becomes even more challenging to engage and retain them in treatment when medication-assisted treatment is not provided.
- Maternal health care and medication-assisted treatment providers are often reluctant to discuss the implications of infant prenatal exposure with pregnant woman prior to delivery.
- Confidentiality regulations are still cited as a reason for not sharing information with critical partners (e.g., physicians, child welfare professionals); and for failure to gain consent from women to share information to develop comprehensive health plans, safety plans, or Plans of Safe Care.

Medical and psychiatric providers, and even specialty substance use disorder treatment providers, are sometimes reluctant to use medication-assisted treatment (buprenorphine, naltrexone). Even more troublesome is the reluctance of some substance use disorder providers to accept patients who already receive medication-assisted treatment, especially methadone. The discomfort may stem from negative attitudes or prejudices against medication-assisted treatment, insufficient or inaccurate knowledge about this type of treatment, inadequate reimbursement for the treatment services, or a lack of resources needed to provide or support this treatment. (Stoller et al., 2016)

- Culturally appropriate and evidence-informed services and treatment options are often not available for American Indian women with opioid use disorders and their families.
- Maternal health care, opioid use disorders providers, child welfare, and other family service providers often do not understand co-existing mental health problems, such as depression, anxiety, and post-traumatic stress disorder. Nor do they recognize that a large percentage of women with co-occurring disorders have been abused in childhood or as adults. When these issues are overlooked, women may not be connected to critical and appropriate services. This situation is especially troublesome during the postpartum period when women may not be connected to any provider or service.

C. Services for Infants, Their Families, and Caregivers

Hospitals have inconsistent and a range of practices in identifying infants with prenatal substance exposure vary. As a result, infants with FASD and other drug exposures are significantly under-reported which, subsequently, makes it difficult to screen these children for developmental delays and help their families access the services they need on a timely basis.

Ongoing Challenges

Ongoing challenges found across the sites are as follows:

- The lack or inconsistent application of hospital protocols for identifying, assessing, monitoring, and intervening, using non-pharmacological and pharmacological methods, for neonates prenatally exposed to opioids.
- The lack of or inconsistently applied hospital protocols that promote mother-infant bonding, including rooming-in, skin-to-skin contact, and breastfeeding, unless the latter is contraindicated.
- Inconsistent or delayed hospital notifications to Child Protective Services for infants that meet CAPTA requirements for prenatal substance exposure.
- Inconsistent responses by Child Protective Services to hospital notifications, which can result in hospital staff not wanting to contact Child Protective Services.
- Hospital discharge plans that do not address the mother's substance use or engage her in services prior to leaving the hospital.
- The lack of programs providing family-centered treatment for women, their children, and other family members.
- Infants not being referred to, or found ineligible for, early intervention (IDEA Part C) services.
- Home visiting providers not equipped to work with pregnant and parenting women with substance use disorders. These programs are voluntary and providers report that some are unable to engage their clients.

- The lack of consistent medical coverage, continuing care, relapse prevention programs, and follow-up for postpartum women and their infants. This barrier emerged as one of the biggest concerns in most sites.
- Insufficient training, engagement, and support for foster parents and other caregivers when infants with prenatal exposure are not discharged to mothers or family.
- Limited access to transportation and childcare services. Access to services in rural areas and tribal communities remains a challenge, especially when families need to travel to adjacent counties for critical services, or when services are not available in the tribal community.

Addressing the Barriers

Site teams have begun to address these barriers in several different ways, as was noted in the site profiles.

- Delaware and New York are working statewide with hospitals on protocols that address the need for timely and consistent identification and management of infants with prenatal exposure, particularly those with neonatal abstinence syndrome. Delaware conducted a hospital survey which helped to inform protocols and practice changes for mothers with substance use disorders and their infants in hospitals across the state.
- Delaware and New York are developing systems of care for pregnant and parenting women and their families that capitalize on multiple intervention opportunities and require a collaborative, coordinated approach from all stakeholders.
- The New York OASAS has funded a wraparound model of care in four regions for pregnant and parenting women with opioid use disorders. The model focuses on care coordination and enhanced support during the postpartum period through the first year of the infant's life.
- In Delaware, the DE HOPE model takes a multidisciplinary team approach to providing services for women in medication-assisted programs and their infants with prenatal substance exposure. Services and supports are provided throughout pregnancy and after delivery to caregivers and their identified infant up to the age of three. Services include Healthy Families America (a home visiting program), Peer Recovery Coaching, and Nurturing Parenting Program.
- Each of the five Minnesota ICHRP grantees have integrated medication-assisted treatment as a treatment option for pregnant and postpartum women with opioid use disorder to at least some degree. ICHRP sites are each implementing a model of care coordination for pregnant and parenting women and their infants.

Implementation Challenges

A. Data Challenges and Needs

Collecting and reporting consistent and reliable data within and across systems continues to be a challenge for these sites, as it was with states in the first round of IDTA-IPSE.

Complete and reliable data are necessary to fully understand several important aspects of program planning and implementation: (1) characteristics of the target population to be served compared to the general population; (2) comparisons of local and statewide data; (3) analysis of the extent of the needs to be addressed; and (4) review of the effects of policy and practice changes and whether they result in improved outcomes. Data dashboards or annual cross-system data reports can illustrate the state and local results achieved when systems collaborate to address a significant problem such as the opioid epidemic.

Sites were asked to provide specific data elements in their IDTA-IPSE application. Although Delaware provided the most extensive data yet on infants with prenatal substance exposure, this state provided limited data on substance use disorder treatment admissions for pregnant women. New York provided data on women in treatment; however, it was primarily local data from Onondaga County, the proposed implementation site. Minnesota provided data related to pregnant women with opioid use disorders and infants and children that were removed from their homes in tribal communities. However, in both New York and Minnesota, the lack of statewide data made it difficult to compare unmet needs of the target populations statewide as well as regionally.

As sites discussed the importance of measuring and reporting on their outcomes, they learned who is responsible for and can provide specific data elements. This includes numbers of pregnant women screened for substance use disorders; pregnant women in treatment programs; Plans of Safe Care developed during pregnancy and at birth; infants with prenatal substance exposure; hospital notifications; and infants remaining with mothers and families upon discharge and at follow-up. States have often found it challenging to obtain and analyze these data from multiple data sources, including state health departments, child welfare agencies, single state substance abuse agencies, and Medicaid. Moreover, they began to understand how data from partner agencies were essential for demonstrating improved outcomes and telling a more complete story of the families they served.

The current sites reported the following challenges:

- A lack of baseline data that defines needs within and across systems to demonstrate potential cost savings and improved outcomes. Data are needed on the number of pregnant women in substance use disorders treatment programs and the number of infants identified as being born with and affected by prenatal exposure.
- Difficulty with getting reliable, unduplicated counts for women who were pregnant at the time of being admitted to substance use disorders treatment in both publicly funded and private programs.

The current sites reported the following challenges:

- Inconsistent reporting of infants with prenatal exposure; that is, hospitals may identify infants with any withdrawal symptoms from substance exposure or with a substance exposure diagnosis, but they may not be notifying Child Protective Services according to CAPTA requirements. Hospitals are more likely to report infants with withdrawal symptoms, but data on infants with FASD or prenatal exposure to other drugs were even harder to find.
- Data on infants with neonatal abstinence syndrome do not differentiate between infants born to mothers who are in medication-assisted treatment programs or who take medications as prescribed as opposed to mothers who take illegal opioids or who do not take medications as prescribed.
- Inconsistencies with collecting and reporting data for CAPTA reporting requirements.

Lessons Learned

It takes time to assemble the array of relationships needed to fully address the needs of pregnant and parenting women, their infants affected by prenatal substance exposure, and other family members and caregivers. Lessons from Delaware, Minnesota, and New York expand upon lessons learned from previous IDTA-IPSE sites.

A. Collaboration

- Teams must have an array of committed partners, including child welfare, substance disorder treatment/women's treatment services, and medication-assisted treatment providers; mental health agencies; Department of Health, maternal and child health, home visiting, and hospital/institution licensing staff; OB-GYNs, midwives, and other prenatal care providers; pediatricians and neonatal staff; and early intervention/IDEA Part C providers. NCSACW also highly recommends encouraging the participation of state or regional ACOGs, hospital associations, Perinatal Quality Collaboratives, and Medicaid and managed care plans.
- Retaining partners and keeping them engaged with state and local teams requires that they derive value from their participation. The work must be relevant to each system and be of value to respective partner goals and initiatives. Partners must understand the expectations for participation and contributions. Building upon existing programs and initiatives and avoiding duplication of efforts will help members stay involved. Partners often feel overburdened by participating in multiple collaborations, which is often the situation as states have implemented strategies in response to the opioid epidemic.
- Ensuring teams reach agreement on goals, outcomes, and indicators from the outset is critical. Teams must also be open to adapting, revising, and prioritizing goals and governance structures when needed to achieve outcomes.
- All partners are responsible for reaching out to and engaging missing partners. Engaging opioid treatment providers, especially office-based providers, continued to be a challenge for partners who need to understand and coordinate all aspects of women's health care, including medications prescribed to treat substance use disorders. Effective strategies for engaging these providers included having other team members visit opioid treatment programs; having in-person meetings or telephone calls to explain the collaboration across agencies and how it would benefit both providers and their patients; developing paper or electronic consent forms that make it easier to secure consent to share information; and offering expert consultation when working with pregnant women with multiple and complex needs. These same strategies can be applied to help engage missing partners.

B. Governance Structure

- Sites with an involved, supportive, and consistent oversight/executive committee were able to break through challenges more quickly and keep issues elevated to the highest level of state government. Core team members not only need a significant level of authority, but direct access to Agency Commissioners and Secretaries when challenges and barriers arise.

- Turnover of staff at all levels—oversight/executive committees, core team members, and team chairs—is expected, but the resulting changes can halt or derail progress. Therefore, team members must share responsibility so that not just one person or agency is responsible for continuing the work. Partner agencies must plan for ongoing participation when they experience turnover of staff assigned to serve on the team.
- The project liaison, chair, or co-chair is critical to the success of this initiative. All three sites had leads or co-leads who left or went on temporary leave during this time. In one situation, the lead agency identified another person better suited to lead the work. However, the sudden and unexpected loss of a project leader or key partner can mean that certain aspects of the work are postponed.
- Keeping stakeholders engaged requires being realistic and creative with the time needed from stakeholders. Getting members to attend regular in-person meetings continues to be a challenge. In-person meetings and face-to-face encounters are especially important in tribal communities. However, meeting in person is often challenging because there is no clear mechanism to support ongoing collaboration in terms of staffing or centralized leadership, both within and across tribal communities.

C. Values and Perceptions

- Discussing differences in values and perceptions is an ongoing process essential for developing trust and fostering collaboration among partners. This is particularly true when engaging providers at the local level who were not involved in initial discussions with state partners. All partners must feel they can engage in conversations about challenging topics related to substance use during pregnancy, keeping mothers and infants together, making reports to Child Protective Services, using medication-assisted treatment with pregnant women, and the like.

D. Services for Women and Their Families

- Programs need to ensure that all partners understand the *Five Points of Intervention Policy and Practice Framework* and look for opportunities to leverage public and private partners at each intervention point. Initially, the priorities focused primarily on intervention during pregnancy, at the birth event, and with the infant and family following discharge from the hospital, state strategies should also include an emphasis on prevention. These strategies include pregnancy prevention, opioid prescribing practices, and services and supports for children and families beyond the first year of life.
 - Mapping community resources, conducting walkthroughs, and analyzing local case studies are important tools for broadening our understanding of existing programs, how systems operate, the role of each partner, and the gaps and barriers encountered by women and their families and partner agencies.
 - Care coordination is an effective strategy for maintaining strong linkages and effective communication across multiple agencies, particularly among maternal health care,
-

medication-assisted treatment, and other substance use disorder treatment providers. Care coordinators are also needed to engage and retain families in services who may find it difficult to navigate multiple agencies and competing demands.

E. Implementation Challenges

- Statewide practice changes cannot be implemented by simply issuing a policy brief or guidance document. Dialogue with local partners is critical, whether that occurs through onsite training and meetings, webinars, or phone consultations. Local partners need opportunities to discuss their concerns, communicate their perceptions, and ask questions. Implementation on a large, statewide scale takes time. Phasing-in across multiple regions and counties is likely to yield greater success and compliance than implementing changes on a wider scale.
- Medicaid directors, managed care entities, and hospitals must be engaged in data collection and reporting, and discussions about outcomes. These systems need to understand what outcomes are expected, how they will be achieved, and identify outcomes that may be contradict each other. For example, a public health outcome may be to show a reduction in neonatal abstinence syndrome births. However, if more pregnant women are engaged in medication-assisted treatment, a goal of the substance use disorder treatment system, the number of neonatal abstinence syndrome births may increase.
- Data should be reviewed across systems to understand how achieving outcomes in one system can have an impact on another. Increasing the number of women screened for substance use is likely to generate a need for more women needing treatment. Increasing the number of pregnant women receiving treatment, including medication assisted treatment, is likely to improve birth outcomes for mother and infant and reduce hospital costs.

Conclusions

Delaware, Minnesota, and New York continue to develop and implement policy and practice changes in response to the rising numbers of infants with prenatal substance 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.

It is noteworthy that during the IDTA-IPSE period, these sites were able to focus on specific intervention points, most often pregnancy and the birth event. Much more work is needed to effect change in these states to reduce the number of women with substance use disorders during pregnancy; to decrease the number of infants affected by prenatal substance exposure; and to ensure these infants continue to receive the care and support they need to ensure optimal health and developmental outcomes.

A cross-system commitment to data collection and reporting, beyond the CAPTA reporting that is required is essential to demonstrate improved outcomes for women, infants, their families, and the communities in which they live. Data dashboards or annual cross-system data reports support continuous monitoring and quality improvement. They can illustrate the achievements of state and local communities, in the areas of prevention through treatment, recovery, and reunification.

Although these sites made significant progress, Delaware is the only state that implemented statewide policy and practice changes related to infants with prenatal substance exposure during their IDTA engagement. Minnesota work's focused on designated tribes; New York's work focused on implementation counties, while planning for statewide implementation. However, Delaware's Child Protection and Accountability Commission and Infants with Prenatal Exposure Committee were in place prior to their IDTA engagement. Furthermore, statewide implementation is much easier to achieve in a state the size of Delaware.

The experience of these IDTA-IPSE sites reinforced that this work is developmental in nature and "success" can be attributed to multiple factors. Success in the program requires a multi-year commitment to enact, adopt, and implement statewide policy and practice changes, especially since this program is expanding collaboration and coordinating care among health care, child welfare, substance use disorder treatment, public health, mental health, the courts, and other family-serving agencies. The technical assistance NCSACW provided was deemed to be effective in helping these sites build or enhance the collaborative relationships, initiate practice changes, and develop systems that are likely to improve specific outcomes for women, their families, and communities. Sites focused changes on opioid prescribing practices, early engagement in prenatal care, early engagement in appropriate treatment, and increased occurrences of infants with prenatal exposure who are discharged with mothers to safe home environments. Still, a long-term commitment from multiple partner agencies working at multiple intervention points across the lifespan is essential to achieving the safety, well-being, and healthcare needs of these infants, their mothers, and their families or caregivers.

Women, infants, and children have unique and specialized needs. When planning programs for each population, a public health approach takes each of their needs into account with a focus on prevention, mitigation, treatment, and recovery. A multi-sector, systems-level approach helps states ensure that policies, practices, and services are aligned to provide services at each of these stages for women with substance use disorders and their families. (ASTHO, 2018)

References

- Agency for Healthcare Research and Quality (AHRQ), Health Care Cost and Utilization Project (HCUP). *Opioid-Related Hospital Stays Among Women in the United States, 2016*. Statistical Brief #247, January 2019. Retrieved January 2019 from <https://hcup-us.ahrq.gov/reports/statbriefs/sb247-Opioid-Hospital-Stays-Women.pdf>
- Association of State and Territorial Health Officials (ASTHO). *The Role of State Health Leaders in Addressing Substance Use Disorders Among Women, Infants, and Families*. December 2018. Retrieved January 2019 from <http://www.astho.org>
- Center for Behavioral Health Statistics and Quality. (2015). *Behavioral health trends in the United States: Results from the 2014 National Survey on Drug Use and Health* (HHS Publication No. SMA 15-4927, NSDUH Series H-50). Retrieved from <http://www.samhsa.gov/data/>
- Centers of Disease Control and Prevention. Opioid Use Disorder Documented at Delivery Hospitalization — United States, 1999–2014. August 10, 2018 / 67(31);845–849. Retrieved January 2019 from <https://www.cdc.gov/mmwr/volumes/67/wr/mm6731a1.htm>
- Centers for Disease Control and Prevention. Prescription Painkiller Overdoses: A Growing Epidemic, Especially Among Women. Updated September 4, 2018. <https://www.cdc.gov/vitalsigns/prescriptionpainkilleroverdoses/index.html>. Accessed December 10, 2018.
- Jones, C. M., Logan, J., Gladden, M., & Bohm, M. K. (July 10, 2015). Vital Signs: Demographic and Substance Use Trends Among Heroin Users – United States, 2002-2013. *Morbidity and Mortality Weekly Report*, 64(26). Retrieved from <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6426a3.htm>
- Minnesota Department of Health, *American Indian Tribal Government*. Retrieved January 15, 2019 from <http://www.health.state.mn.us/divs/opi/gov/chsadmin/governance/tribal.html>
- National Institute on Drug Abuse, National Institutes of Health, U.S. Department of Health and Human Services. (September 2015). *Dramatic Increases in Maternal Opioid Use and Neonatal Abstinence Syndrome*. Retrieved February 2, 2017 from <https://www.drugabuse.gov/related-topics/trends-statistics/infographics/dramatic-increases-in-maternal-opioid-use-neonatal-abstinence-syndrome>
- Opioid abuse, dependence, and addiction in pregnancy. Committee Opinion No. 524. American College of Obstetricians and Gynecologists. 2012; 119: 1070-6. Retrieved March 1, 2017 from <https://www.acog.org/-/media/Committee-Opinions/Comitee-on-Health-Care-for-Underserved-Women/co524.pdf?dmc=1&ts=20170304T1416109744>
- Patrick, S. W., Davis, M. M., Lehmann, C. U., & Cooper, W. O. (2015). Increasing Incidence and Geographic Distribution of Neonatal Abstinence Syndrome: United States 2009 to 2012. *Journal of Perinatology*, 35(8), 650-655.
- Patrick SW, Schiff DM, AAP Committee on Substance Use and Prevention. A Public Health Response to Opioid Use in Pregnancy. *Pediatrics*. 2017;139(3): e20164070

References

- Radel, L., Baldwin, M., Crouse, G., Ghertner, R., & Waters, W. (2018). Substance Use, the Opioid Epidemic, and the Child Welfare System: Key Findings from a Mixed Methods Study. Office of the Assistant Secretary for Planning and Evaluation. U.S. Department of Health and Human Services. <https://aspe.hhs.gov/system/files/pdf/258836/SubstanceUseChildWelfareOverview.pdf>
- Scholl L, Seth P, Kariisa M, Wilson N, Baldwin G. Drug and Opioid-Involved Overdose Deaths – United States, 2013–2017. *MMWR Morb Mortal Wkly Rep* 2019; 67:1419–1427. DOI: <http://dx.doi.org/10.15585/mmwr.mm675152e1>.
- Substance Abuse and Mental Health Services Administration. *Clinical Guidance for Treating Pregnant and Parenting Women with Opioid Use Disorder and Their Infants*. HHS Publication No. (SMA) 18-5054. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2018.
- Substance Abuse and Mental Health Services Administration. *A Collaborative Approach to the Treatment of Pregnant Women with Opioid Use Disorders*. HHS Publication No. (SMA) 16-4978. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2016. Available at: <http://store.samhsa.gov/>
- Substance Abuse and Mental Health Services Administration, Center for Behavioral Health Statistics and Quality. (2015). *Behavioral health trends in the United States: Results from the 2014 National Survey on Drug Use and Health* (HHS Publication No. SMA 15-4927, NSDUH Series H-50). Retrieved February 25, 2017 from <http://www.samhsa.gov/data/sites/default/files/NSDUH-FRR1-2014/NSDUH-FRR1-2014.pdf>
- Substance Abuse and Mental Health Services Administration, Results from the 2013 *National Survey on Drug Use and Health: Summary of National Findings*, NSDUH Series H-48, HHS Publication No. (SMA) 14-4863. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014.
- Terplan, M., Longinaker, N., & Appel, L. (2015). Women-centered drug treatment services and need in the United States, 2002–2009. *American Journal of Public Health*, 105(11): pp. e50-e54.
- Tolia, V.N, Patrick, S.W., Bennett, M.M., Murthy, K., Sousa, J., Smith, P.B., Clark, R.H., & Spitzer, A.R. (2010). Increasing Incidence of Neonatal Abstinence Syndrome in U.S. Neonatal ICUs. *New England Journal of Medicine*, 372, 2118-2126.
- U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Children, Youth and Families, Children’s Bureau. The AFCARS Report. Retrieved January 2019 from <https://www.acf.hhs.gov/sites/default/files/cb/afcarsreport22.pdf>
- U.S. Food and Drug Administration. Women and Pain Medicines. Updated October 1, 2018. <https://www.fda.gov/ForConsumers/ByAudience/ForWomen/WomensHealthTopics/ucm621707.htm>. Accessed December 10, 2018.
- Weiss AJ (IBM Watson Health), McDermott KW (IBM Watson Health), Heslin KC (AHRQ). Opioid-Related Hospital Stays Among Women, 2016. HCUP Statistical Brief #247. January 2019. Agency for Healthcare Research and Quality, Rockville, MD. www.hcup-us.ahrq.gov/reports/statbriefs/sb247-Opioid-Hospital-Stays-Women.pdf.
- World Health Organization. (2014). *Guidelines for identification and management of substance use and substance use disorders in pregnancy*.

Appendix

A. Technical Assistance Process

Technical assistance provided to each of these states/tribal communities was based on the NCSACW IDTA model and 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*, along with other tools developed by NCSACW and the Center for Children and Family Futures.

The IDTA model is based on the premise that significant and lasting practice and policy changes are more likely to occur by providing training and technical assistance in sufficient depth and duration, through strategic phases and by a change liaison with whom the site can establish a trusting relationship. NCSACW uses the IDTA model to help build linkages between substance abuse treatment, child welfare, the courts, and other partners, as needed, and includes medical/healthcare, early childhood education/childcare, and other child-serving agencies to improve outcomes for infants with prenatal substance exposure and their families. To support this collaborative framework, NCSACW will use several policy tools that help state and county level partners as they improve their practice and policy responses. These tools, which have been developed by NCSACW and the Center for Children and Family Futures, have been used for years to successfully support collaborative practice.

Building capacity to move from local practice improvements to broader systemwide change is a difficult undertaking. It requires the commitment of child welfare, substance abuse treatment and public health, along with other essential partners, including hospitals, medical and early intervention providers, the courts, and other community leaders. It requires a readiness and ability to devote adequate time and resources, an understanding of and coordination with related initiatives, and meaningful involvement of key stakeholders.

NCSACW-IDTA is typically provided for 18 to 24 months. Extensions have been granted based on the needs of and progress achieved by the site and with the approval of NCSACW Contracting Officer's Representatives.

B. The Change Liaison

A change liaison was assigned to work with each site to facilitate this work and support the collaborative in identifying and meeting their goals and objectives. Change liaisons are senior level professionals with extensive experience and knowledge in the areas of child welfare, substance abuse treatment, the courts, and healthcare systems. Most have worked at multiple tiers in at least two of the four lead systems, from the frontlines of community-based organizations to executive-level experience in government agencies. They possess the necessary technical expertise that allows them to knowledgeably communicate on multi-systems issues.

Change liaisons provided technical assistance to the project liaison and other core team members through weekly or biweekly calls and regular email correspondence. Other technical assistance activities included leadership coaching, monthly webinars, peer-to-peer networking and cross-site calls, literature searches and development of comprehensive resource packages, and planning and facilitating in-person meetings. Site visits may involve meetings with the oversight committee and other state and community leaders.

By providing guidance, facilitation, and content expertise, the change liaisons supported:

- A new way of communicating among professionals across systems on program, practice, and policy issues
- Increased sensitivity among diverse stakeholders about differences in system language, mandates, values, and priorities that must be recognized and incorporated into a new way of doing business
- A platform for reviewing the capacity of all systems to address the needs of families with substance use and mental disorders collectively, reducing fragmented and competing efforts
- Access to technical experts to help address barriers
- The collection and synthesis of data and critical information across all systems that allows stakeholders to set priorities and make informed decisions regarding those priorities
- Strategies that facilitate sustainable change

C. Technical Assistance Tools and Methods

Leadership Coaching and Education

Through leadership coaching and education provided by the change liaisons, the project liaisons and lead partners developed a collaborative and engaging approach to accomplishing goals. Discussions with the change liaisons provided a much clearer understanding of national and state-level trends, emerging issues and current practices, gaps, and barriers related to identifying and treating pregnant women with substance use disorders and serving their infants and children. Change liaisons also educated sites about the importance of compiling data to better understand current practice and how to track outcomes that demonstrate progress or change.

Development of a Governance Structure and Identification of Partners

Change liaisons assisted sites as they developed governance structures that manage planning and implementation processes specific to their individual needs and environmental context. The following governance structure was implemented with some adaptations by IDTA-IPSE sites. Minnesota developed a governance model that worked with and for the tribal communities and state leaders, as each tribe has its own tribal governance structure.

1. *The Oversight Committee* – This committee is comprised of state agency leaders from the primary collaborative partners. This committee provides project oversight, review and approval of practice and policy recommendations, and assurance of active participation by each agency's designated staff. Members of this committee are typically state level directors, commissioners, and secretaries committing their organizations to serve as the lead entities for the IDTA-IPSE effort.

2. *The Core Team* – This team is comprised of project leaders and managers with enough levels of responsibility to ensure activities and recommendations are carried out in a timely manner. The core team is responsible for completing goals and activities identified through the IDTA-IPSE process, for demonstrating active involvement of each partner agency in the completion of the goals and objectives, for addressing barriers and communication problems

in a timely fashion, and for keeping their respective oversight committee member informed of the progress, challenges, barriers and emerging issues.

3. *Project Liaison* – A select core team member serves as the project liaison for the IDTA-IPSE activities. This person is the primary point of contact between the IDTA-IPSE change liaisons and the site. Sites are encouraged to have a co-liaison or backup because most project liaisons have multiple responsibilities and competing demands on their time.

4. *Ad Hoc Committees* – These committees are convened to work on specific projects or issues (e.g., data, screening, or Plan of Safe Care committee). Membership is generally comprised of at least one core team member and other state and local partners and stake holders. Committee chairs keep the core team apprised of progress, challenges, and barriers.

Identification of Strategies to Address Gaps and Barriers

To help sites identify unmet needs, gaps, and barriers and create strategies to address these concerns, change liaisons encouraged sites to gather information about their own site and provided direction to the site's leadership on where and how to obtain this information. This process fueled the progress of workgroups tackling barriers and gaps related to prenatal screening; referral to treatment; postnatal screening of infants; notifications to child welfare (as directed per CAPTA); and engagement in early intervention services. Most sites discovered a lack of connection between the treatment community, the medical community, and the child welfare system. Change liaisons continued to communicate with the project liaisons and lead partners when additional needs, barriers, and gaps were discovered in communities. Sites began to better understand how key systems can increasingly work together, during the prenatal stage, at the birth event, and at hospital discharge to help bridge these gaps in services. Change liaisons will continue to facilitate strategic planning and formulate next steps with site leadership as new gaps and barriers are addressed.

Data to Demonstrate Need

Change liaisons provided coaching related to compiling data, where available, to understand the depth and breadth of current practices (usually related to prenatal screening, referral to treatment, and referral to early intervention services). The change liaisons encouraged project liaisons to establish workgroups focusing on data systems, educated sites about how to gather data to present to other committees, and explained how to identify changes in existing data that are necessary to rollout statewide reform. Change liaisons also facilitated discussion with lead partners about concurrent initiatives, such as Governor's task forces that have been convened to address the opioid epidemic and generate broader strategies aimed at the general population (e.g., improved monitoring of prescription pain medications and protocols for reducing overdoses).

Tools and Resources

Change liaisons utilized existing tools and resources, or adapted tools developed by NCSACW to assist sites with identifying the practices, policies, or legislation needed to improve outcomes for pregnant and parenting women and their infants and children. Resources were disseminated to the project liaisons and/or core team through an email listserv, and site-specific training and

technical assistance needs were addressed through literature searches and resource development conducted by change liaisons and other NCSACW staff.

The following tools and resources were provided to and discussed with sites:

1. *A Planning Guide: Steps to Support a Comprehensive Approach to Plans of Safe Care*

NCSACW, a program of SAMHSA andACYF, prepared this document to support policy makers, administrators, and service providers. The goal of the document is to foster collaborative responses across multiple systems to improve safety, permanency, and well-being outcomes for infants, recovery for their parents, and to meet the needs of families and caregivers. The information is derived from NCSACW's years of practice-based experience providing technical assistance to states, tribes, and communities. This document does not provide policy direction or guidance; it is a technical assistance tool to help stakeholders as they consider what steps to take in developing a comprehensive and effective approach to using Plans of Safe Care to improve the outcomes for infants with prenatal substance exposure and their families.

2. *Clinical Guidance for Treating Pregnant and Parenting Women with Opioid Use Disorder and their Infants*

Prepared for SAMHSA CSAT, this document provides comprehensive, national guidance for the optimal management of pregnant and parenting women with opioid use disorders and their infants. The guidance is based on the recommendations of experts reviewing the limited evidence available for this population as of 2017. The guide is designed to help healthcare professionals and patients determine the most clinically appropriate action for a given circumstance, with the expectation that healthcare professionals will make individualized treatment decisions. A cornerstone of the guide is that a healthy pregnancy results in a healthy infant and mother. The guide recognizes the mother and infant as a dyad, and the recommendations have considered which actions will optimize outcomes for the mother–infant dyad. Guidance covers the timeframe from preconception to several months postpartum and for the first few years of child development.

3. *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*

This publication guides states, tribes, and local communities on the best practices for collaborative treatment approaches for women with substance use disorders. The document highlights data on the effects of opioids on pregnant women and the risks and benefits associated with medication-assisted treatment. The document includes:

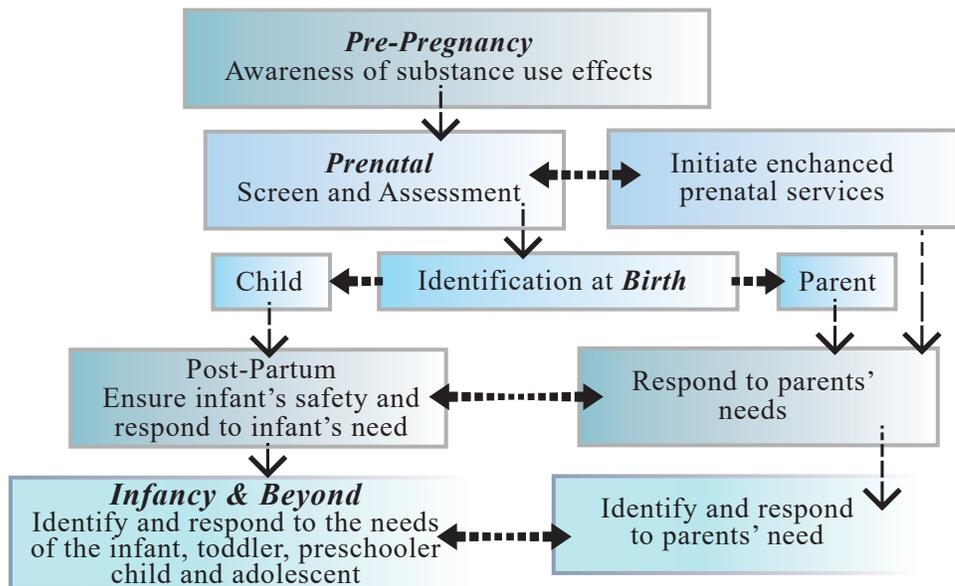
- An overview of the extent of opioid use by pregnant women and the effects on the infant;
 - Evidence-based recommendations for treatment approaches from leading professional organizations;
 - An in-depth case study, including ideas that can be adopted and adapted by other jurisdictions; and
 - A guide for collaborative planning, including needs and gaps analysis tools for priority setting and action planning.
-

4. *Collaborative Guidance Questions*

These questions were developed for the publication entitled A Collaborative Approach to the Treatment of Pregnant Women with Opioid Use Disorders and are presented in two categories: cross-system questions and discipline-specific questions. The change liaisons use the guidance questions with sites to identify and discuss differences in values and perceptions held regarding pregnant women with substance use disorders and their infants. Also identified and discussed are the roles and responsibilities of the systems involved with the target population of women and children. The discipline-specific questions help sites discover key issues and barriers to identifying, engaging, and retaining pregnant women in appropriate treatment services and meeting the needs of their infants following the birth event. The questions also help sites prioritize which barriers to address first.

5. *Policy and Practice Framework: Five Points of Intervention*

This framework outlines critical intervention opportunities from pre-pregnancy through childhood and adolescence. Change liaisons helped sites identify which of the five intervention points they would initially focus on, while recognizing the site would need to address the full continuum of this framework. Most sites focused on interventions beginning in pregnancy and ending with identification and referral of the infant for early intervention services



6. *Resource Mapping*

Change liaisons work with sites to identify current resources, gaps, and barriers. After determining the specific intervention points and priorities on which they would focus, sites could utilize the resource mapping template to map each agency's current programs and practice(s), local and statewide; populations served; and source of funding.

7. *Hospital Surveys*

The hospital survey is a tool to help sites assess current policies. These surveys are used in local hospitals to identify and treat infants with prenatal substance exposure and delineate services offered to their mothers. Responses to questions on prenatal screening; identification of infants with prenatal exposure to substances at birth; treatment of infants with neonatal abstinence syndrome were included. The results inform policies, protocols, and practices that promote mother-infant bonding and attachment, as well as notifications to child protection services.

8. *System Walkthroughs*

A system walkthrough is a process designed to assess the effectiveness of a system in achieving its desired results or outcomes, such as family reunification, successful treatment completion, and child safety by ensuring children are living in safe and stable environments. The process is designed to provide all key stakeholders with a good understanding of how cross system processes for serving families currently operate in a local community.

9. *Case Studies*

Sites provided examples of actual cases that had both positive and negative outcomes. Participants talked through each case, identifying practices that resulted in positive outcomes, and those that may have created barriers to success. The process helps partners understand how current practices may inadvertently discourage parents from engaging with or remaining in needed services.

10. *Policy and Practice Matrix*

This matrix utilizes the Five Points of Intervention Framework across the lifespan of pre-pregnancy through children/adolescence, with recommended policies and practices for mothers' medical providers, infants' medical providers, women's treatment providers, child welfare, and the courts mapped across each intervention point. Sites are encouraged to use the matrix to assess current practices and determine what practice and policy changes are needed.

D. Webinars and Peer-to-Peer Networking

In addition to working individually with each site, the NCSACW team facilitated peer-to-peer networking calls and webinars.

- *September 28, 2016*: Partnering to Treat Pregnant Women with Opioid Use Disorder: Lessons Learned from a Six Site Initiative; https://www.youtube.com/watch?v=oDQSYLc_au4&feature=youtu.be
- *December 12, 2017*: IDTA-Infants with Prenatal Substance Exposure and Their Families Learning Exchange; <https://cff-ncsacw.adobeconnect.com/pw6w8o12q85x/>

- *March 21, 2018*: Infants with Prenatal Substance Exposure and Their Parents: Family Approach of Yale New Haven Children’s Hospital, presented by Dr. Matthew Grossman. <https://www.youtube.com/watch?v=Ak-kfFwIyVM&feature=youtu.be>
- *May 29, 2018*: A Learning Exchange dialogue with Michelle Eastman, Glens Falls Hospital, NY, Neonatal Intensive Care Unit (NICU) Nurse Manager, regarding their system walkthrough. https://youtu.be/T9FM_QtbVp0
- *August 8, 2018*: A Learning Exchange dialogue with Laurel Aparicio, Founding Director of Early Impact Virginia, regarding their home visiting training and learning modules. <https://cff-ncsacw.adobeconnect.com/pdmcvz2wqwmt>

E. Site Visits

Site visits were a critical component of the intensive technical assistance and training provided. Change liaisons conducted up to two site visits per project year. Site visits typically lasted two to three days, providing time for change liaisons to meet with the core team and oversight committee, and to visit implementation sites. Meeting with local teams was especially important to providing consistent direction, getting buy-in from frontline stakeholders, and facilitating successful implementation. For each site, change liaisons coordinated logistics with the project liaison and core team; developed goals for the site visit; created an agenda; and provided pertinent materials and resources for participants. Site visits enabled the change liaisons to better understand contextual challenges and facilitate fruitful discussions regarding stigma, values, and perceptions; missing partners; gaps and barriers in services; and effective strategies for addressing such issues. Site visits provided the face-to-face time with change liaisons and NCSACW staff, which was the number one request from all sites. As noted earlier in this document, in-person meetings were especially important for engaging tribal leaders and members.