

*CT K.I.D.*

*Keeping Infants Drug-free*

*Strategic Plan Report*

*2016 - 2021*

Addressing the Needs of Substance Exposed Infants, Children,  
and their Families in Connecticut

CT Department of Children and Families and  
CT Department of Mental Health and Addiction Services  
In partnership with  
Advanced Behavioral Health, Inc.

# Table of Contents

ACKNOWLEDGEMENTS .....	1
BACKGROUND .....	3
CURRENT EFFORTS .....	4
Substance Exposed Infants In-Depth Technical Assistance (SEI IDTA) .....	4
Structure of SEI IDTA in Connecticut .....	4
Executive Implementation Team .....	4
Core Team.....	4
Early Identification & Screening Workgroup.....	5
Data Workgroup.....	5
Training Workgroup .....	5
What We Know About FASD .....	5
What We Know About NAS.....	6
Connecticut Data .....	7
Births.....	7
Alcohol Use by Pregnant Women .....	7
Substance Use.....	8
Parental Substance Use and the Child Welfare System .....	8
Fiscal Impact .....	9
Cost of FASD .....	9
Cost of NAS.....	9
FUTURE EFFORTS.....	10
Developing a State Plan to Address SEI .....	10
CT K.I.D. STRATEGIC PLAN OUTLINE 2016 to 2021 .....	11
APPENDICES .....	17
Appendix A. Resources .....	17
Substance Use, Maternal and Infant Health .....	17
Fetal Alcohol Spectrum Disorders .....	17
Appendix B: Legislation .....	18
The Child Abuse Prevention and Treatment Act .....	18
Connecticut Laws on Reporting Child Abuse and Neglect .....	18
Appendix C: References.....	20

## ACKNOWLEDGEMENTS

In the fall of 2014, the Department of Children and Families (DCF) in partnership with the Department of Mental Health and Addiction Services (DMHAS) received Substance Exposed Infants In-Depth Technical Assistance (SEI IDTA) from the National Center for Substance Abuse and Child Welfare (NCSACW). The Substance Abuse and Mental Health Services Administration (SAMHSA) funded SEI IDTA to strengthen the capacity of states to improve the safety, health, and well-being of substance exposed infants and support the recovery of pregnant and parenting women and their families.

The SEI IDTA project in Connecticut is known as CT K.I.D. - Keeping Infants Drug-free.

The CT K.I.D. *Addressing the Needs of Substance Exposed Infants, Children and Their Families Five Year Strategic Plan* was developed by members of the Executive Implementation Team and the Core Team established and led by the Connecticut Department of Children & Families with the Department of Mental Health and Addiction Services.

The many agencies and individuals who collaborated on the drafting of the Plan are experts, stakeholders, service providers and parents from across the state and represent diverse voices and perspectives. Members of specific work groups gathered needed information and formulated recommendations from their respective focus areas for deliberation by the larger Core Team. Several Advanced Behavioral Health, Inc. staff provided subject matter expertise, staffing and coordination for this initiative and oversaw development of the Strategic Plan. The various partners who made valuable contributions to this Strategic Plan are recognized with appreciation at the beginning of this report.

### Executive Implementation Team

Mary Painter	CT Department of Children and Families
Melissa Sienna	CT Department of Children and Families
Karen Ohrenberger	CT Department of Mental Health and Addiction Services
Kimberly Karanda	CT Department of Mental Health and Addiction Services
Janet Storey	CT Department of Mental Health and Addiction Services
Michael Williams	Advanced Behavioral Health, Inc.
Diane Achenbach-Zatorski	Advanced Behavioral Health, Inc.
Marilou Giovannucci	Advanced Behavioral Health, Inc.
Nancy Turner	Advanced Behavioral Health, Inc.

## Core Team

Mary Painter	CT Department of Children and Families
Ricka Wolman	CT Department of Children and Families
Allon Kalisher	CT Department of Children and Families
Christine Lau	CT Department of Children and Families
Nachi Bhatt	CT Department of Children and Families
Melissa Sienna	CT Department of Children and Families
Karen Armstrong	CT Department of Children and Families Training Academy
Kimberly Karanda	CT Department of Mental Health and Addiction Services
Karen Ohrenberger	CT Department of Mental Health and Addiction Services
Janet Storey	CT Department of Mental Health and Addiction Services
Michael Williams	Advanced Behavioral Health, Inc.
Diane Achenbach-Zatorski	Advanced Behavioral Health, Inc.
Marilou Giovannucci	Advanced Behavioral Health, Inc.
Nancy Turner	Advanced Behavioral Health, Inc.
Margaret Doherty	Connecticut Association of Foster and Adoptive Parents
Susan R. Yancy, Ed.D.	Connecticut Association of Foster and Adoptive Parents
Karen Andersson	CT Behavioral Health Partnership/Value Options
Jillian Wood	Connecticut Chapter, American Academy of Pediatrics
Kelly Anelli	Connecticut Coalition Against Domestic Violence
Karen Jarmoc	Connecticut Coalition Against Domestic Violence
Carol Cruz	Connecticut Community for Addiction Recovery
Monica Robertson	Connecticut Community for Addiction Recovery
Christine Backman	CT Department of Correction
Margie Hudson	CT Department of Public Health
William Halsey	CT Department of Social Services
Robert Zavoski, M.D.	CT Department of Social Services
Pat Baker	Connecticut Health Foundation
Carl Schiessl	Connecticut Hospital Association
Martie Boyer	CT Judicial Branch
Linda Harris	CT Office of Early Childhood
Karen Foley Schain	CT Office of Early Childhood
Scott Newgass	CT State Department of Education
Antonio Diaz-Carrera	Community Health Center Association of Connecticut
Kate Sims	Hartford Health Care
Faith Vos Winkle	State of CT Office of the Child Advocate
Cathy Sisco	Connecticut Clearinghouse
Collette Anderson	Connecticut Women's Consortium
Sherrie Weaver	The Connection, Inc.
MariAnn Pappagallo, M.D.	UConn Health Neonatal Intensive Care Unit
Matthew Grossman, M.D.	Yale-New Haven Hospital Neonatal Intensive Care Unit
Megan Smith, DrPH	Yale-New Haven MOMs Partnership
Carol Weitzman, M.D.	Yale School of Medicine

## BACKGROUND

In Connecticut, the Department of Children and Families (DCF) and the Department of Mental Health and Addiction Services (DMHAS) have a history of strong collaboration to address the needs of children and their families and caregivers affected by substance use. In addition, state leaders, community agencies and organizations, healthcare providers, private non-profits and others have long recognized the importance of prevention, education, and early intervention to assist women struggling with prenatal substance use and the potential detrimental effects on infants and children.

One such long-standing example of the collaborative environment is Project SAFE (Substance Abuse Family Evaluation). With Advanced Behavioral Health, Inc. (ABH) as its administrative services organization, DCF and DMHAS, through Project SAFE, provide primary caregivers of children involved with the child welfare system with centralized intake and priority access to substance abuse evaluations, drug screening, and an array of outpatient treatment services.

DCF and DMHAS also jointly fund the Recovery Specialist Voluntary Program (RSVP), a recovery support program for parents and caregivers who are at risk for having their children removed by the Juvenile Court because of parental neglect attributed in large part to parental substance abuse.

DCF and DMHAS also have long-standing partnerships with a number of other state and local agencies and organizations providing children and adult behavioral health services, early childhood education, prevention, research, legislation and funding initiatives.

Of great significance in Connecticut was Governor Dannel P. Malloy's leadership in proposing and sheparding through the General Assembly session in 2014 legislation to combat substance abuse and opioid overdose. The strong support of the Governor resulted in the passage of the Act Concerning Substance Abuse and Opioid Overdose Prevention (Public Act 15-198) signed into law in 2015. This law made significant changes concerning prescription drugs and drug abuse prevention. Specifically, it requires practitioners to check patient records in the Prescription Monitoring and Reporting System (CPMRS); allows pharmacists to prescribe opioid antagonists to prevent overdose deaths; requires healthcare providers to take continuing education in controlled substances and pain management; and reconstitutes the Connecticut Alcohol and Drug Policy Council (ADPC).

Having the Commissioners of DCF and DMHAS as the Co-Chairs of the ADPC further strengthens the ongoing commitment of the two agencies to work together. Along with other state and local agencies and organizations, CT K.I.D. will work with the ADPC on joint efforts to improve the State's response to Substance Exposed Infants (SEI) and ensure needed attention is given to those who struggle with opioid and other substance use using a multi-faceted approach to prevention, screening and intervention.

**SEI refers to infants exposed in utero to alcohol or drugs, including prescription medications, whether or not this exposure is detected. SEI includes Fetal Alcohol Spectrum Disorders (FASD) and Neonatal Abstinence Syndrome (NAS).**

## INITIAL EFFORTS

### Substance Exposed Infants In-Depth Technical Assistance (SEI IDTA)

The focus of SEI IDTA in Connecticut has been to identify key stakeholders and work collaboratively with them to advance the state's capacity to improve the safety, health, permanency and well-being of substance exposed infants and support the recovery of pregnant and parenting women and their families through statewide infrastructure development.

The objectives of the SEI IDTA were to:

- Assess the state's capacities and needs related to SEI to serve as the architecture for identifying data infrastructure strengths and challenges and establishing policy and developing infrastructure for prevention and intervention services including workforce development; and developing recommendations for improving the state's data infrastructure to collect data on prenatal exposure.
- Develop a statewide plan to address SEI in a coordinated fashion to offer a continuum of services to vulnerable families, including prevention, through raising public awareness of services and supports, early intervention, and intensive intervention.
- Conduct financial and asset mapping to identify, coordinate, and maximize fiscal resources to support ongoing SEI efforts.

### Structure of SEI IDTA in Connecticut

In March 2015, a two day kick-off event was held to bring together stakeholders across systems to begin the process of identifying needs and gaps and to develop

the structure for the IDTA work moving forward. The kick-off provided an opportunity for a wide range of stakeholders to learn about SEI and to identify unmet needs and gaps within existing systems that serve pregnant women, infants and children. Shortly after the kick-off, the Statewide Coordinator was hired by Advanced Behavioral Health, Inc. under a contract with DCF and DMHAS.

### Executive Implementation Team

The Statewide Coordinator, together with DCF and DMHAS leadership, formed an Executive Implementation Team (EIT) to begin organizing Connecticut's work under the IDTA. The EIT meets monthly, along with the Change Leaders from the National Center for Substance Abuse and Child Welfare (NCSACW).

### Core Team

The first task for the EIT was to identify and engage key stakeholders for the Core Team, who would provide leadership and direction for the planning process. Individuals and agency representatives with expertise in maternal and child health, behavioral health, substance use, child welfare, and advocacy for women and children were assembled to comprise the CT K.I.D. Core Team. It began meeting in June 2015 and holds quarterly meetings.

In addition to the CT K.I.D. Core Team, three other work groups were formed to gather additional stakeholder input on efforts to conduct an assessment of unmet needs and gaps, and to propose strategies for addressing emerging concerns. The following workgroups were formed to address issues and now meet regularly.

## Early Identification & Screening Workgroup

- Outreach and screening
- Early identification of substance use pre-pregnancy and during pregnancy
- Health of women of child bearing years and pregnant women, infants and children
- Access to treatment and services

## Data Workgroup

- Compile and interpret available SEI data and information from across the state, especially among disadvantaged populations
- Identify data infrastructure strengths, challenges, and deficits as well as potential sources for data
- Improve the state's infrastructure and ongoing data collection

## Training Workgroup

- Identify and coordinate training content and tools to provide education across various professions
- Develop educational programs and community forums to raise awareness

Following examination of the current system, the work groups began to identify and prioritize areas for inclusion as goals and objectives in the State Plan.

## What We Know About FASD

FASD is 100% preventable. Prenatal alcohol exposure is the leading preventable cause of birth defects in the United States.

The term FASD is not meant to be a clinical diagnosis but is rather an umbrella term for several conditions, including Fetal Alcohol

Syndrome, partial Fetal Alcohol Syndrome, Alcohol Related Neurodevelopmental Disorder (ARND), Alcohol Related Birth Defects (ARBD) and other conditions. These conditions can occur in any person who was exposed prenatally to alcohol and affect each person in different ways. There is no cure for FASD, and those affected by are vulnerable to failure in school, substance abuse, mental illness, and involvement in the criminal justice system.

The effects of FASD can range from mild to severe, and may impact physical, behavioral, mental, and/or cognitive development with possible lifelong implications.<sup>1</sup> Often, a person with FASD faces a combination of these challenges.

**A 2014 study published by the American Academy of Pediatrics indicates that "the total rate of FASD is estimated at 24 to 48 per 1000 children or 2.4% to 4.8%"<sup>2</sup>**

According to the National Institute on Alcohol Abuse and Alcoholism (NIAAA):

- Research shows no amount of alcohol is safe for pregnant women to drink.
- Alcohol can disrupt fetal development at any stage during a pregnancy – including at the earliest stages and before a woman may know she is pregnant.
- Alcohol passes easily from a mother's bloodstream into the developing fetus' blood potentially interfering with the development of critical organs and body parts, including the brain.
- Data from prenatal clinics and postnatal studies reveal that 20 to 30 percent of women do drink at some time during pregnancy.

- Binge drinking, which means consuming four or more drinks per occasion and regular heavy drinking puts a fetus at the greatest risk for severe problems.

**“Among pregnant women aged 15 to 44 years, 11.8% report drinking some alcohol during the previous month, which may put the fetus at risk for FAS.”<sup>3</sup>**

A study conducted by the University of Washington shows the percentages of persons aged 6 to 51 with a FASD who had difficulties in the following areas:

- 94% had mental health problems
- 83% of adults experienced dependent living
- 79% of adults had employment problems
- 60% of those age 12 and older had trouble with the law
- 50% experienced inpatient treatment for mental health or substance abuse problems or spent time in prison
- 45% engaged in inappropriate sexual behavior
- 43% had disrupted school experiences (e.g., dropped out)
- 24% of adolescents, 46% of adults, and 35% overall had alcohol and drug problems.”<sup>4</sup>

### **What We Know About NAS**

**The 2012-2013 National Survey on Drug Use and Health noted that 5.4% of pregnant women 15 to 44 years of age reported recent use of illicit drugs (e.g., marijuana, cocaine, hallucinogens, heroin, methamphetamines, and nonmedical use of prescription drugs).<sup>5</sup>**

NAS refers to a group of withdrawal symptoms that occur in newborns exposed prenatally to drugs or prescription medications. In addition to opioids, the use of antidepressants or benzodiazepines can lead to NAS.

Newborns who are exposed to drugs in utero, particularly opioids, can experience difficulty feeding, irritability, problems with calming, and difficulty with sleeping.

The symptoms of NAS may last days or weeks. These newborns are more likely to have lengthy stays in the hospital after birth.

The Federal Agency for Healthcare Research and Quality (AHRQ), Healthcare Cost and Utilization Project findings state:

- The rate of neonatal hospital stays involving substance use had a cumulative increase of 71 percent between 2006 and 2012, from 5.1 to 8.7 per 1,000 neonatal stays.
- The rate of maternal hospital stays involving substance use had a cumulative increase of 33 percent, from 13.4 per 1,000 maternal stays in 2006 to 17.9 per 1,000 maternal stays in 2012.
- In 2006, the rate of maternal stays related to substance use was 2.6 times the rate of neonatal stays related to substance use; in 2012, the rate of substance-related maternal stays was also more than double the rate of substance-related neonatal stays (2.1 times higher).”<sup>6</sup>

These neonatal hospital stays translate to substantially higher costs, according to AHRQ; the cost associated with neonatal stays attributed to substance use increased by 135% between 2006 and 2012.



A 2015 AHRQ Statistical Brief reports:

"Between 2006 and 2012, inflation-adjusted aggregate hospital costs for neonatal stays related to substance use had a cumulative increase of 135 percent, from \$253.4 million in 2006 to \$594.6 million in 2012.<sup>7</sup>

**"Neonatal stays related to substance use were approximately 4 times as long and 4 times as costly as other neonatal stays.**

"The mean length of stay was 14.7 days for neonatal stays related to substance use compared with 3.7 days for other neonatal stays. Similarly, average hospital costs were substantially more for neonatal stays related to substance use (\$19,684) than for other neonatal stays (\$4,500)."<sup>8</sup>

## Connecticut Data

Connecticut currently lacks a robust infrastructure to consistently collect data about the extent and prevalence of substance use by pregnant women and the resulting effects on infants and children. Available state data points to alarming trends in substance use by women of child bearing age and pregnant women and substantial costs related to hospital stays for substance exposed infants.

The backdrop for the prevalence of substance exposed infants begins with the contextual framework of the number of children born in Connecticut, what is known about alcohol use among pregnant women, drug use among children and adults, and DCF involvement with families affected by substance use.

## Births

There were 36,512 live births to Connecticut residents in 2012, a small decline from the number of births occurring in 2011. This birth

rate, based on the entire population of state residents, was 10.2 live births per 1,000 population.<sup>9</sup>

## Alcohol Use by Pregnant Women

The 2012 Connecticut Registration Report, which documents births each year in the state, indicates that, "Few women self-reported alcohol use during pregnancy... In 2012, among births for which information was available, 149 mothers reported drinking alcohol during pregnancy, representing 0.4% of all births in Connecticut. Information on alcohol use during pregnancy was not available for 303 births."<sup>10</sup> It also reports that the rate of low birth weight births among women who reported alcohol consumption during pregnancy was 14.8%, nearly double that of women who did not drink alcohol while pregnant (7.8%).

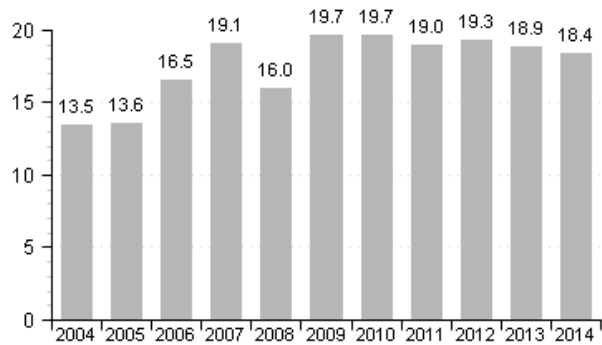
The most recent complete Connecticut data about alcohol use by women during pregnancy is derived from the Pregnancy Risk Assessment Tracking System (PRATS) conducted by the CT Department of Public Health published in 2006.<sup>11</sup> This PRATS report was a voluntary, anonymous survey of 1,982 women who gave birth between November 2002 and June 2003. The PRATS collected information from women about their alcohol use during pregnancy. It reveals that:

- Almost 15% of women consumed at least some alcohol during the last months of their pregnancy.
- Approximately 3% of women reported binge drinking on one or more occasions during the last three months of their pregnancy.

The CDC Behavioral Risk Factor Surveillance System indicates that in Connecticut in

2014, 18.4% of women of childbearing age (18-44 years) reported binge drinking in the past month, compared to 16.9% overall in the U.S. Chart 2 indicates the ten year trend for binge drinking among women 18 to 44.

**Chart 1: Binge alcohol use among women of childbearing age: Connecticut, 2004-2014<sup>12</sup>**



**Substance Use**

The National Survey on Drug Use and Health provides national and state-level data on the use of tobacco, alcohol, illicit drugs (including non-medical use of prescription drugs) and mental health.

In the 2013-2014 survey, 9.9% of Connecticut residents age 12 and older reported using illicit drugs in the past month. The national average was 10.2%. In 2010-2011, Connecticut was one of the top ten states for rates of illicit drug dependence among persons 26 years and older.<sup>13</sup>

Chart 2 (below) depicts recent treatment admission data from DMHAS for women of child bearing years from July 1, 2014 to June 30, 2015. The data show that the primary substances of choice reported at treatment admission were heroin and alcohol.

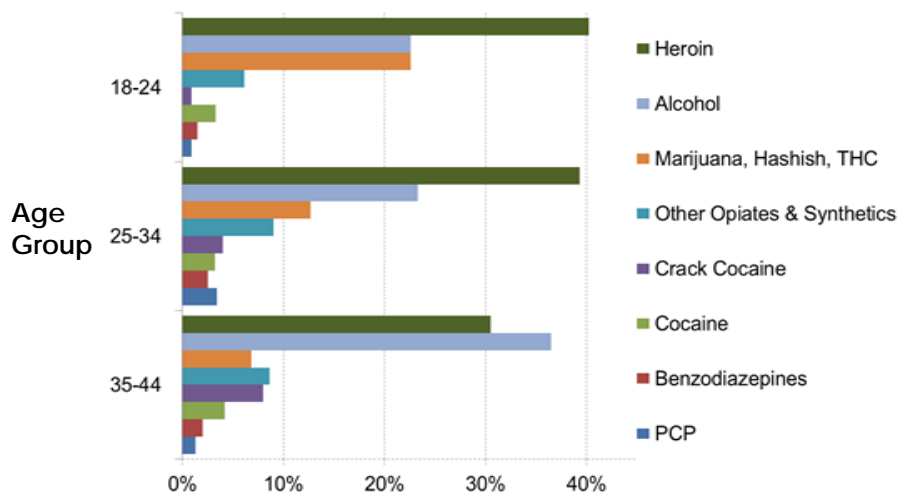
**Parental Substance Use and the Child Welfare System**

There is no specific state data about the number of child removals that can be attributed to prenatal substance exposure. However, there are data that shows parental substance use poses a significant problem for DCF.

DCF collects and is required to report data to a federal child welfare database, the Adoption and Foster Care Reporting and Analysis System (AFCARS). The data shows that from 2010 to 2013, children under the age of one year represented the highest percentage of children entering foster care for four consecutive years.

For Federal Fiscal Year 2013, DCF data indicates that the reasons for removal of children from their parental homes were attributed to parental substance use approximately 34% of the time. The national average was 31%.<sup>14</sup>

**Chart 2: Primary Substance of Choice at Treatment Admission, Women in CT, Jul 1, 2014 to Jun 30, 2015**



## Fiscal Impact

### Cost of FASD

There are no recent studies on the economic burden of FASD in the United States. Many sources discuss the cost of substance abuse, but few specifically study costs of problems from FASD.<sup>15</sup>

In 2004, the estimated cost for each individual in the US with a FASD over the course of their lifetime was \$2.0 million. This includes medical treatment, special education, residential care for persons with mental retardation, and social service costs. It does not include lost productivity, mental health services or criminal justice costs.<sup>16</sup>

Adjusting for inflation since 2004, in 2016

**...the estimated lifetime cost for each individual in the US with FASD is \$2.5 million.**

### Cost of NAS

Information and data is available from the state Department of Public Health, Office of Health Care Access (OHCA) in association with the ChimeData program administered by the Connecticut Hospital Association (CHA).

ChimeData is used to help hospitals meet regulatory reporting requirements and to support CHA's advocacy efforts. ChimeData is the most comprehensive hospital database in the state, containing over 31 million patient encounters dating back to 1980. It includes administrative discharge (UB-04 claims-based) data from inpatient admissions, hospital-based outpatient surgery, and emergency department non-admissions.

According to Connecticut ChimeData:

- Hospital discharges related to NAS rose 164% in the 10 year period between 2003 and 2012.
- Total patient days for these infants also increased by 150% from 2,589 to 6,474 during this time period.
- The costs associated with NAS are significant and rising. Statewide hospital discharge data for FFY12 show that the median charges at discharge for a NAS infant was \$49,103 compared to \$5,163 for a non-NAS infant.<sup>17</sup>
- The majority of medical costs are covered by the state's Medicaid Program (82%), a percentage that closely aligns with the national average of 80%.
- Sixteen percent of NAS infants have their care paid for by private insurance, while the remaining 2% of NAS infants' medical costs were covered out-of-pocket.
- In 2012, Medicaid was the expected primary payer for 79.9 percent of neonatal stays related to substance use compared with 46.2 percent of all other neonatal stays.

Nationally, according to AHRO:

- Substance-related neonatal stays were also more likely to be uninsured, compared with all other neonatal stays (5.6 vs. 3.9 percent).
- In contrast, private insurance was the expected primary payer for 11.8 percent of neonatal stays involving substance use versus 46.4 percent of all other neonatal stays.<sup>18</sup>

## FUTURE EFFORTS

### Developing a State Plan to Address SEI

The overarching rationale for a state plan stems from the recognition that a major challenge in Connecticut is the lack of coordination between state agencies and organizations, local entities and healthcare providers around the issue of substance exposed infants. Comprehensive data is not readily available, and systems are not communicating enough about programs and services they offer for this population. As a result, pregnant and parenting women with substance use disorders and their children face multiple challenges in finding and engaging services.

Connecticut has no state laws or policies regulating screening for substance exposure by medical health providers. Infants and children go undiagnosed or misdiagnosis resulting in the delay of service provision or no services being provided. Connecticut does not have statutory mandates or policy obligating health care providers to report to child welfare services when substance exposure among infants and children is detected, other than a generic "mandated reporter" law requiring a report to child protective services for child abuse and neglect issues. These policy gaps mean that decisions to conduct screenings and make reports to child protective services when an infant is substance exposed are subject to interpretation by individual medical providers, and this ambiguity could result in bias, disparities and inequalities in care and access to needed support services.

During a series of CT K.I.D. workgroup meetings, the specifics of these needs and gaps were identified as follows:

- There is a lack of understanding among multiple professional disciplines about the effects of substance use during pregnancy;
- Public awareness is needed about substance use and associated risk factors for child maltreatment during pre-pregnancy, pregnancy and postpartum for youth, women of child bearing years and fathers;
- There continues to be stigma and disparate treatment associated with pregnant women who disclose substance use to medical professionals and others;
- Practices and protocols for screening women of child bearing age and pregnant women for substance use vary greatly throughout the state, leading to disparate treatment;
- Child welfare practices for responding to reports of infants born substance exposed is uneven across the state;
- Connecticut needs to develop a coordinated, multidisciplinary approach inclusive of additional key stakeholders to support the identification and service delivery to substance exposed infants;
- Identification of newborns for NAS is not done in a consistent manner;
- While some data exists about substance use among women of child bearing years, pregnant women and newborns born substance exposed, the data is not collected in systematic or usable fashions;
- Children and youth are often not correctly screened or diagnosed for FASD;
- There are limited assessment resources to identify children identified with FASD;
- Parents, including foster and adoptive parents, and relative caregivers need support in raising children with FASD;
- There is a gap in the collection of data about children diagnosed with FASD;
- Lack of transportation and child care hamper women's access to substance use treatment;
- Special populations including youth and pregnant women and fathers who are incarcerated need to be included in prevention/intervention approaches.

## CT K.I.D. STRATEGIC PLAN OUTLINE 2016 to 2021

**Goal 1: Increase knowledge and expertise among professionals, systems stakeholders, and the community at large about substance use during pregnancy and the effects on infants and children**

### PROFESSIONAL DEVELOPMENT

OBJECTIVE	STRATEGY
1. Create a broader understanding of prenatal substance exposure and its effects	Create an operational definition of Substance Exposed Infants to include a broad representation of infants and children
2. Educate relevant groups about the teratogenic effects of drugs and alcohol during pregnancy	Partner with professional organizations, multiple state agencies and public/private universities to design and provide professional development to target groups/populations
	Provide professional development across the DCF workforce
	Educate all in-home service programs about SEI and FASD to provide primary prevention through information/education to pregnant and parenting women and fathers; serve as a first line of screening/identification for women and children for further assessment/treatment

### COMMUNITY EDUCATION AND AWARENESS

OBJECTIVE	STRATEGY
1. Increase awareness about "Safe Haven" laws and "Safe Sleep" methods	Leverage existing campaigns and strategies for additional target populations
2. Raise awareness within the community about the effects of use of alcohol and drugs before and during pregnancy	Develop a public relations and marketing plan that includes using multiple media sources targeting multiple organizations
	Educate fathers about effects of substance use during pregnancy
	Educate youth and young adults in state level and community/school based programs that provide services or treatment about high risk alcohol and drug use and sexual behaviors

**Goal 2: Increase capacity and availability of screening and assessment for substance exposure in infants and children**

**SCREENING OF INFANTS AND CHILDREN FOR SUBSTANCE EXPOSURE**

OBJECTIVE	STRATEGY
1. Build an understanding and consensus about current protocols and practices used to screen infants and children for substance exposure	Create and beta test a survey that includes questions about current hospital and practitioner methods for screening neonates, infants and children
2. Make the CPS response for newborns testing positive for substance exposure standardized and understandable	<p>Include SEI in the DCF policy being developed for “high risk infants”</p> <p>Produce a guidance document to hospitals that articulates the CAPTA requirements for reporting drug-affected neonates to CPS, specifies the timeliness of CPS response to a referral for SEI, and engages the hospital as a partner in a plan for discharge and care for mother and newborn</p>
3. Ensure early identification of neonates for substance exposure	Develop protocols for hospitals and practitioners that reflect best practices for testing newborns for drug exposure including appropriate consents
4. Provide support for parents and family members who are parenting children with FASD	Reconstitute NOFAS Chapter in Connecticut
5. Provide support to foster and adoptive families who are parenting children with FASD	Create specialized support groups for foster and adoptive parents
6. Provide greater access to child's medical records, especially for foster and adopted parents, including children adopted through private agencies	Clarify and disseminate DCF policy associated with access to DCF records
7. Ensure early identification and a continuum of screening of infants, toddlers, children and youth for substance exposure	<p>Encourage screening for substance exposure by pediatricians, family practitioners and community/school- based programs that provide services or treatment</p> <p>Use existing Child Development Infoline and in-home services as the front line for identification of infants and children with developmental delays that require further assessment</p>

**Goal 2: Increase capacity and availability of screening and assessment for substance exposure in infants and children**

**SCREENING OF INFANTS AND CHILDREN FOR SUBSTANCE EXPOSURE**

OBJECTIVE	STRATEGY
<p>8. Increase capacity and availability for assessment and diagnosis of FASD</p>	<p>Explore the use of facial recognition software by additional clinical providers</p>
	<p>Utilize pediatric geneticists to assist with identification of FASD and provide guidance to DCF</p>
	<p>Use existing resources to encourage parents to report developmental delays in their children</p>
	<p>Teach pediatricians and other family practitioners how to screen for FASD and/or drug exposure</p>
	<p>Utilize pediatric geneticists to train teams from the Multidisciplinary Exam provider clinics on how to conduct assessments and develop plans for care with caregivers and others</p>
	<p>Standardize practice within the child welfare population for screening children who enter care for FASD to include record keeping and mining</p>
	<p>Expand availability of high-end FASD assessment services through supporting expansion of existing resources or create a pilot program modeled after the University of Washington FASD Clinic; collect data to evaluate concept</p>
	<p>Identify age-appropriate treatment methods for children diagnosed with FASD</p>

**Goal 3: Increase capacity and availability of screening for substance use with women of child bearing years and pregnant women**

**SCREENING & TESTING OF WOMEN FOR SUBSTANCE USE DURING PREGNANCY**

OBJECTIVE	STRATEGY
1. Build an understanding and consensus about current protocols and practices used to screen and test women	Create and beta test a survey that includes questions about current hospital and practitioner methods for screening and testing women
2. Ensure early identification of women for substance exposure	Develop trauma-informed, culturally competent and socioeconomically neutral protocols and practices for universal screening that supports women’s disclosure of substance use during pregnancy
	Increase the capacity of prenatal care providers and hospitals to conduct substance use testing of pregnant women
	Identify and address gaps in insurance coverage through Medicaid and private provider for appropriate levels of care for pregnant and postpartum women
	Use existing in-home services as the front line for screening pregnant women for substance use
3. Reduce the negative response by providers to pregnant women’s disclosures of substance use	Create or utilize existing “health care advocates” to help pregnant women navigate the health care, substance use treatment, and social services systems



**Goal 4: Ensure that women and their children have access to services/treatment to meet their needs**

**SERVICES FOR MOTHERS AND INFANTS**

OBJECTIVE	STRATEGY
<p>1. Maximize the use of existing resources available to mothers and their children including: substance use treatment, health care, developmental assessments, and treatment services for children of all ages</p>	<p>Use multiple methods to articulate what services are available and how they can be accessed</p>
	<p>Disseminate referral criteria for Birth to 3 to allow seamless referrals for infants suspected to have been exposed to substances</p>
	<p>Encourage full use of the DPH Birth Defects Registry and Vital Records Registry</p>
<p>2. Provide mothers and their babies priority access to services and care</p>	<p>Negotiate with in-home providers to give priority access to pregnant and parenting women and their newborns</p>
	<p>Leverage the existing substance use treatment system to provide priority access to pregnant and parenting women</p>
	<p>Support mothers' engagement in treatment by ensuring quality child care is available where they attend outpatient services, including MAT</p>
<p>3. Minimize barriers to health care for pregnant women, mothers and children</p>	<p>Collaborate with other initiatives to ensure that women and their infants/children have quality health care available</p>

**Goal 5: Gather and use data to understand and plan for the needs of substance exposed infants/children, their mothers and families**

**DATA COLLECTION AND ANALYSIS**

OBJECTIVE	STRATEGY
1. Create a broader understanding of prenatal substance exposure and its effects	Create an operational definition of Substance Exposed Infants to include a broad representation of infants and children
	Survey hospitals and practitioners about current protocols and practices for collecting and reporting information including to DPH (Birth Records and Birth Defects Registry), DCF (Neonates born Substance Exposed, Children with FASD Diagnosis); and Newborn Screening and Hospital Discharge Data
2. Increase hospital reporting to DPH Birth Defect Registry and Birth Registry	Encourage full use of DPH Birth Defects Registry and Vital Records Registry
3. Create and provide data in a "report card" format using administrative data from multiple venues to better understand the problems associated with SEI, its impact on all affected systems, and how the various systems are responding	Identify data currently collected by each agency
	Collect administrative data from systems partners on: maternal alcohol and drug use (both illicit and prescription), distinct populations of infants and children (i.e. grouped by ages categories), types of services, and access and use of those services
4. Create a data sharing agreement across key systems	Seek funding for data analysis by a university or other entity
	Convene key stakeholders to determine what data each collects that could be useful, if possible, to share across systems
	Prepare a draft agreement for review by each agency
	Finalize the data agreement and distribute for signature

## APPENDICES

### Appendix A. Resources

#### Substance Use, Maternal and Infant Health

<https://www.childwelfare.gov/pubPDFs/drugexposed.pdf>

<https://www.ncsacw.samhsa.gov/files/Substance-Exposed-Infants.pdf>

<https://www.ncsacw.samhsa.gov/resources/substance-exposed-infants.aspx>

<http://www.samhsa.gov/atod>

<http://store.samhsa.gov/product/TIP-51-Substance-Abuse-Treatment-Addressing-the-Specific-Needs-of-Women/All-New-Products/SMA15-4426>

<https://www.ncsacw.samhsa.gov/resources/resources-mat.aspx>

#### Fetal Alcohol Spectrum Disorders

<http://www.cdc.gov/ncbddd/fasd/index.html>

<http://www.cdc.gov/ncbddd/fasd/data.html?mobile=nocontent>

<http://store.samhsa.gov/shin/content//SMA13-4803/SMA13-4803.pdf>

<http://www.nofas.org/>

## Appendix B: Legislation

### The Child Abuse Prevention and Treatment Act

The **Child Abuse Prevention and Treatment Act (CAPTA)** (Public Law 93-247) provides federal funding to states in support of prevention, assessment, investigation, prosecution, and treatment activities and also provides grants to public agencies and nonprofit organizations for demonstration programs and projects. Additionally, CAPTA identifies the federal role in supporting research, evaluation, technical assistance, and data collection activities; establishes the Office on Child Abuse and Neglect; and mandates the National Clearinghouse on Child Abuse and Neglect Information. CAPTA sets forth a minimum definition of child abuse and neglect.

The federal legislation addressing child abuse and neglect is the Child Abuse Prevention and Treatment Act (CAPTA), originally enacted in 1974 (Public Law 93-247). This Act was amended several times and was most recently amended and reauthorized on December 20, 2010, by the CAPTA Reauthorization Act of 2010.

The **CAPTA Reauthorization Act of 2010 (P.L. 111-320)** requires states to include in their State Plans specific strategies for addressing the needs of substance exposed children and their families. It includes the following language:

**SEC. 106. GRANTS TO STATES FOR CHILD ABUSE OR NEGLECT PREVENTION AND TREATMENT PROGRAMS. [42 U.S.C. 5106a] b. ELIGIBILITY REQUIREMENTS—**

2. CONTENTS—A State plan submitted under paragraph (1) shall contain a description of the activities that the State will carry out using amount received under the grant to achieve the objectives of this title, including...

- B. (ii) policies and procedures (including appropriate referrals to child protection service systems and for other appropriate services) to address the needs of infants born with and identified as being affected by substance abuse or withdrawal symptoms resulting from prenatal drug exposure, or a Fetal Alcohol Spectrum Disorder, including a requirement that health care providers involved in the delivery or care of such infants notify the child protective services system of the occurrence of such condition in such infants, except that such notification shall not be construed to-
- (I) establish a definition under Federal law of what constitutes child abuse or neglect; or
  - (II) require prosecution for any illegal action;
- (iii) the development of a plan of safe care for the infant born and identified as being affected by substance abuse or withdrawal symptoms, or a Fetal Alcohol Spectrum Disorder to ensure the safety and well-being of such infant following release from the care of health care providers, including through-
- (I) addressing the health and substance use disorder treatment needs of the infant and affected family or caregiver; and
  - (II) the development and implementation by the State of monitoring systems regarding the implementation of such plans to determine whether and in what manner local entities are providing, in accordance with State requirements, referrals to and delivery of appropriate services for the infant and affected family or caregiver...<sup>1</sup>

---

<sup>1</sup> Revised January 19, 2017

## Connecticut Laws on Reporting Child Abuse and Neglect

Connecticut, similar to other states, has gaps in policy and practice related to CAPTA regulations, Neonatal Abstinence Syndrome and Fetal Alcohol Spectrum Disorders. A concern is that these gaps contribute to the variability in hospital and healthcare provider practice and procedures around conducting screenings and making reports to CPS. Such ambiguity can contribute to bias and disparate treatment of pregnant women and their infants.

### CT Laws

- Mandated reporters are required to report or cause a report to be made when, in the ordinary course of their employment or profession, they have reasonable cause to suspect or believe that a child under the age of 18 has been abused, neglected or is placed in imminent risk of serious harm. (Connecticut General Statutes §17a-101a)
- Child abuse occurs where a child has had physical injury inflicted upon him or her other than by accidental means, has injuries at variance with history given of them, or is in a condition resulting in maltreatment, such as, but not limited to, malnutrition, sexual molestation or exploitation, deprivation of necessities, emotional maltreatment or cruel punishment. (Connecticut General Statutes §46b-120)
- Child neglect occurs where a child has been abandoned, is being denied proper care and attention physically, emotionally, or morally, or is being permitted to live under conditions, circumstances or associations injurious to his well-being. (Connecticut General Statutes §46b-120)

## Appendix C: References

1. Retrieved from: <http://fasdcenter.samhsa.gov/aboutUs/aboutFASD.aspx#1>
2. May PA, Baete A, Russo J, Elliott AJ, Blankenship J, Kalberg WO, Buckley D, Brooks M, Hasken J, Abdul-Rahman O, Adam MP, Robinson LK, Manning M, Hoyme HE. Prevalence and characteristics of fetal alcohol spectrum disorders. *Pediatrics*. 2014;134:855-66.
3. At-Risk Drinking and Illicit Drug Use: Ethical Issues in Obstetric and Gynecologic Practice, ACOG Committee Opinion, Number 422, December 2008 (Replaces No. 294, May 2004)
4. Streissguth, AP, Bookstein, FL, Barr, HM, Sampson, PD, O'Malley, K, & Young, JK (2004). Risk factors for adverse life outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects. *Developmental and Behavioral Pediatrics*, 25, 228-238.
5. 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
6. Fingar KR (Truven Health Analytics), Stocks C (AHRQ), Weiss AJ (Truven Health Analytics), Owens PL (AHRQ). Neonatal and Maternal Hospital Stays Related to Substance Use, 2006-2012. HCUP Statistical Brief #193. July 2015. Agency for Healthcare Research and Quality, Rockville, MD. <https://www.hcup-us.ahrq.gov/reports/statbriefs/sb193-Neonatal-Maternal-Hospitalizations-Substance-Use.jsp>
7. Ibid.
8. Ibid.
9. Retrieved on May 18, 2016 from: <http://www.ct.gov/dph/lib/dph/hisr/pdf/rr2012.pdf>
10. Smart, A.C., Stone, C.L., Mueller, L.M., Amadeo, F.A., Backus, K. (2016). Connecticut Registration Report for the Year Ended December 31, 2012, Connecticut Department of Public Health, Hartford, CT (<http://www.ct.gov/dph/RegistrationReport>).
11. Retrieved from [http://www.ct.gov/dph/lib/dph/family\\_health/prats\\_round\\_2\\_report.pdf](http://www.ct.gov/dph/lib/dph/family_health/prats_round_2_report.pdf)
12. Retrieved on May 18, 2016 from:  
<http://www.marchofdimes.org/peristats/ViewSubtopic.aspx?reg=09&top=9&stop=143&lev=1&slev=4&obj=1>
13. SAMHSA, Center for Behavioral Health Statistics and Quality, National Survey on Drug Use and Health, 2013 and 2014.
14. Source: AFCARS Data 2013
15. FASD Center for Excellence, 2003: <http://fasdcenter.samhsa.gov/Products/cost.aspx>
16. Lupton, C.; Burd, L.; and Harwood R. 2004. Cost of fetal alcohol spectrum disorders. *American Journal of Medical Genetics* 127C (671):42-50.
17. CT DPH Office of Health Care Acute Care Discharge Database and Hospital Reporting System Report, p.185.
18. Agency for Healthcare Research and Quality (AHRQ), Center for Delivery, Organization, and Markets, Healthcare Cost and Utilization Project (HCUP), State Inpatient Databases (SID) from 38 States, 2012.