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Substance-Exposed Infants: State Responses to the Problem



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
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Acknowledgments

This document was prepared by the National Center on Substance Abuse and Child Welfare (NCSACW) under Contract No. 270-027108 for the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Administration for Children and Families (ACF), both within the U.S. Department of Health and Human Services (HHS). Nancy K. Young, Ph.D., developed the document with assistance from Sid Gardner, M.P.A.; Cathleen Otero, M.S.W., M.P.A.; Kim Dennis, M.P.A.; Rosa Chang, M.S.W.; Kari Earle, M.Ed., L.A.D.C.; and Sharon Amatetti, M.P.H. Sharon Amatetti, M.P.H., served as the Government Project Officer from the Center for Substance Abuse Treatment (CSAT) and Irene Bocella, M.S.W., served as the Project Officer from Children's Bureau.

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Recommended Citation

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

Originating Office

Office of Program Analysis and Coordination, Center for Substance Abuse Treatment, Substance Abuse and Mental Health Services Administration, 1 Choke Cherry Road, Rockville, MD 20857

HHS Publication No. (SMA) 09-4369

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EXECUTIVE SUMMARY

In 2005–2006, the National Center on Substance Abuse and Child Welfare (NCSACW) undertook a review and analysis of States’ policies regarding prenatal exposure to alcohol and other drugs, in order to help local, State, and Tribal governments:

1. Gain a better understanding of current policy and practice in place at the State level that address substance-exposed infants (SEIs); and
2. Identify opportunities for strengthening interagency efforts in this area.

This study assessed State policy from the broadest perspective: prevention, intervention, identification, and treatment of prenatal substance exposure, including immediate and ongoing services for the infant, the mother, and the family. It reviewed States’ policies regarding:

- Pre-pregnancy prevention efforts;
- Screening and assessment in the prenatal period;
- Testing at birth and notification of child protective services (CPS) in cases in which infants are identified as substance-affected;
- The provision of services to SEIs and their parents after a CPS referral is made or other agencies become involved; and
- The processing of SEI-related referrals to developmental disabilities agencies.¹

This review discovered considerable variations among the States in both policy and practice regarding SEIs. States have responded in different ways to mounting concerns over the negative effects that prenatal exposure to illicit drugs and alcohol have on developing infants. They have also responded differently to Federal legislation (the Child Abuse Prevention and Treatment Act [CAPTA] amendments of 2003) requiring that a newborn determined to be exposed prenatally to illegal drugs must be referred to CPS.

States have instituted a range of policies to address prenatal substance exposure. These policies are carried out by multiple agencies and organizations, and practice does not always conform to official policy. To gain a better understanding of what States are currently doing about the issue, this study reviewed States’ policies and practices by examining legislation and policy in all States and by conducting intensive interviews with State-level staff in 10 selected States.

The report describes the findings of the study, which NCSACW conducted under its contract with the Substance Abuse and Mental Health Services Administration, Center for Substance Abuse Treatment (CSAT), and the Administration on Children, Youth and Families (ACYF)/Children’s Bureau (CB). This report identifies opportunities for strengthening interagency collaboration to address the SEI problem. The findings will be of interest to policymakers and officials concerned with the issue of SEIs, and to professionals in the fields of maternal and child health, child welfare, treatment of substance use disorders, education, and community services.

FIVE-POINT INTERVENTION FRAMEWORK

Since many SEIs are not identified prenatally or at birth, an approach that addresses all stages of development for the affected child is critical. Most previous work related to SEIs has focused on pregnancy and the birth event. However, a more comprehensive view is needed that takes multiple intervention opportunities into account, beginning with pre-pregnancy and continuing throughout a child's developmental milestones.

The framework around which this report is organized asserts that there are five major timeframes when intervention in the life of the SEI can reduce the potential harm of prenatal substance exposure:

1. PRE-PREGNANCY

This timeframe offers the opportunity to promote awareness of the effects of prenatal substance use among women of child-bearing age and their family members;

2. PRENATAL

This intervention point encourages health care providers to screen pregnant women for substance use as part of routine prenatal care and make referrals that facilitate access to treatment and related services for women who need those services;

3. BIRTH

Interventions during this timeframe incorporate testing newborns for substance exposure at the time of delivery;

4. NEONATAL

Developmental assessment and the corresponding provision of services for the newborn as well as the family at this intervention point, immediately after the birth event, are the emphasis; and

5. THROUGHOUT CHILDHOOD AND ADOLESCENCE

This timeframe calls for ongoing provision of coordinated services for both child and family.

This framework formed the basis for a review of State practices with SEIs. Within this context, States' policies and practices in developing system linkages within and among State agencies were reviewed. States need interagency collaboration to address the SEI problem. This need makes the issue of developing system linkages as important as the issue of handling each of the five intervention points, since the linkages pull the interventions in the five areas together.

METHODOLOGY

The information presented in this report draws from the in-depth review of 10 States and the broader review of State policy across the Nation. Information was gathered and analyzed from three sources: a review of Federal policies and actions; a review of existing literature and summaries of State policies; and structured interviews with key informants in 10 States. These 10 States were selected for in-depth review of their policies and practices pertaining to SEIs. This approach required contacting multiple informants in each State to gather information about SEI initiatives sponsored, operated, and funded by different State, local, and private agencies. The variations within and among States are the result of the independent roles of the States and counties; variations in attitudes in different States toward addiction, parenting, and child safety; and differences in how the set of agencies that handle SEI issues is organized.

This initial review of SEI issues based on prior surveys done by other organizations found that 39 of the 50 States and the District of Columbia had developed legislation, policies, or programs that addressed at least one of the five intervention points (pre-pregnancy interventions, prenatal interventions, identification at birth, immediate postnatal interventions, and postnatal services to children and their parents). Ten of these 39 States were selected for in-depth reviews. States were included from different regions of the Nation and of different sizes to provide a useful sample. States were also selected based on references in publications on SEI policy and practice. The States selected were California, Hawaii, Illinois, Maryland, Massachusetts, Minnesota, Rhode Island, South Carolina, Virginia, and Washington.

Three to five individuals were contacted in each of these 10 States, typically beginning with the Women's Treatment Coordinator in the drug and alcohol treatment agency. The typical informants were officials in State agencies responsible for child welfare, maternal and child health, and drug and alcohol treatment. Other contacts included staff from family or dependency courts, developmental disabilities agencies, and hospitals.

An interview guide was drafted based on the primary policy questions to be assessed. Pilot test interviews were conducted with two States, and final revisions to the interview guide were then made. Each interview lasted 30–60 minutes; follow-up calls were made as needed to verify specific points or to pursue documents referenced in the interviews. A content analysis emphasizing the five-point framework was conducted on the qualitative interview data. Additional documentation, such as State legislation, administrative guidelines, and practice protocols, was compiled from the States based on information provided in the interviews. These materials were added to the literature reviewed for each State.

During the data collection phase, information was reviewed and contacts were made with additional States, including Arkansas, Colorado, Maine, and Texas. These States had asked NCSACW for guidance on CAPTA-related issues. News reports on the current legislative proposals in these States were collected, reviewed, and summarized for inclusion in this report as additional detail.

HIGHLIGHTS

This in-depth review of State legislation and regulations, interagency agreements, and budget allocations provided the evidence of State policy. Each of the 10 States interviewed had policies in place that addressed one or more of the five intervention points, and the national research on other State policy across the Nation revealed other examples of policy focused on SEIs. These are summarized briefly below.

Pre-Pregnancy Awareness

Nineteen of the States have public education campaigns that emphasize the harm done by using alcohol, tobacco, and illicit drugs during pregnancy. Some States also have worked with institutions of higher education to disseminate this message. However, the national rates of use during the first trimester suggest that the message is not getting through to many women before they are aware of their pregnancies, especially those who are younger.

Prenatal Screening

To reduce substance exposure during the pregnancy and improve chances for a healthy birth outcome, an effective link must exist between screening and facilitating a woman's access to necessary treatment and related support services. Good model programs for prenatal screening operate in most of the 10 States, but no service delivery system in the Nation *requires* prenatal screening for substance use. Although Medicaid covers the cost of 37% of births nationally, there is no Medicaid requirement for prenatal screening for substance use. Although several States have done one-time prevalence studies, no State has current prevalence data on substance use during pregnancy. And it is difficult to assess the results of SEI policy because of the lack of data on prenatal screening and referrals for treatment.

Testing at Birth

Hospitals' policies and practices vary widely regarding the testing of newborns for evidence of substance exposure, with very few using universal screening and most conducting testing that is based on somewhat subjective criteria. Seven of the 10 States interviewed consider prenatal exposure to be evidence of child abuse or neglect, whereas three others do not. Hospitals do not usually provide CPS or other State agencies with data on the total number of infants tested at birth, results of the tests, or referrals to CPS. However, recent legislation in some States has expanded the requirement that a CPS referral be made when drug exposure is detected, based on States' effort to follow Federal policy in the CAPTA amendments. Fetal Alcohol Spectrum Disorders (FASD) have received increased attention in some States, although detection of FASD is challenging.

Immediate Postnatal Services for Newborns and Families

Responses to the CAPTA legislation requiring that substance-affected infants receive a developmental assessment under the Individuals with Disabilities Act (IDEA) are still evolving. There are few estimates of referral trends resulting from the new Federal policy. Of the 10 States studied in depth, only two have strong links between IDEA referrals and CPS agencies. Because of the lack of uniformity in child welfare-referred developmental assessments used in most States, it is difficult to assess status in immediate postnatal services and the variability in State policy and practice is itself a finding.

Services for Children and Families

Ideally, services for the infant or child and the parents are woven together in a comprehensive approach. More typically, the primary emphasis is on the child or the parents, rather than on both simultaneously. However, there are strong models of family-centered services in some States. SEIs are at higher risk of coming into contact with the child welfare system at some point, and findings regarding children in foster care indicate that most children do not actually receive the assessments and services they need. It is important to understand the intended, potential, and actual linkages between the programs that address postnatal interventions for developmental disabilities, in order to take the next step related to developing effective policy and practice in postnatal intervention.

Data Systems and Interagency Organizational Efforts

SEI issues must be handled in an intensely collaborative setting, since no single agency has the resources, the information base, or the dominant role to address the full range of needs of all substance-exposed or substance-affected newborns and their families. The lack of critically needed data that could be shared across agencies was noted as a major barrier to collaboration. There are gaps in how SEIs are tracked by State data systems through screening, assessment, and service delivery that inhibit States' ability to measure whether they are making progress on addressing the problem. The information gaps at each of these hand-off points are substantial. Such gaps weaken the ability of the systems to work together to track children and families as they move from one agency to another. State SEI policies and practices tend to develop within a complex system that includes diverse agencies within Federal and State government. States' interagency organizational efforts usually relegate SEI efforts to other interagency activities.

CONCLUSION AND KEY RECOMMENDATIONS

When the needs of substance-exposed children are addressed, it is apparent that the connections across the five points discussed in this report are as important as the actual interventions. The handoffs from one point to the next and the linkages needed to coordinate services become a comprehensive services framework, rather than a series of fragmented initiatives. The following action steps are recommended to provide the proper foundation for this framework to result in better outcomes:

- Given that Medicaid pays for 37% of births nationally and well above that level in several States, States could use Medicaid regulations and resources to their greatest advantage. They could influence hospitals and providers to adopt prenatal screening policies that embody the guidelines set forth by the American College of Obstetricians and Gynecologists (ACOG) (described in Section 3) in their Medicaid schedules and reimbursements;
- Current statewide prevalence estimates of substance-exposed births are needed to establish baseline data for each State in order to understand the level of need and define the priorities for meeting that need sufficiently;
- The necessary statutory or administrative support must be in place to authorize the appropriate interagency coordinating bodies to address SEI policy in a comprehensive and systemic manner as part of their mandates, and to establish and monitor interagency outcomes for SEI programs annually;
- States need to augment the capacity of their existing information systems to collect data on how many parents of SEIs are referred, how many enter treatment, how many complete treatment, and how many succeed in continuing their recovery. Existing data collection systems should be better linked to understand from where clients are referred and what responses are available from treatment systems. These data are crucial to understanding the costs and cost-effectiveness of programs (Yates, 1999); and
- States must creatively use multiple funding sources to support the implementation and expansion of SEI-related interventions. Comprehensive treatment is essential for SEI families, and capacity-building for this level of service requires the strategic use of multiple funding streams. As one powerful example, States can take better advantage of Medicaid to finance mental and behavioral health assessments, therapies, wraparound services, and other interventions for children who are at high risk of emotional problems because of substance abuse by one or both parents (Johnson, Knitzer, & Kaufmann, 2002). Also, prioritizing an investment of funds in prevention and early intervention services to women results in significant cost-savings opportunities to the child welfare, health care, education, and criminal justice systems.

Definitions

Assessment refers to a verbal interview by a substance-abuse treatment professional to determine the nature and extent of the mother's substance use disorder and to establish an effective plan of treatment.

Screening refers to verbal questioning designed to determine whether the mother has a substance use disorder.

Substances, in this report, refers to alcohol and illegal drugs, since these substances are emphasized in the policy guidelines reviewed.²

Note: There is substantial evidence that alcohol and tobacco cause harm, and potentially more severe harm, to more children than do illegal drugs (Andres & Day, 2000; Britt, Ingersol, & Schnoll, 1999; Lambers & Clark, 1996; Levin & Slotkin, 1998; Slotkin, 1998). There is also substantial evidence that mothers who use substances during pregnancy often use more than one substance (e.g., alcohol, tobacco, and an illegal drug) (SAMHSA, 2007; Arria et al., 2006). This factor makes it difficult to distinguish the effects of a particular substance from the effects of a second substance or the combination of substances.

Substance use is the use of any drug or combination of drugs in social situations, or for social reasons (U.S. Department of Health and Human Services, 1999). Social alcohol and other drug use can lead to further and elevated use, but most social users remain in this classification.

Substance use disorder is a complex behavioral disorder characterized by preoccupation with obtaining alcohol or other drugs (AOD) and by a narrowing of the behavioral repertoire toward excessive consumption and loss of control over consumption. It is usually also accompanied by the development of tolerance and withdrawal and impairment in social and occupational functioning.

Substance abuse is characterized by the presence of consequences related to the person's alcohol and other drug use. One definition is the use of a psychoactive drug to the extent that its effects seriously interfere with health or occupational and social functioning (Center for Substance Abuse Treatment [CSAT], 1994). Abuse may or may not involve physiological dependence or tolerance. The essential feature of substance abuse is a "maladaptive pattern of substance use manifested by recurrent and significant adverse consequences related to the repeated use of substances." Neglect of children is specifically listed as a potential symptom of substance abuse (American Psychiatric Association [APA], 2000).

Substance dependence involves continued alcohol and other drug use or abuse despite significant substance-related problems. There is “a pattern of self-administration that usually results in tolerance, withdrawal, and compulsive drug-taking behavior” (APA, 2000). The American Society of Addiction Medicine includes psychological or physical dependence in its definition (CSAT, 1994). Psychological dependence centers on the user’s need of a drug to reach a level of functioning or well-being. Physical dependence involves the establishment of tolerance or withdrawal upon cessation of alcohol and other drug use (CSAT, 1994).

Substance-affected infants refers to infants for whom prenatal substance exposure produces negative effects, which may or may not be detected. The effects of substance exposure depend on many factors, including the timing, frequency, and intensity of the exposure. The phrase “substance-affected infant” is used in the CAPTA legislation, but is not defined there or in Federal regulations; each State is able to use its own interpretation.

Substance-exposed infants, or SEIs, refers to infants exposed to AOD ingested by the mother in utero, whether or not this exposure is detected.

Note: Some sources may use other terms to refer to these infants, such as substance-exposed births (SEBs), substance-exposed newborns (SEBs), drug-exposed births (DEBs), and prenatally exposed infants (PEIs).

Testing refers to a laboratory test, such as urinalysis or meconium testing, that indicates whether alcohol or illicit drugs are present in the mother’s or infant’s body.

SECTION 1: FRAMING THE ISSUE

Each year, an estimated 400,000–440,000 infants (10–11% of all births) are affected by prenatal alcohol or illicit drug exposure, as described in the analysis in this section. Prenatal exposure to alcohol, tobacco, and illicit drugs has the potential to cause a wide spectrum of physical, emotional, and developmental problems for these infants. The harm caused to the child can be significant and long-lasting, especially if the exposure is not detected and the effects are not treated as soon as possible.

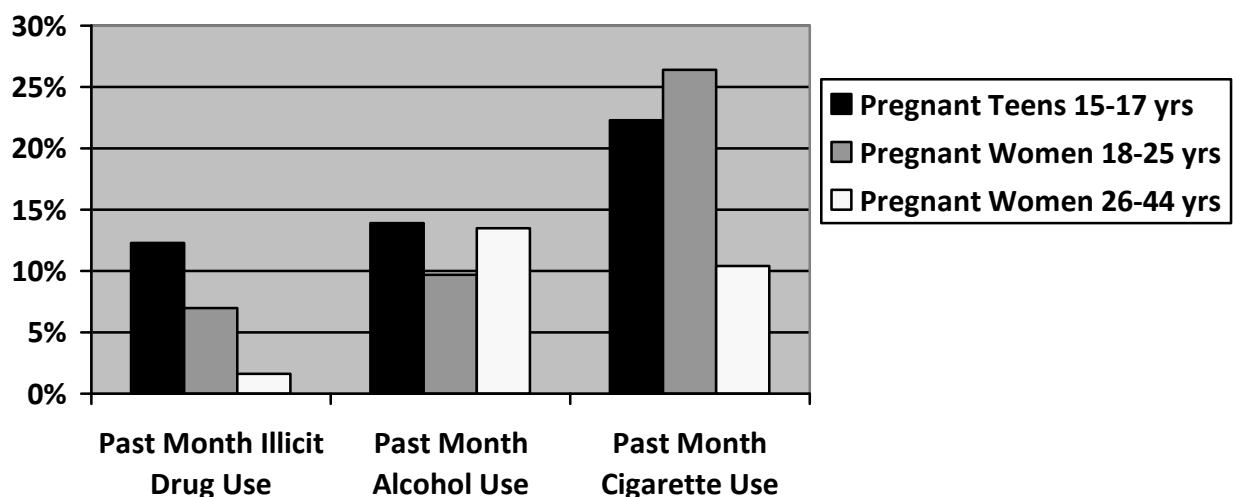
The current system of identifying these infants and responding to their needs is fragmented and fails to identify and serve most of these children. There are, however, Federal efforts to monitor substance use among pregnant and recently pregnant women, which enable the estimates of prenatal *exposure* to drugs and alcohol cited previously. The following studies are examples of reports that have estimated substance use by pregnant women and the number of infants exposed.

National Survey on Drug Use and Health (NSDUH). The latest Federal data available from the NSDUH report 2004–2005 annual averages of substance use by pregnant women aged 15–44. As Table 1 shows, rates of use vary by type of substance and trimester of pregnancy. For all substances, prevalence rates are highest in the first trimester. Lower rates in the second and third trimesters are encouraging and suggest that pregnant women are responding to education and other interventions to reduce prenatal substance use. However, the data also highlight a need to strengthen efforts to identify and reach women before they get pregnant, as well as in early pregnancy, when substance exposure can have significant consequences for the developing fetus. Prior studies based on this annual survey have found similar rates of substance use.³ When these percentages are applied to the approximately 4.1 million infants born each year, the projections result in a wide range of estimated substance-exposed infants (SEIs).

Table 1: Substance use by pregnant women, by length of gestation and estimated number of infants exposed (2004–2005 annual averages)			
Substance Used (past month)	First Trimester	Second Trimester	Third Trimester
Any Illicit Drug	7.0% women 286,510 infants	3.2% women 130,976 infants	2.3% women 94,139 infants
Alcohol	20.6% women 843,158 infants	10.2% women 417,486 infants	6.7% women 274,231 infants
Binge Alcohol	7.5% women 306,975 infants	2.6% women 106,418 infants	1.6% women 65,488 infants
Cigarettes	23.7% women 970,041 infants	12.9% women 527,997 infants	13.7% women 560,741 infants

As Figure 1 makes clear, substance use rates among pregnant women also vary by age groups, with both past month illicit drug and alcohol use highest among teenagers (Substance Abuse and Mental Health Services Administration [SAMHSA], 2006).

Figure 1: Substance Use by Pregnant Women, by Age Groups (2004–2005)



The NSDUH also provides information beyond substance *use* to capture the number of individuals who need alcohol or drug treatment for substance *abuse* or *dependence*. Table 2 shows the results of an analysis using the 2005 NSDUH public use file on the percentage of females classified as needing alcohol or drug treatment, by pregnancy status.

Table 2: Percentage of females aged 15–44 classified as needing treatment, by pregnancy status: 2005 (Source: Online Analysis of NSDUH Public Use File)		
Needed Treatment in Prior Year for:	Pregnant	Not Pregnant
Alcohol or Illicit Drug Use	7.6%	10.5%
Illicit Drug Use	3.5%	3.9%
Alcohol Use	5.5%	8.4%

Fetal Alcohol Surveillance Network (FASSNet) and State-Based Fetal Alcohol Syndrome (FAS) Prevention Program. From 1997–2003, the Centers for Disease Control and Prevention (CDC) funded FASSNet, a statewide, population-based surveillance network to determine the prevalence of FAS within a geographically defined area. CDC studies from FASSNet showed FAS prevalence rates ranging from 0.2–1.5 cases per 1,000 live births in different areas of the United States. Other prenatal alcohol-related conditions, such as alcohol-related neuro-developmental disorders (ARND) and alcohol-related birth defects (ARBD), are believed to occur about three times as often as FAS (CDC, 2005). Although the FASSNet cooperative agreements with five States ended in 2003, the FASSNet methodology has been adapted for use by the CDC’s more recently funded FAS Prevention Program, which includes cooperative agreements with seven States.⁴ The CDC also monitors the prevalence of alcohol use among women of child-bearing age through the Behavioral Risk Factor Surveillance System survey.

Screening During Pregnancy. In a study of more than 7,800 pregnant women enrolled in prenatal care clinics in five communities and screened for substance use with the *4P’s Plus*[®], approximately one-third (32.7%) had a positive screen. Four of the communities conducted follow-up assessments on all women with a positive screen and found that 15% of those women continued to use substances after learning of the pregnancy (Chasnoff et al., 2005).

The Pregnancy Risk Assessment Monitoring System (PRAMS). PRAMS, currently used in 32 States, collects data based on self-reported maternal behaviors and experiences that occur before, during, and shortly after pregnancy. Through cooperative agreements between the CDC and these 32 State governments, information on the use of alcohol and tobacco before and during pregnancy is compiled; questions on illegal drug use are included in the survey at the discretion of the State.⁵

In some of these States, maternal substance use is reported at levels that corroborate States’ other estimates and national survey data. For instance, PRAMS indicates that during their last trimester of pregnancy 2–12% of women used alcohol and 7–25% used tobacco. Of the 10 States reviewed for this report, only two of the PRAMS States, Hawaii and South Carolina, compile data on illicit drug use, which are included in Table 3.

Table 3: Substance use during pregnancy— available State prevalence data		
State	Estimate	Sources/Date
California	11.35% tested positive for drugs or alcohol	Statewide random screening (California Department of Alcohol and Drug Programs, 2006)
Hawaii	12.7% tested positive for drugs	Random screening/(Hawaii State Department of Health, 1996)
South Carolina	12.1% used alcohol and drugs (urine) 22.4% used alcohol and drugs (meconium only) 25.8% used alcohol and drugs (both methods)	Sample (South Carolina Department of Health and Environmental Control, 1991)
27 PRAMS States	6.8% (Utah) to 25.3% (West Virginia) smoked during last 3 months of pregnancy 2.0% (West Virginia) to 11.6% (Vermont) used alcohol in last 3 months of pregnancy	State PRAMS reports/2002; self-reported (Williams et al., 2006)

None of the States in which interviews were conducted for the current study had up-to-date statewide prevalence estimates of substance-exposed births (SEBs). Such estimates require regularly updated surveys or other data collection methods. Most States have a historic baseline based on a one-time survey that has not been regularly renewed or updated. Section 3 describes States' experiences with these intermittent prevalence surveys as a component of their interagency coordinating and monitoring efforts.

The need for routine data collection and monitoring remains important, given that the number of women with substance use disorders has not decreased significantly over the last few years. For example, the percentage of females aged 12 and older with illicit drug or alcohol dependence or abuse increased slightly from 6.1% in 2002 to 6.4% in 2005 (Office of Applied Studies, 2005).

When the figures in Tables 1–3 are analyzed together, the data can be summarized as follows:

- An estimated 10–11% of the 4.1 million live births (in 2005) involved prenatal exposure to alcohol or illegal drugs;
- Prenatal exposure to alcohol rises to as high as one in five pregnancies during the first trimester; and
- When tobacco data are included, the three data elements—prenatal use of alcohol, tobacco, and illegal drugs—are the basis for the statement that “more than one million” children are affected by prenatal exposure (McGourty & Chasnoff, 2003). This figure differs from the 400,000–440,000 figure because the smaller figure measures only prenatal use that can be detected at a point in time—birth—whereas the surveys that are the basis for the larger figure cover prenatal substance use during the entire period of pregnancy.⁶

Child Abuse Prevention and Treatment Act (CAPTA) Requirements for States

In reauthorizing CAPTA legislation in 2003, Congress responded to concerns about prenatal drug exposure by making three important changes in the law. In order to maintain their CAPTA grant funding, States must assure that they have:

- Policies and procedures (including appropriate referrals to child protection service systems and for other appropriate services) to address the needs of infants born and identified as affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure, 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 establish a definition under Federal law of
- what constitutes child abuse or require prosecution for any illegal action;
- A plan of safe care for the infant born and identified as being affected by illegal substance abuse or withdrawal symptoms;
- Procedures for the immediate screening, risk and safety assessment, and prompt investigation of such reports.

CAPTA also requires States to establish procedures to refer children younger than 3 years who have substantiated cases of child abuse or neglect to early intervention services, funded under the Individuals with Disabilities Education Act (IDEA). Although the CAPTA amendments regarding SEIs state that the identification of an SEI shall not be construed as establishing actual child abuse or neglect, these infants can be included in the group of children who can be referred for developmental assessments.

(National Early Childhood Technical Assistance Center, 2006; DHHS, Administration for Children and Families, 2006)

HISTORICAL PERSPECTIVE

The issue of SEBs first came to public attention in the United States during the 1980s and early 1990s because of the concern about infants affected by their mother's use of crack cocaine during pregnancy. Earlier work on fetal alcohol exposure took place in the late 1960s and early 1970s.⁷ National focus on the problem has re-emerged over the past few years in response to several developments:

- In 2003, Congress passed amendments to CAPTA requiring that substance-affected infants be referred to CPS (see the CAPTA sidebar);
- A growing body of research on Fetal Alcohol Spectrum Disorders (FASD) and alcohol-related neuro-developmental disorders (ARND) has included longitudinal studies documenting the long-term mental and emotional effects of prenatal exposure to alcohol. This research has led to the development of new federally funded resource centers and the formation of a congressional caucus to address the SEI problem;
- Concern has grown about the increasing number of pregnant women and children affected by maternal use of methamphetamines and about households in which children are exposed to the dangers of methamphetamine manufacture;⁸ and
- Some States have enacted or proposed legislation directed at maternal substance abuse, including legislation in some States that has led to the incarceration of mothers of SEIs.

Increased interest and attention to FASD in particular has taken several different forms at the State level, and has been the focus of considerable legislative activity. This increase is partly in response to the leadership and information clearinghouse services provided by the SAMHSA FASD Center for Excellence. The Center summarized in its 2004 report on FASD State legislation that:

Analysis of the data shows that State legislatures are responding to the societal cost of FASD by placing continually more emphasis on prevention and intervention services. State legislative actions range from calling for coordinated State FASD efforts to requiring FASD information to be given to persons applying for marriage licenses. (DHHS, SAMHSA, FASD Center, 2006)

For example, the 2004 Hawaii legislature adopted a proposal to address FASD more comprehensively and charged the Department of Health with developing a coordinated statewide effort to address the issue.⁹ Similar legislation is currently pending in Maryland. Also, the 2004 Minnesota legislature transferred funds from the Commissioner of Health to a statewide organization focused solely on prevention of and intervention with FASD. Shortly thereafter, a contract was signed between the Minnesota Organization on Fetal Alcohol Syndrome and the Minnesota Department of Health to address issues of research on FASD, public education, professional education, and community grants.

The focus on prenatal substance exposure is also intensified by increasing evidence that for SEIs and children, *early intervention makes a difference*. In the early 1990s, some practitioners and researchers held that prenatal drug exposure inevitably produced lasting damage, especially when the drug was cocaine. Others held that drug-exposed children were not significantly different from other infants who faced similar socioeconomic challenges. As information has accumulated over the past decade, both positions have been supported. There is growing evidence of the harmful effects of prenatal exposure to illegal drugs, alcohol, and tobacco. At the same time, it is clear that early intervention and nurturing home environments are important mediating factors that can lead to positive outcomes for substance-exposed children (Chasnoff, 2001).

POLICY PERSPECTIVE

This study reviews State legislation and regulations, interagency agreements, and budget allocations as the best evidence of State policy. Although there are several national compilations of State policy information, data collection is not standardized and different definitions are applied to commonly used terms. For example, some national compilations categorize States in groups according to their reporting requirements and definitions of child abuse and neglect, but the categorization is dependent on the author's interpretation of legislative intent and implementation practices.¹⁰ The interviews helped clarify some of these inconsistencies.

The problem of prenatal substance exposure can be viewed from a narrow perspective focused primarily on the birth event (identification of prenatally exposed newborns through toxicological testing and screening for maternal risk factors). Or, it can be viewed from a comprehensive perspective that extends beyond the birth event to include the wider issues of pre-pregnancy prevention, prenatal and postnatal intervention, and support for affected children throughout childhood and adolescence. This broader view addresses the prevention and treatment of substance use disorders among women of child-bearing age, pregnant women, and parents, as well as the ongoing effects of these disorders on the women's children and families.

The policies and practices that States adopt reflect varying values for parenting, addiction, treatment, foster care, and parents' versus children's rights. These underlying values lead some jurisdictions to prefer a prevention-focused health and social services response to the issue of SEIs. Other jurisdictions may adopt a more response-oriented approach that encompasses a wider array of issues surrounding prenatal and postnatal substance exposure and effects. The particular perspective of a given State subsequently influences which agencies are involved in carrying out a State's SEI policies. These agencies can range from a "core" representation of hospitals, maternal and child health agencies, and child welfare agencies, including a broader spectrum of substance abuse prevention and treatment, education, early intervention, mental health, and developmental services.

This study assessed State policy from the broadest perspective: prevention, intervention, identification, and treatment of prenatal substance exposure, including immediate and ongoing services for the infant, the mother, and the family. It reviewed States' policies regarding:

- Pre-pregnancy prevention efforts;
- Screening and assessment in the prenatal period;
- Testing at birth and notification of CPS in cases in which infants are identified as substance-affected;
- The provision of services to SEIs and their parents after a CPS referral is made; and
- The processing of SEI-related referrals to developmental disabilities agencies.¹¹

A Snapshot of Need: Data From the States Interviewed

- Washington State officials and publications indicate that from 8,000–10,000 infants were exposed to drugs and alcohol in 2002, of 99,672 births statewide. They estimate that from 800–1,000 of these infants are “drug or alcohol affected,” indicating a more serious impact. The estimate is based on a projection by State staff, given their review of national data, that 10–12% of all substance-exposed births (SEBs) are also substance-affected. An assessment of Medicaid claims and review of medical charts for prenatal care in Washington State from 1989–1995 documented that 6% of births involved prenatal exposure to alcohol or illicit drugs (Washington State Department of Health, 2002).
- In 1997, Maryland’s General Assembly passed the Children in Need of Assistance—Drug Addiction at Birth—Parental Rights Act (DABA) in response to the heightened awareness of substance-exposed infants (SEIs). During the same year DABA was enacted, Maryland considered legislation that sought to increase screening at birth. In conjunction with the proposed legislation, State agency staff provided an estimate of 6,783 SEIs born each year (interview on February 10, 2005).
- The Illinois Department of Public Health, Division of Epidemiologic Studies, issued a report titled “Surveillance of Illinois Infants Prenatally Exposed to Controlled Substances 1991–1999,” in November 2001. The report is no longer compiled, and some respondents expressed concern that the data are incomplete because they show a 25% decrease in SEI reports from 1991–1999. According to the Department of Children and Family Services, a total of 1,172 SEBs were reported in fiscal year 2004, and 1,060 of these were substantiated (Fornoff, Egler, & Shen, 2001).
- Some States have assessed the number of cases in which a woman gives birth to more than one SEI. For example, Washington reviewed its prenatal databases during 1994–1995. The State found that 53% of women delivering drug-exposed infants had previously given birth to a drug-exposed infant. It also found that 27% of women delivering drug-affected infants had previously given birth to a drug-affected infant. First births were not included in the study (Washington State Department of Health, 2002).
- Similarly, Illinois found that the percentage of repeat SEIs, defined as a subsequent reported SEI for the same mother, increased from 14% in 1990 to 46% in 1999 but declined slightly to 42% in 2001 (Fornoff et al., 2001).
- Virginia conducted a one-time assessment in 2001, revealing that 23.2% of the women in the sample (43 cases randomly selected from 256 statewide SEB reports) had other children in foster placement because of maternal substance abuse. Also, of these women, 14% had given birth to other prenatally exposed children, with an average of 2.5 children for each mother (Virginia Department of Health, 2004).
- A final set of estimates focus on the special needs for treatment among child welfare parents. In one of the only studies of substance abuse treatment need that assessed a child welfare population, researchers in Illinois found that of women with children in the child welfare system, 46.6% needed treatment, compared with 4.2% in the general female population in Cook County (Fornoff et al., 2001).

SECTION 2: COMPREHENSIVE FRAMEWORK FOR INTERVENTION

Since many substance-exposed infants (SEIs) are not identified prenatally or at birth, an approach that addresses all stages of development for the affected child is critical. Additions to the Child Abuse Prevention and Treatment Act (CAPTA) legislation require States to establish procedures to refer children younger than 3 years with substantiated cases of child abuse or neglect to early intervention services, funded under the Individuals with Disabilities Education Act. These services constitute an additional opportunity beyond perinatal settings to identify and respond to both substance exposure in children and substance use disorders in the family.

Infants and very young children are especially vulnerable to abuse and neglect. Federal data show that in 2003 children from birth–3 years had the highest rates of victimization, at 16.4 per 1,000 children. Of the estimated 1,500 children who died as a result of child abuse or neglect, 79% were younger than 4 years. Additionally, infants and toddlers are the fastest-growing age group of children being removed from their homes as a result of abuse or neglect and placed in foster care in the United States (Goldson, 2001; Shaw & Goode, 2005). Children with disabilities are at two to three times the risk for abuse or neglect than children without disabilities (Sullivan & Knutson, 2000). The fact that substance-exposed children may have disabilities that put them at higher risk for maltreatment adds to the need for a framework that assists States and communities in organizing their policies and services across the developmental continuum.

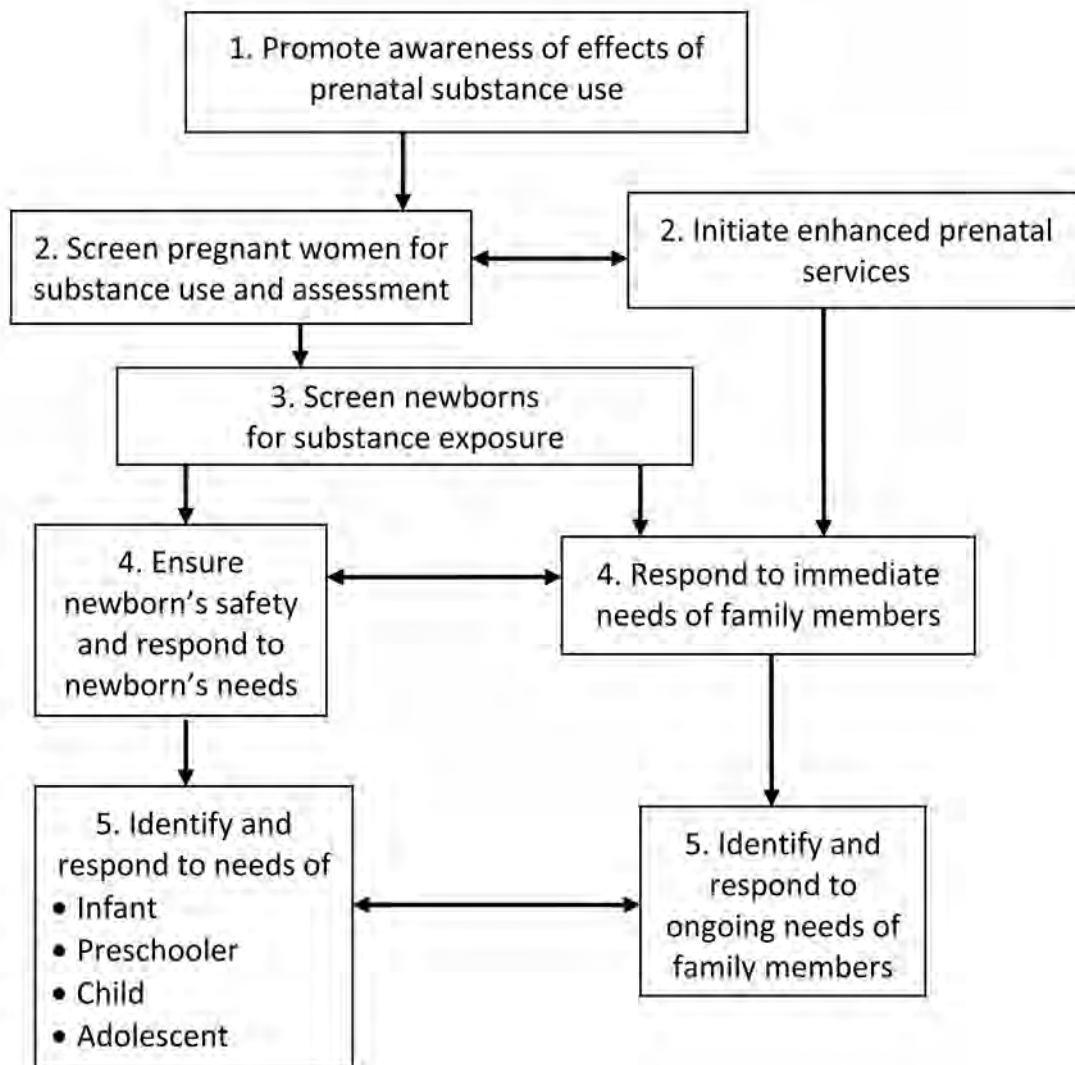
The Policy and Practice Intervention Points for Children and Families framework (see Figure 2) defines the points when policy and practice interventions can benefit substance-exposed children and their families. It begins with the period before pregnancy, when the intervention is to increase awareness of the effects of prenatal substance use. It proceeds through the prenatal period and birth, when the interventions include the screening of pregnant women for substance use and the testing of infants for substance exposure. It ends with the long-term development of the child and the ongoing needs of the family, when multiple services are needed.

Many States have policies and/or practices addressing one or more of these five intervention points. In addition to identifying the intervention points, the framework indicates points when system linkages would allow coordination of needed interventions and services provided by multiple agencies.

The framework illustrates a number of important issues:

- The birth event is only one of several opportunities to affect outcomes for the SEI and family, and interventions are needed throughout the child’s developmental stages;
- All family members need services, which is the basis for the movement toward a family-centered approach; and
- The importance of system linkages is emphasized in coordinating services across the spectrum of prevention, intervention, and treatment.

Figure 2: Policy and Practice Intervention Points for Children and Families



The vertical arrows indicate potential linkages between systems or agencies that provide interventions at the different developmental stages in the life of the child and family. An example of this kind of system linkage is communication between the prenatal clinics involved at intervention point 2 and the birthing hospitals involved at intervention point 3 to support the identification of newborns affected by prenatal substance exposure.

The horizontal arrows indicate potential linkages between the systems and agencies that provide interventions for either the child or the parents within the same developmental timeframe. For example, a woman may be identified at intervention point 2 as abusing substances while she is pregnant; she would need a substance abuse intervention as well as prenatal care. Communication between her prenatal care provider and substance abuse service provider would allow coordination of services to ensure appropriate care.

MULTIPLE AGENCIES AND COLLABORATIVE EFFORTS

State SEI policies and practices develop in a complex system that includes diverse agencies within Federal and State government. These agencies have important *program* roles, but do not typically come together to develop and monitor comprehensive *policy*. As a result, this study required contacting multiple informants in each State to gather information about SEI initiatives sponsored, operated, and funded by different State, local, and private agencies. The variations within and among States are the result of the independent roles of the States and counties; variations in attitudes in different States toward addiction, parenting, and child safety; and differences in how the set of agencies that handle SEI issues is organized.

Policy innovation in the States can take place across and within a broad array of agencies. These agencies include child welfare, substance abuse treatment, family/dependency courts, child care and development, special education, maternal and child health, developmental disabilities, family support, and juvenile justice agencies. Important stakeholders in the private and non-profit sectors include hospitals, health care management plans, and private physicians responsible for obstetric and pediatric care. However, the involvement of a large number of agencies and stakeholders has the potential to inhibit innovation, unless resources and communications are sufficient to enable effective interagency efforts and monitoring of their effectiveness.

To fully address SEI issues, they must be handled in an intensely collaborative setting, since no single agency has the resources, the information base, or the lead role to address the full range of needs of all substance-exposed or substance-affected newborns and their families. If concern for these children is to continue past birth, the number of families who may need services increases to several million; these are the families of preschoolers who were prenatally exposed, many of whom may also be affected by continuing substance use disorders in their families. These increases in the scope and complexity of States' interagency networking are important aspects of the context for State SEI policy and its implementation.

For these reasons, this study reviewed States' policies and practices in developing system linkages within and among State agencies. States need interagency collaboration to address the SEI problem. This need makes the issue of developing system linkages as important as the issue of handling each of the five intervention points, since the linkages pull the interventions in the five areas together.

SECTION 3: INTERVENTION POINTS

PRE-PREGNANCY

Policies and practices that address the substance-exposed infant (SEI) problem by preventing substance abuse *before* a woman becomes pregnant tend to focus on three areas:

1. Health warnings;
2. Provision of educational materials; and
3. Public education and awareness media campaigns.

The relevance of these strategies has increased because of the prevalence data on drug and alcohol use, in particular binge drinking, by both pregnant women and women of child-bearing age.

Health Warnings

Studies show that warning signs raise awareness and may reduce alcohol consumption among light to moderate drinkers (Fenaughty & MacKinnon, 1993). Warning signs are most effective if they are part of a larger, comprehensive strategy to provide information and link women to needed treatment services.

In 1981, the U.S. Surgeon General issued a public health advisory warning that alcohol use during pregnancy could cause birth defects. This advisory suggested that pregnant women limit the amount of alcohol they drink. In 2005, in the light of new information on Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders (FAS/FASD), the Surgeon General updated and reissued the advisory on alcohol use during pregnancy—this time stating that “no amount of alcohol consumption can be considered safe during pregnancy” (DHHS, 2005).

In addition to the Surgeon General’s efforts, the Federal government has enacted legislation to help inform and educate the general public about the health hazards that may result from the use or abuse of alcoholic beverages. The Alcoholic Beverage Labeling Act of 1988 mandates health-warning labels on all alcohol containers that must include warnings against drinking during pregnancy because of the risk of birth defects. Although an important step, the legislation prohibits States from mandating any additional or alternative warnings on alcohol containers.

Aside from beverage warning labels, no Federal statutes require alcohol retailers or health care providers to post warnings against drinking during pregnancy. Still, many States have taken the initiative to mandate warning signs that further caution women and the larger public about the risks of prenatal alcohol and drug use.

Provision of Educational Materials

Several States also have enacted legislation requiring educational information (e.g., a brochure or pamphlet) about the effects of substance use during pregnancy. This information is to be provided to women in select venues at opportune times, such as physicians' offices where women go for medical services or the county clerk's office where couples go to request a marriage license (DHHS, SAMHSA, n.d.).

Policy at the Federal level also promotes the distribution of education materials. The Drug-Free Schools and Communities Act Amendments of 1989 require universities and educational institutions receiving Federal funding to establish substance abuse prevention programs for their employees and students. The act mandates that institutions annually distribute to each student and employee written materials that include a description of the various health risks associated with the use of illicit drugs and abuse of alcohol. These risks include the dangers of drinking during pregnancy.

Public Education and Awareness Media Campaigns

Public education media campaigns are a third strategy to address pre-pregnancy prevention. These campaigns target three audiences:

- Women of child-bearing age and their partners, family, and friends;
- Health and social service providers who serve women; and
- The general public.

Minnesota is an example of one State whose public awareness campaigns have spanned all these audiences. (See "Findings" in this section for more details.)

The Federal government is often a key promoter and funding source for such public education campaigns (see sidebar). State and local agencies and private non-profits also contribute significant resources to these prevention efforts.

How the Federal Government Supports Local Outreach

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) recently completed a 2-year multimedia public awareness campaign, "Play it Smart. Alcohol and Pregnancy Don't Mix."

The research-based campaign targeted African-American women aged 21–29, their friends, and family living in Washington, DC. NIAAA conducted the campaign with oversight from the National Organization on Fetal Alcohol Syndrome (NOFAS) and supplementary funding from the National Center on Minority Health and Health Disparities. The multimedia campaign included:

- Print materials (posters, magnets, and bookmarks);
- Broadcast materials (television and radio public service announcements, information booths, magazines, newspapers, and mass transit advertising);
- Community events with neighboring churches, hospitals, and government agencies;
- Metrorail placards and advertising in select movie theaters; and
- Help line telephone services.

(NIAAA, 2004)

The existence of State policy (i.e., legislation, statutes, and regulations) that actually mandates these types of public education campaigns is minimal. Still, States such as California and Maryland have stepped up prevention efforts by enacting legislation that helps facilitate the development and implementation of such large-scale public education campaigns.

Sample State Initiatives

Table 4: Summary of State policy initiatives on pre-pregnancy intervention			
	Health Warnings	Educational Materials	Media Campaigns
Alaska	X		
Arizona	X		
<i>California</i>	X	X	X
Delaware	X		
Georgia	X		
<i>Hawaii</i>		X	
<i>Illinois</i>	X		
Kentucky	X	X	X
Maryland		X	
<i>Massachusetts</i>	X		
<i>Minnesota</i>	X	X	X
Missouri	X	X	
Nebraska	X		
Nevada	X		
New Hampshire	X		
New Jersey	X		
New Mexico	X		
New York	X		
North Carolina	X		
Oregon	X		
South Dakota	X		
Tennessee	X		
<i>Washington</i>	X		
West Virginia	X		
Washington, DC	X		

(States in italics were part of the in-depth review sample.)

***Policies and Practices Bridging Intervention Points 1 and 2—
Kentucky’s Early Childhood Initiative***

In 2001, with State Tobacco Settlement funds, Kentucky developed a comprehensive Early Childhood Initiative that placed the issue of substance use during pregnancy at the forefront. This initiative included a statewide Healthy Babies Campaign to increase public awareness and education about Fetal Alcohol Syndrome, the impact of substance abuse on pregnancy and childrearing, and the importance of smoking cessation.

The campaign distributed 800,000 marketing pieces in the first 6 months, established a toll-free number and Website to access information and resources, provided all new parents with written materials and a videotape emphasizing the significance of a child’s first few years for growth and development, and ran a series of Healthy Baby television and radio spots. Early focus group results showed a general awareness of the importance of not using drugs and engaging in other healthy behaviors while pregnant.

The Early Childhood Initiative also established the KIDS NOW Substance Abuse and Pregnancy Initiative to provide alcohol, drug, and tobacco screening, as well as prevention education and treatment services to all pregnant women in the State. KIDS NOW provides services to all pregnant women identified and referred by health care and other social service providers. KIDS NOW has evolved since its inception in 2001 (KIDS NOW, n.d.).

Year 1 began with the Kentucky Medical Association encouraging physicians to screen and refer pregnant women. Screening and referrals began in year 2, as practitioners were trained on how to use the 4P’s screening tool. With screening underway, the next couple of years focused on establishing strong linkages with community agencies and health departments to facilitate the screening, assessment, and treatment entry process (Kentucky’s Early Childhood Initiative, 2006).

On average, about 3,000 women are screened each year; the percentage of women who are referred to and enter treatment has ranged from 33–57% (Kentucky’s Early Childhood Initiative, 2006).

PREGNANCY AND THE PRENATAL PERIOD

The second opportunity to intervene and engage women at risk of delivering an SEI is during pregnancy, when screening by health care providers can result in early identification, referral for comprehensive assessment, and a timely connection to appropriate substance abuse treatment services. These interventions should occur as early in the pregnancy as possible, to minimize risk of exposure for the developing infant.

This part of the intervention framework emphasizes the incorporation of brief (non-laboratory) screening methods into standard prenatal care practice. Such methods detect potential substance use during pregnancy and provide follow-up referrals to treatment and other supportive services for pregnant women who are identified as needing those services.

Screening

Screening methods can include self-report, interviews, or clinical observation. Prenatal care guidelines issued by the American College of Obstetricians and Gynecologists (ACOG) Committee on Obstetric Practice clearly state that “all pregnant women should be questioned at their first prenatal visit about past and present use of alcohol, nicotine, and other drugs” (American Academy of Pediatrics & ACOG, 2002). In 2004, ACOG’s Committee on Ethics issued a statement asserting that “physicians have an ethical obligation to learn and use techniques for universal screening questions. . . .” In the same document, ACOG concluded that “physicians have been slow to implement universal [prenatal] screening . . .” (ACOG, 2004).

One barrier to implementing standardized prenatal screening identified by those interviewed in this study is the lack of a widely accepted screening tool. Yet several screening tools that take 10 minutes or less to administer have been validated for pregnant women. These include the T-ACE, the TWEAK, and the *4P’s Plus*[®] (see sidebar)

The 4P’s Plus[®]—An Evidence-Based Screening Tool

The 4P’s Plus[®] is a quick, five-question screen designed to identify pregnant women who need an in-depth assessment or follow-up monitoring for risk of alcohol, drug, and tobacco use. The tool is administered during a woman’s prenatal care visit; it asks:

- Did either of your parents ever have a problem with alcohol or drugs?
- Does your partner have a problem with alcohol or drugs?
- Have you ever drunk beer, wine, or liquor?
- In the month before you knew you were pregnant, how many cigarettes did you smoke?
- In the month before you knew you were pregnant, how many beers/how much wine/how much liquor did you drink?

A recent study evaluated the 4P’s Plus[®] and found that it was effective in identifying severe, moderate, or mild alcohol and drug use by pregnant women, thereby increasing opportunities for early intervention. Because of the brevity of the tool, it is practical to implement in clinical practice. And because of its early identification and intervention capabilities—which can prevent or reduce the major financial, physical, psychological, and socioeconomic costs associated with a substance-exposed infant—this tool is potentially very cost-effective.

(Chasnoff et al., 2005)

Most States that have prenatal screening programs track the total number of women participating in the program and the total number of drug-free babies delivered at the end of the program. However, these data are not compared with the State's total number of births or its baseline estimate of SEIs. The focus is on the number of identified women served, rather than on the total number of pregnant women who need services.

Complete data on prenatal screening programs would enable these States to better assess the effectiveness of the prevention program or to expand its scope. Such data on how these programs relate to the larger context of all births and all pregnant and parenting women who need substance use treatment would also help States in those efforts. In addition, measuring only drug-free births, while significant, does not address longer-term recovery outcomes. Some States have done one-time effectiveness studies of prenatal prevention efforts, but without the resources set aside to update the evaluation on an ongoing basis.

Given that Medicaid pays for 37% of births nationally, and well above that level in several States, Medicaid can provide substantial impetus for States to adopt prenatal screening policies that embody the ACOG guidelines in their Medicaid schedules and reimbursements. For example, in Washington, Medicaid covered 43% of births in 2002, and in South Carolina, it covered 47% (Williams et al., 2006; South Carolina Department of Health and Environmental Control, 1991). However, few States have leveraged their Medicaid resources and regulations to make such screening part of all prenatal care.

Follow-Up Referrals for Treatment and Supportive Services

To reduce substance exposure during the pregnancy and improve chances for a healthy birth outcome, there must be an effective link between screening and facilitating a woman's access to necessary treatment and related support services. Too often, there is a gap at this critical juncture. This gap is, in part, due to a perceived lack of appropriate treatment options for pregnant women held by those outside the substance abuse treatment system who are not familiar with its resources. For cases in which primary care providers have some knowledge of treatment options available in their community, they may not have sufficient information regarding how to access that information. Additionally, primary care providers are often reluctant to broach the delicate topic of a potential substance use disorder with their patients, for fear of driving substance-using women away from seeking prenatal care.

To counteract this last concern, some States have implemented policy to remove or reduce punitive policies regarding prenatal substance use in order to facilitate access to treatment for pregnant women. Washington, for instance, promotes "information only" referrals of pregnant women who might be using substances to local prenatal support programs; these types of referrals are not recorded as formal child protective services (CPS) cases. Hawaii passed legislation in 2004 that provides immunity from criminal prosecution for drug offenses for pregnant women seeking prenatal treatment.

To some extent the perceived lack of treatment resources is accurate. National data clearly indicate a significant treatment gap for pregnant women: in 2005, only 6% of the pregnant women aged 15–44 who were classified as needing treatment for alcohol or illicit drug use actually received treatment.¹² Further, although 86% of substance abuse treatment facilities *accept* women, the number with a *specific program* for pregnant and postpartum women is only 17% (Office of Applied Studies [OAS], 2006. Online Analysis of National Survey of Substance Abuse Treatment Services [N-SSATS] Profile: United States 2005).

The Federal Treatment Episode Data Set (TEDS) is a key tool that States can use to obtain a picture of SEI issues at both the national and State levels. In addition to tracking trends on the percentage of women who are pregnant at treatment admission, TEDS data on pregnant women can also be analyzed for drug of choice, number of substances used, prior treatment admissions,¹³ primary source of referral, and other useful information.¹⁴ As Table 5 shows, 6 of the 10 States interviewed for this report had admission rates for pregnant women above the national average—as a percentage of all female admissions (OAS, SAMHSA, 2005).

Table 5: Percentage of female and pregnant female treatment admissions among the 10 study States, 2005			
(Source: Online Analysis of TEDS, OAS, SAMHSA, 2006)			
State	Percentage of Female Admissions	Pregnant Admissions—As Percentage of All Admissions (male and female)	Pregnant Admissions—As Percentage of All Female Admissions
National Average	32.0	1.3	3.9
California	35.5	2.0	5.7
Hawaii	35.5	1.1	3.0
Illinois	32.6	1.3	4.1
Maryland	33.2	1.8	5.4
Massachusetts*	28.5	Not Available	Not Available
Minnesota	32.1	1.2	4.0
Rhode Island	32.0	1.1	3.5
South Carolina	30.2	1.5	5.2
Virginia	32.4	1.5	4.3
Washington	37.5	1.3	3.4

*Massachusetts reports these data differently from all other States and is thus not comparable.

Part of making an effective link to treatment is ensuring that the treatment provided is appropriate for pregnant women and comprehensive enough to meet a pregnant woman’s unique needs. Colorado’s Prenatal Plus program augments routine medical prenatal care with additional needed services (see sidebar on the following page).

At the Federal and State levels, policies and practices are in place to help increase treatment access for pregnant women. The Federal Substance Abuse Prevention and Treatment Block Grant (SAPTBG) requires that States set aside a certain percentage of their block grant funds (equal to or greater than a State’s fiscal year 1994 expenditures) for services designed for pregnant women and women with dependent children. It also mandates that such women receive priority access to treatment and be provided with treatment services within 48 hours of request.¹⁵

Colorado’s Prenatal Plus Program

In 1996, Colorado implemented Prenatal Plus to improve the health of high-risk Medicaid-eligible women to help assure healthy birth outcomes. The program seeks to decrease the prevalence of low birth weight infants, improve the nutritional and psychosocial health of the target population, and help women develop and maintain healthy lifestyles—in particular, stopping alcohol, drug, or tobacco use—both during and after pregnancy. Clients are referred by a health or human service practitioner or are self-referred.

Services provided by a multidisciplinary team are designed to complement regular medical prenatal care and include risk assessments, care coordination, mental health services, and nutrition counseling. Women receive services throughout their pregnancy and for up to 60 days after delivery. The “model care” package that results in the best outcomes is a minimum of eight office visits and two home visits.

Prenatal Plus is funded using a combination of Medicaid, Federal Maternal and Child Health (MCH) Block Grant dollars, and local funds. The Department of Health Care Policy and Financing and the Department of Public Health and Environment, Women’s Health Unit, manage the program collaboratively.

(Colorado Department of Public Health and Environment, Women’s Health Unit, Prenatal Plus, n.d.; Colorado Department of Public Health and Environment, 2006)

The Federal government monitors these requirements via States’ SAPTBG applications, which must certify this policy is in effect. State substance abuse agencies are well aware of the SAPTBG requirements and monitor county and provider compliance primarily through contract compliance audits and provider program plans. Some States, such as Virginia, have procedures in place in which the mandated regional perinatal councils are advised to call State agency headquarters to seek priority treatment within the 48-hour limit for pregnant women.

State child welfare agencies may not be as familiar with SAPTBG requirements and typically do not monitor referrals of pregnant women for treatment, since they do not routinely screen for substance abuse. In fact, none of the child welfare representatives in the 10 States interviewed could provide a count of women enrolled in treatment under the 48-hour provision.

Approximately 21 States have specific substance abuse treatment standards or protocols for women and/or pregnant women. Most of these standards include a common set of regulations that reflect SAPTBG requirements. Pregnant women must receive priority admission and must be admitted within 48 hours, or must be provided with interim services if admission is not possible. Emphasis is placed on ensuring that pregnant women receive prenatal care and education on the effects of substance use during pregnancy. California provides a more comprehensive list of interim services. Colorado’s standards specify that pregnant women may not be discharged from treatment solely for failure to maintain abstinence and that every effort shall be made to retain pregnant women for the duration of their pregnancies (Dennis, 2005).

Sample State Initiatives

All 10 States interviewed for this study indicated that they had policies requiring or encouraging prenatal screening to identify a woman’s substance use and prevent a substance-exposed birth (SEB). However, formal policies on universal screening for the general population are rarely implemented universally, as intended. Table 6 summarizes the policy initiatives that States have launched related to pregnancy and prenatal intervention. See the narrative in the Appendix for further detail.

Table 6: Summary of State policy initiatives on pregnancy and prenatal prevention				
	Prenatal Screening Encouraged	Universal Screening Policy	Brief Intervention	Referral for Treatment and/or Supportive Services
<i>California</i> <i>(select counties)</i>	X		X	X
Colorado				X
Kentucky	X			X
<i>Massachusetts</i>	X		X	
<i>Minnesota</i>				X
<i>Virginia</i>		X		X
<i>Washington</i>		X	X	X

(States in italics were part of the in-depth review sample.)

Washington State's Model: Prenatal Screening and Linkages to Services

In 1998, Washington passed legislation directing the Department of Health to develop screening criteria for identifying pregnant and nursing women at risk of having a substance-exposed baby. With input from an Advisory Workgroup and key informant surveys, guidelines for screening pregnant women were developed and widely disseminated to health care providers. The guidelines are organized using a framework of Ask, Advise, Assess, Assist, and Arrange, emphasizing the importance of linking this critical prenatal stage to other early intervention opportunities and treatment services for pregnant women. The guidelines highlight the benefits of universal screening and strongly urge health care providers to conduct screening on all pregnant women. Providers are advised to use interview-based or self-administered screening tools (examples are provided); the limitations and weaknesses of urine toxicology screens are outlined. The guidelines also stress the need for open, ongoing relationships between patients and providers; provider training on how and when to screen; and a team approach involving the primary provider, clinic nurse, social worker, public health nurse, substance abuse treatment providers, and the patient (Washington State Department of Health, 2002).

Washington also has established the following two noteworthy programs that provide early intervention and other services to pregnant women.

Safe Babies, Safe Moms (Cawthon, 2004; Cawthon & Westra, 2003). In 1999, in accordance with legislative mandate, Washington developed a comprehensive program for mothers with substance use disorders and their young children through age 3. The overall purpose of the project is to improve early identification of pregnant women who are using substances and to increase access to and coordination of health care, substance abuse treatment, and family-oriented intervention services for mothers and their children. Key service components include: targeted intensive case management, residential and outpatient substance abuse treatment, parenting education, housing support services, and child developmental assessments and referrals. Each woman receives an individualized care plan. The project is an interagency collaborative effort, and referrals come from multiple systems, including substance abuse treatment, hospitals, criminal justice (e.g., drug courts and law enforcement), child welfare, and welfare, as well as friends and family. Three pilot sites served 445 women and their children from January 2000 through June 2003. Program evaluation findings demonstrate positive outcomes that include: decreased low birth weight rates, decreased rates of child protective services referrals, decreased criminal justice involvement, and decreased parenting stress levels.

Parent-Child Assistance Program (PCAP).¹⁶ In 1991, with multiyear funding from the Center for Substance Abuse Prevention (CSAP), Washington developed and implemented the Parent-Child Assistance Program (originally known as the Seattle Birth to 3 Program) to measure the effectiveness of intensive, long-term paraprofessional advocacy with high-risk pregnant women who abuse alcohol or drugs and are disconnected from community service providers. PCAP's goals are to help mothers establish healthy lifestyles, assure children are in safe and stable environments, and prevent future substance-exposed births. Rather than provide direct treatment services, PCAP paraprofessional advocate case managers link families with community services, coordinate services between multiple providers and systems, and help mothers follow through with recommendations of substance abuse treatment providers.

When Federal funding ended in 1996, the State legislature appropriated funding to maintain and expand the initiative to include sites in Tacoma, Spokane, and Yakima. PCAP has the capacity to serve 360 families statewide. Participating mothers are identified through community referrals and a postnatal screening process conducted at two hospitals in Seattle and Tacoma. Women are enrolled during pregnancy and receive services for 3 years. Since its inception, PCAP has served more than 650 women and their families. This program also has demonstrated positive short- and long-term outcomes in areas such as substance abuse treatment completion, sustained recovery, and prevention of substance use during subsequent pregnancies.

TIME OF BIRTH

This intervention point, time of birth, presents perhaps the most complex set of issues on the ramifications of State policy for both parents and children. One complex issue is that the need to identify infants prenatally exposed is perceived by some to conflict directly with privacy rights. Another is that methods of detection at birth are limited to very recent use. This section will summarize those complexities in an effort to provide some guidance for jurisdictions that are grappling with the need to establish well-informed policy.

To date, none of the States have mandated universal testing of newborns for illegal drugs, and testing of newborns is a controversial issue in all States.ⁱ This is partially illustrated in an Illinois report covering 1991–1999, in which officials expressed concern that a decline in reported SEIs may indicate reduced testing rather than reduced incidence.¹⁷ To understand the context for this intervention point, it is necessary to consider that an estimated *90–95% of babies born prenatally exposed to alcohol or illegal drugs do not have that exposure detected at birth and simply go home with their birth parents.*ⁱⁱ

Most States lack clear, standardized procedures for newborn testing. Nearly all States test infants for other health conditions like human immunodeficiency virus (HIV)¹⁸ and phenylketonuria (PKU),¹⁹ which, in reality, impact far fewer children than prenatal exposure to alcohol and illicit drugs. Yet States do not consider SEI screening to be in the same category as these procedures.²⁰

A number of factors influence the approach that States have taken to address the issue of testing for substance exposure at birth. And policy has often been formed within a debate between advocates for expanded testing and those who argue that mandated testing may deter women from seeking prenatal treatment. As noted, no State has a universal testing policy in place (Ondersma, Simpson, Malcoe, & O'Steen, 1999). On the one hand, there is the argument that universal testing of all neonates would ensure fairness and maximize the chances that an exposed infant will receive any needed services at the earliest possible time. But there are those who cite the numbers of false positives that may result, the costs of universal or widened testing, and the possibility of violating civil liberties and privacy.

ⁱ Although screening (i.e., an interview or protocol for review of a case) is not the same as drug testing, the terms are used interchangeably by most States. We distinguish them only when drug testing is specifically intended to be the focus.

ⁱⁱ Many hospitals may not test or may have inconsistent policies on testing, as noted in the Abandoned Infants Assistance report, and in fact, most births are not tested in most hospitals. Furthermore, tests detect only very recent use, within the last 24–72 hours, so use during the critical first trimester and beyond would not be detected by a test at birth. The total number of documented SEI reports on the prevalence of substance exposure estimates ranges from 2–10% of the estimates. CPS reports on 0–1 year olds and on removals of children in the first year of life, for all reasons, state that these children are a very small percentage of the more than 4 million births each year. This estimated percentage is based on an analysis of the several States and localities that have reported a specific number of detected drug-exposed births, compared with total births in those sites. More detailed analysis of this percentage will be available once reports of drug-affected births mandated by the Child Abuse Prevention and Treatment Act (CAPTA) are aggregated at State and Federal levels in future years.

They also cite the lack of certainty that testing will in fact lead to treatment and supportive services for infants or their mothers, as opposed to consequences that may include child removal from the home and prosecution of the mother.

As the treatment improvement protocol (TIP) issued by the Center for Substance Abuse Treatment (CSAT) explains:

State and local laws that require maternal alcohol and other drug use and fetal drug exposure to be reported to authorities have a significant impact on women and their children. . . . Knowing that such a report is in the offing, some women may forgo their prenatal care or the follow-up services they need. The closer communities move toward measures that *detain* pregnant, substance-using women, the more punitive, detrimental, and potentially dangerous it becomes for these women and their children. (Center for Substance Abuse Treatment, 2003; TIP 2. Emphasis added.)

Further complicating the issue is the fact that State policies vary widely in:

- How child abuse and neglect are defined in prenatal substance exposure;
- What the parameters of testing at birth for substance exposure are;
- What the appropriate follow-up is in response to a positive test (e.g., filing an abuse/neglect report or making a referral to CPS); and
- Which types of substances are covered by policy.

Defining Prenatal Substance Exposure as Child Abuse or Neglect

The Alan Guttmacher Institute indicates that as of 2005, 16 States consider substance abuse²¹ during pregnancy to be a form of child abuse, up from 12 States in 2000 (Dailard & Nash, 2000). (The actual definitions used by States rarely distinguish between substance abuse and substance use, equating the two in most cases.) Seven of the 10 States interviewed in this study have formulated policy that defines prenatal substance exposure, however it is detected, as evidence of or the legal equivalent to child abuse or neglect (Illinois, Maryland, Massachusetts, Minnesota, Rhode Island, South Carolina, and Virginia) (Dailard & Nash, 2000). Minnesota, South Dakota, and Wisconsin consider the use of illicit substances during pregnancy as grounds for civil commitment that may include forced admission to treatment. Only three of the States interviewed do not consider prenatal exposure alone to be evidence of child abuse or neglect (California, Hawaii, and Washington State).

In the 5-year period from 2000–2005, the Guttmacher Institute’s analysis indicates that the number of States that require health care professionals to report suspected prenatal drug abuse to CPS (in contrast with those that define exposure and abuse or neglect) has increased from 7 to 10 (Alan Guttmacher Institute, 2005). Additionally, four States (Iowa, Minnesota, North Dakota, and Virginia) require that health care agencies test women and/or infants for prenatal drug exposure if they suspect substance use.

Beyond policies and statutes, States and localities demonstrate varying practices in documenting prenatal substance exposure as substantiating child abuse or neglect, and in filing subsequent petitionsⁱⁱⁱ for court intervention and child removal. A national study of 200 counties responding to a 1999 survey found that:

- 21% of counties reported that they never file dependency petitions on behalf of substance-exposed newborns;
- 47% of the responding counties note that they file petitions in at least 41% of such cases; and
- 25% of the counties file in 75% of the cases. (Ondersma et al., 1999)

A landmark decision by the South Carolina State Supreme Court in 1997 (*Whitner v. State of South Carolina*) held that if the health or welfare of a viable fetus has been or may be adversely affected by the abuse of an illegal drug, then this action is defined as “child abuse” for which the mother could be imprisoned for up to 10 years. Only illegal drugs (cocaine, heroin, LSD, amphetamines, marijuana, and their derivatives) are included under the South Carolina law. The U.S. Supreme Court refused to review this case, and South Carolina remains the only State that has successfully prosecuted a woman for the transmission of controlled substances to her child in utero. (It is believed that no more than 10 women have been sentenced under this law for infant exposure to illegal substances, and none in recent years. The prosecution referred to occurred in 2001.)

In Texas, a controversy continues over the interpretation of Senate Bill 319, a bill addressing the definition of child abuse, passed by the legislature and signed by the Governor in 2003. Despite a ruling by the Attorney General that under Texas law a “physician is not obligated to report a pregnant patient’s use of a controlled substance as child abuse,” a local district attorney prosecuted eighteen women after their doctors shared their confidential information. In response, more than 70 child welfare and public health organizations sent a letter protesting this interpretation of the new law (Drug Policy Alliance, 2005). The controversy is unresolved, but the rapid mobilization of a wide array of organizations in response to policy changes underscores the volatility of these issues.

ⁱⁱⁱ Filing a petition does not necessarily result in a substantiated report of abuse or neglect, nor does it mean that a child is subsequently removed from his or her parents. The petition simply triggers a hearing at which the judge must decide on the further status of the child and whether additional action is needed.

Defining the Parameters for Testing at Birth

It should be emphasized that CAPTA does not require testing at birth; it requires that “health care providers involved in the delivery or care of such infants (i.e., those “born and identified as affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure”) notify the child protective services system of the occurrence of such condition in such infants . . .” and ensure “the development of a plan of safe care for the infant born and identified as being affected by illegal substance abuse or withdrawal symptoms . . .” as well as “procedures for the immediate screening, risk and safety assessment, and prompt investigation of such reports.”

The interviews conducted for this paper did not reveal any reports that either CAPTA changes or other State policies in this area deterred women from seeking prenatal care. However, it is a concern frequently vocalized by women’s advocates and others concerned with family preservation. Barth has written in favor of a policy that moves toward wider testing, but also points out that testing, and subsequent reporting, provides no guarantee for connecting a woman to adequate treatment services (Barth, 2001).

He notes that “. . . most women who received child welfare services received little more than a referral to possible services or no more than six months of in-home services in concert with their children in their own home” (Barth, 2001). Barth recommends a differential referral system, in which reports of positive tests to CPS would trigger services, rather than punitive action. He emphasizes that it is critical for services to be in place for this system to be effective.

In addition to the concern that testing at birth may negatively impact the likelihood of whether a woman with a potential substance use disorder will obtain prenatal care, there is a commonly held perception that neonatal testing is more likely to be focused on poor minority women than on their higher-paid, white counterparts. Indeed, past studies have documented this bias (Chasnoff, Landress, & Barrett, 1990; Ondersma, Malcoe, & Simpson, 2001). However, several interviewees for this report also expressed this concern, but the only evidence suggested by several of the State interviewees was that data on SEIs were more readily available from hospitals with higher percentages of Medicaid births.

Legal interpretations of consent requirements, and the requirements of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), are perceived by some States to further complicate decisions about testing at birth. Washington State addressed this issue in its State HIPAA guidelines (2002):

No uniform policy or State law exists regarding consent for newborn drug testing. This is a complex issue and care providers may wish to seek legal consultation regarding regional practice standards. . . , the intent of the testing may determine the type of consent. Women with admitted histories of drug use, or women and infants exhibiting signs of drug exposure, can be tested under the general consent because results of the test influence medical care and follow up. However, if the total or partial intent of the testing is to bring legal action against the woman, a consent containing specific language defining possible consequences is advisable. . . . If a patient refuses testing, this should be documented and testing not performed . . . Many hospitals do not seek parental consent for newborn testing, citing its use as a medical diagnostic tool. (Washington State Department of Health, 2002)

In 2002, Zellman and her colleagues obtained responses from 506 hospitals across the Nation and found that only one-third of the 166 responding hospitals had prenatal substance exposure protocols. Of those with protocols, only 56% included any instructions for reporting SEBs to external agencies such as CPS, and only 41% included any discussion of consent issues, all of which varied widely. The study also noted a lack of communication between physicians and staff regarding these issues, and a further lack of communication between obstetricians and pediatricians. The Zellman study concluded that the hospitals' protocols were "insufficiently precise, and most fail to address one or more key components of appropriate detection and medical management of prenatal substance exposure . . . the authors of the protocols did little to encourage their use, increase their credibility or facilitate modifications and improvements to them" (Jacobson, Zellman, & Fair, 2003).

Further evidence of the variance in hospital policy is apparent in the study of eight large urban areas, performed by the National Abandoned Infants Assistance (AIA) Resource Center, which is summarized as follows:

. . . this study revealed that, regardless of state policy, hospital staffs report virtually all newborns that test positive for an illicit drug and, with varying degrees of expedience, child welfare agencies investigate almost all such reports. Whereas most hospitals have a protocol to determine who to test for substances, these protocols are used inconsistently with resulting bias in who gets tested. Moreover, some hospitals do not even test delivering women or newborns for alcohol, and child welfare agencies are inconsistent in their response to reports of prenatal alcohol exposure. Thus, it is likely that not all substance exposed newborns are being identified or offered services.

Additionally, according to the nursing and social work staff in participating hospitals, very little data is collected on the numbers of mothers and newborns that are tested for substances or the outcomes of the tests. Further, hospital staff generally do not track or follow up on referrals that they make to drug treatment services, and many limit their involvement in this area to providing women with a list of treatment providers. (Drescher-Burke & Price, 2005)

This evidence supports the report of interviewees. They repeatedly suggested that policy does not always translate into practice and that there can be tremendous disparity between what is written down and what actually occurs.

What Happens Next? Reports Versus Referrals

Some State officials make a distinction between reports and referrals, pointing out that a report may be defined as a formal case being opened by the CPS agency, whereas a referral may mean only that a call was placed to the CPS agency. In other States, the definitions are reversed, with reports being calls from another agency and referrals being calls formally logged in by the CPS agency.

Whatever the language used, the issue of reporting requirements overlaps with the issue of whether prenatal exposure is legally viewed as abuse and/or neglect, since exposure must be reported if it is defined as abuse or neglect. In either case, the distinction between a mandate to test and a mandate to report test results remains critical, and States have considerable discretion in reporting. For example, one State agency official interviewed indicated that in some cases, the parent would not be reported to CPS, even after obtaining a positive toxicology result, when the parent accepted a voluntary referral to services. This particular interpretation of policy is premised on the value that enrolling the parent in treatment is more beneficial than filing a CPS report. The result of a report filing might be to deter future treatment admission.

Even in States with specific screening and referral policies, it is not clear how widely these procedures are actually used. In most States, there are no available counts of such referrals from hospitals. In those States in which hospitals report SEBs to child welfare agencies, whether or not the reports are mandated, no State indicated that the State child welfare agency had received hospital data. Also, no State indicated that its child welfare agency had compiled summaries from such data on the total number of screenings at birth, results of the screenings, or the number of referrals to the CPS agency as a percentage of screenings. Furthermore, no child welfare agency cited the use of Medicaid oversight as a resource, despite the high percentage of births covered by Medicaid.

In some cases, State legislation exists that answers the question posed by CAPTA: what happens *after* the telephone call to CPS? In one State, for instance, a detailed protocol specifies that after a positive toxicology report, a response team consisting of the attending physician, a worker from the CPS agency, a hospital social worker, law enforcement, and drug treatment personnel must meet to track the family's progress. However, a respondent from the State said that it was unclear about whether the prescribed teams actually convene on any regular basis. The perception was that this decision is typically at the discretion of the CPS agency.

For this particular State, neither the information on the State’s annual totals of positive toxicology reports to CPS nor the meeting of teams in response to reports was available through the CPS agency. Therefore, it was understandably difficult for that agency to discern when and whether the protocol should be put into action.

Defining “Substances”

The attempt to define what is meant by “substance,” or to distinguish between licit and illicit substances, can create further confusion for those trying to carry out the letter of the law in an effort to establish practice that will achieve the law’s actual intent. This quandary is alluded to in Virginia’s 2002 summary of SEI reports from its regional agencies, which notes that:

Drug exposed infants are more likely to be identified at birth than alcohol exposed infants. Unless a woman is intoxicated at delivery, it is extremely unlikely her alcohol use will be identified. Although Virginia’s legislation requires physicians to report Fetal Alcohol Syndrome (FAS) when identified at delivery, both FAS and alcohol related birth effects are extremely difficult to detect in a newborn and typically aren’t identified until the child is significantly older.²²

As with the other complexities surrounding this third intervention point, States vary significantly in specifying what kind of substance use is considered child abuse or neglect when detected at birth. For example:

- Minnesota’s definition refers to “*a controlled substance*”;
- Massachusetts refers to “*an addictive drug*” (which interviewees from Massachusetts said, in practice, includes alcohol, and the State’s screening criteria explicitly refer to FAS). Massachusetts policy also explicitly mentions methadone and screens out reports of methadone use if the mother is in an approved program (interview on September 14, 2005);
- State policy in both South Carolina and Illinois refers to “*a controlled substance*,” but also includes “*a medical diagnosis of fetal alcohol syndrome*”;
- Virginia refers to “*non-prescription, controlled substances or signs of fetal alcohol syndrome*”;
- Maryland’s definition is the most restrictive of the States interviewed in this study, referring only to “*cocaine, heroin or a derivative thereof*.” Methamphetamine was added in 2007. In Maryland, a proposal to include alcohol as one of the substances to be screened for in the 1997 legislation Children in Need of Assistance—Drug Addicted Babies, was rejected in a legislative committee (Reese & Burry, 2004);
- Washington refers to “*controlled substances*,” but also calls for identifying “*pregnant or lactating women addicted to drugs or alcohol*”; and

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- California, which does not define fetal exposure as child abuse or neglect, refers in its latest legislation on this subject (1991) to “a positive toxicology screen,” “maternal substance abuse,” and “a substance-exposed infant,” without defining any of these terms (California Department of Alcohol and Drug Programs, 2006). (Note: The 1992 California prevalence study found that a higher percentage of women tested positive for alcohol than for illegal drugs, consistent with national findings from the National Survey on Drug Use and Health [Vega et al., 1993].) In some California counties, methadone use is treated as addiction and is reported as use of a drug; however, there is no statewide policy regarding this.

Sample of State Initiatives

Table 7 summarizes the policy initiatives that States have established related to intervention at the time of birth. See the narrative in the Appendix for further detail.

Table 7: Summary of State policy initiatives on intervention at the time of birth (2007)					
	Maternal and/or Newborn Drug Testing Policy	Hospital and/or State Protocols to Handle Newborn Exposure	Prenatal Exposure Defined as Abuse/Neglect	Reporting Requirements	Screening and Referral Policies
<i>California</i>		X			
Colorado			X		X
<i>Illinois</i>			X		X
Iowa				X	
Louisiana			X	X	
Maine		X			
<i>Maryland</i>					X
<i>Massachusetts</i>	X		X		
<i>Minnesota</i>			X	X	
Missouri		X		X	
Nevada				X	
North Dakota				X	
<i>Rhode Island</i>			X		
<i>South Carolina</i>			X		
<i>Virginia</i>		X	X	X	X
<i>Washington</i>			X		X

(States in italics were part of the in-depth review sample.)

POSTNATAL SERVICES FOR INFANTS, CHILDREN, AND PARENTS

The final two points in the intervention framework occur in the postnatal period immediately after birth, as well as throughout the SEI's childhood. These intervention points emphasize the delivery of services for the infant, parents, and other family members. Ideally, services for the infant or child and the parents are woven together in a comprehensive approach, although it is more commonly the case that the primary emphasis is on the child or the parents, rather than on both simultaneously.

Extensive literature exists on the need for developmental assessments to determine the degree to which prenatal drug exposure affects infants and toddlers, and on the importance of postnatal follow-up services (Lester, Boukydis, & Twomey, 2000; Mayes, Bornstein, Chawarska, & Granger, 1995; National AIA Resource Center, 2003). SEIs are at higher risk of coming into contact with the child welfare system at some point, and findings regarding children in foster care indicate that most children do not actually receive the assessments and services they need (Halfon, Mendonca, & Berkowitz, 1995). In fact, Lester's analysis of State policies beginning in 2003 notes that only two States (California and Wisconsin) require postnatal assessment of a newborn who is referred to CPS because of a positive toxicology result (Lester, 2000).

For resources, three distinct programs authorized by Federal legislation address postnatal interventions for developmental disabilities. These include:

- CAPTA provisions of the Keeping Children and Families Safe Act (Administration for Children and Families [ACF]);
- Part C of the Individuals with Disabilities Education Act (IDEA) (which is specific to Early Intervention Programs for Infants and Toddlers with Disabilities in the Department of Education); and
- Head Start provisions that provide services for young children, including children who may be substance-exposed (ACF).

It is important to understand the intended, potential, and actual linkages between these three programs, in order to take the next step related to developing effective policy and practice in postnatal intervention.

Services for Children: Linkages Between CAPTA, IDEA, and Head Start

CAPTA provisions (see text box on page 14) require notification of CPS when an infant is identified as affected by illegal substance abuse or withdrawal symptoms. CAPTA also refers to the intent to “identify infants at risk of child abuse and neglect so appropriate services can be delivered to the infant and mother to provide for the safety of the child.” This section of the legislation requires State child welfare agencies to have procedures in place for the referral of children 0–2 years (where abuse or neglect is already substantiated) to early intervention services under Part C of IDEA (Section 114, P.L. 108-36).

Similarly, IDEA 2004 mandates that States have policies and procedures in place that require the referral of a child younger than age 3 for early intervention services who:

- (a) is involved in a substantiated case of child abuse or neglect; or
- (b) is identified as affected by illegal substance abuse, or withdrawal symptoms resulting from prenatal drug exposure.

This IDEA requirement was written to be consistent with CAPTA, but in separate, linked legislation to apply specifically to the IDEA agencies that handle developmental disabilities. The American Bar Association summarized the importance of the IDEA section of the CAPTA amendments in the following statement:

Possibly no other new change to CAPTA can have a greater impact than this mandatory Part C referral provision, if it is effectively implemented for maltreated children with the help of attorneys, judges, and other advocates. For this to have the most meaningful effect on accessing the \$400 million-plus Federal program to help these children, CPS personnel, foster parents, family services providers, and legal/judicial system personnel will need to be trained on this new requirement, the Part C law and its regulations, and strategies for accessing applicable evaluation and treatment services. (Davidson, 2004)

The State policy on referrals is required to be included in CAPTA plans on the child welfare side and in States’ IDEA plans on the disabilities side. In an attempt to maximize access to intervention services, IDEA identifies FAS as a condition of risk that can create eligibility for 0–2 year olds through “presumptive eligibility.”²³ Five States add prenatal exposure through parental substance abuse as an environmental risk factor that should result in a referral for developmental screening.²⁴

There are important challenges to developing stronger linkages between CPS and developmental disabilities agencies. An assessment of one model project, the Massachusetts Early Childhood Linkage Initiative, highlighted the challenges in standardizing the referral of young children from child protection agencies to Part C systems:

In addition to the increased numbers of children that Part C will assess and serve if referrals from child protection are regularized, the types of Part C services required may change. Specifically, it seems likely that children involved with child protection will have social-emotional and behavioral issues more frequently than other children served by Part C . . . Part C may also need to enhance its ability to address parental issues that affect children's mental health, such as parental substance abuse, domestic violence, and parental mental health problems, especially maternal depression. (Robinson & Rosenberg, 2004)

Starting with this review, none of the States interviewed had compiled information on total referrals to IDEA agencies from hospitals detecting SEIs at birth. These States also had not compiled information on the number of substantiated allegations of abuse or neglect based on subsequent CPS identification of prenatal exposure (although Arizona officials estimated that a 20% increase in referrals to Part C agencies took place in the first 9 months of implementation of the new requirement²⁵). States involved in federally funded pilot projects that addressed the needs of children with developmental delays in child welfare cases have a growing body of information that provides further support and justification for the new requirement. For example, in the first year of the Massachusetts project that began in 2002 before the CAPTA/IDEA amendments, 67% of the referred child welfare cases that involved children younger than 3 years old were demonstrated to be eligible for early intervention services for children with developmental problems (Massachusetts Early Intervention Project, 2005).

Based on this review of State policies, linkage appears to be minimal at the State level between the SEI efforts and Part C programs, except in Rhode Island and Massachusetts. A few States reported that the CAPTA legislation has prompted them to assess how well their referrals to early intervention programs are working. Minnesota's Department of Education, for example, is preparing an interagency agreement regarding Part C referrals made by child protection workers. And Maryland staff indicated that they have recently reviewed referral linkages because of the new IDEA-CAPTA changes. However, in most States reviewed, no interagency effort had yet taken place between the Part C agency and the child welfare agency to estimate the number of increased referrals that might result, or to plan different procedures for handling those referrals that actually occur.

Finally, at the Federal level, language has been added over the past 5 years to Head Start legislation that gives greater emphasis to coordination with child welfare agencies, training in services related to child abuse and neglect, and eligibility that makes more children in the child welfare systems eligible for Head Start. The extent to which child welfare agencies use these provisions for preschool-aged children who were prenatally or postnatally exposed is unknown, but few program descriptions refer to such eligibility.

Hawaii's Healthy Start Program

In response to significant increases in substantiated child abuse and neglect cases in the mid-1970s to the mid-1980s, Hawaii's State legislature authorized the Healthy Start Program (HSP). The program screens all statewide births for an array of at-risk factors that are typically associated with child abuse and neglect. Examples of these factors include a history of substance abuse, poverty, marital status, employment, and housing. If a family meets eligibility criteria, HSP provides home visiting in which trained paraprofessionals enter the family's home to assist parents in adjusting to the daily stressors of childrearing. Initially, the home visitors' goal is to establish rapport and trust with the parents to facilitate their role in increasing positive family functioning and child development. As a result, home visitors assume multiple roles as mentors, advocates, educators, and role models.

Hawaii's HSP has added substance abuse counseling as a parent support service in recent years, and is able to follow up on about 80% of the most at-risk births. (One-fifth of all births are defined as high-risk, using a protocol of several items.) Hawaii is also under a mandate for special education funding that created a consent decree requiring students with disabilities to receive services, including early intervention services, as part of a system of care. And HSP now provides strengthened developmental assessment for newborns as part of the State's compliance with the consent decree requirement for a system of care.

(Duggan et al., 1999)

Services for Parents

The parents of an SEI often are unable to provide a safe and nurturing environment for their children. Parents' failure to address their problems could eventually lead to their children being taken into custody and placed out of home. In order to work toward family preservation and reunification, responding to the parents' needs is a critical segment of SEI policy and practice.

Although most substance-affected births are not detected at birth, the opportunities for intervention continue as parents come into contact with numerous other agencies and organizations: home visiting programs for high-risk families, developmental screening programs of the type just described, child welfare agencies investigating reports of alleged abuse and neglect, preschool providers, hospitals, and others. Referrals to treatment agencies result from some of these contacts, and some parents seek treatment voluntarily, recognizing that they would be better parents if they were in recovery.

For those parents who arrive at substance abuse treatment because of a referral under the CAPTA requirement to report drug-affected infants to CPS or another child welfare contact, there are policy issues. The issues surround the type and quantity of treatment that is available, the quality of that treatment, and the likely outcomes of treatment for the substance-exposed child.

Type and Quantity of Treatment Available

According to the 2005 National Survey of Substance Abuse Treatment Services (N-SSATS), most substance abuse treatment facilities *accept* women (86%), yet only 33% of treatment facilities reported they had a women-specific program, and 14% had a program for pregnant and/or postpartum women. (The Federal definition of “pregnant and parenting” means that these policies, in effect, cover some women for continuing treatment after the birth of a drug-exposed child.) Unfortunately, just 4% of programs provide residential beds for clients’ children (OAS, 2006).

In 2005, treatment admissions of pregnant women represented only 1.3% of total public treatment admissions and 3.9% of all female admissions, equaling 24,000 women. Yet an analysis of the 2005 NSDUH public use file indicated that more than 182,000 pregnant women aged 15–44 needed treatment for either alcohol or illicit drug abuse or dependence. Moreover, as described in Section 1, of the 4.1 million live births in 2005, an estimated 8–11% (328,000–451,000) involved prenatal exposure to alcohol and illegal drugs.

As previously discussed, the federally required TEDS information system captures information on the pregnancy status of most females admitted to publicly funded treatment. But the admission of *parenting* women to treatment is not documented, nor is their referral status from child welfare caseloads. In Federal data collected as part of the Treatment Outcomes and Performance Pilot Study, Enhancement II (TOPPS-II), approximately 60% of the admissions had minor children. Still, neither the child welfare system nor the treatment system knows the number of mothers referred to treatment, nor does either system know the number of mothers admitted to treatment programs with children who may have been prenatally exposed to a substance.

Some programs serving parents of drug-exposed infants originated under the federally funded demonstration programs awarded by SAMHSA/CSAT in the mid-1990s to residential programs that served pregnant and postpartum women and children. Several of these programs have since become some of the best-known models of comprehensive treatment available, and extensive literature is available on their lessons learned (Chen, Burgdorf, & Herrell, 2001; Treatment Improvement Exchange, n.d.).

Family Drug Treatment Courts

A further model of postnatal parent-targeted services is the network of family/dependency court-sponsored drug treatment courts. The main goals of Family Treatment Drug Courts are to protect infants and children whose safety and welfare may be negatively impacted by substance-abusing parents, to support and reinforce the family unit, to increase parental capacity to meet the physical and developmental needs of their infants, and to accelerate permanency for infants and children under the State's care.

In October 2001, the Specialized Treatment and Recovery Services (STARS) program was created in Sacramento County, California, to assist parents in the child welfare system with substance abuse disorders. An integral part of the Sacramento County Drug Dependency Court (DDC), STARS also focuses on engaging fathers in intensive treatment and case management. Through identifying the obstacles in seeking drug treatment and by offering many support services, STARS is committed to increasing reunification rates for parents and their children.

Initially, parents undergo a thorough intake process in which they are assessed for substance abuse during their Detention Hearing. Immediately thereafter, alcohol and drug treatment services are available, and parents are assigned to a Recovery Specialist. Three main strategies of the STARS program are motivational interviewing, role modeling, and accountability. Motivational interviewing techniques integrate four key components that include showing empathy, supporting self-efficacy, rolling with resistance, and developing discrepancy between thoughts, aspirations and personal behaviors that interfere with reaching their goals. Recovery Specialists play a critical role in helping parents to achieve program goals through their unyielding support, non-judgmental attitude, continuous belief, and ability to relate through their own experience in recovery. Since the program's inception through 2006, 1,738 parents have participated in the DDC.

At 12-month follow-up:

If the parent graduated, 58.9% of the children were reunified;

If the parent received a 90-day certificate, 42% of the children were reunified;

If the parent did not meet either landmark, only 15.6% of the children were reunified.

At 18-month follow-up:

If the parent graduated, 72.9% of the children were reunified;

If the parent received a 90-day certificate, 52.3% of the children were reunified;

If the parent did not meet either landmark, only 18.7% of the children were reunified.

At 24-month follow-up:

If the parent graduated, 70.9% of the children were reunified;

If the parent received a 90-day certificate, 49.9% of the children were reunified;

If the parent did not meet either landmark, only 17.9% of the children were reunified.

(The dip in reunification rates from 18–24 months is due to the re-entries seen with the DDC cohorts.)

(Sacramento County Department of Health and Human Services, 2006; Boles & Young, 2007)

The capacity of these programs, however, is small relative to the need for them, given estimates of SEI prevalence. In fact, where programs do exist, the small scale of some programs leads staff outside the treatment funding world to assume that few or no slots are available to parents of SEIs. However, for those States reporting information on treatment wait times to TEDS, the picture seems much more promising. In 2005, 60.8% of the treatment admissions involved no wait, and another 23% were admitted to treatment within one week. Even more surprisingly, there were no substantial differences in wait times among men, non-pregnant women, and pregnant women.²⁶

In order to maximize use of the available treatment services, it is vital for communities and referral sources to understand what services and resources are available. This point is underscored by a recent analysis of the treatment slots available in one large county, compared with the needs of the child welfare system. This analysis demonstrated that a shift of less than 1% of the total treatment system resources would enable the child welfare agency to meet its Federal reunification targets by serving approximately 100 more clients (California Department of Alcohol and Drug Programs, 2006).

A study in California in the mid-1990s revealed that half of hospital nurse-managers believed that substance abuse treatment resources were not available for women giving birth in their communities. This assumption is often held by health care practitioners and other community service providers, and is invariably based on a lack of awareness among child welfare, health, and other staff about the treatment system, its funding streams, the turnover in treatment slots, and how to access services. Not surprisingly, the picture improves in some settings where this information is available.

Sample of State Initiatives

Table 8 summarizes the policy initiatives that States have established related to postnatal services for infants, children, and parents. See the narrative in the Appendix for further detail.

Table 8: Summary of State policy initiatives on postnatal services				
	Postnatal Assessment	Referral Protocols	Care Coordination Policies	Initiatives to Improve Linkages to Services
<i>California</i>	X			
Colorado				X
<i>Illinois</i>				X
Iowa			X	
<i>Maryland</i>		X	X	X
<i>Massachusetts</i>				X
<i>Minnesota</i>				X
Missouri		X		
Ohio		X	X	X
<i>Rhode Island</i>				X
Wisconsin	X	X	X	

(States in italics were part of the in-depth review sample.)

SECTION 4: BARRIERS TO ADDRESS: THE NEED FOR SYSTEM LINKAGES

When the needs of substance-exposed children are addressed, it is apparent that the connections across the five points discussed in this report are as important as the actual interventions. The handoffs from one point to the next and the linkages needed to coordinate services become a comprehensive services framework, rather than a series of fragmented initiatives.

The States interviewed for this report employed various coordination strategies, including the establishment of interagency entities, some of which focus on substance-exposed infant (SEI) issues directly and some of which address those issues within a broader context (e.g., perinatal services, maternal and child health, developmental disabilities, and child welfare reform). State staff readily acknowledge that there are unique collaborative challenges associated with addressing any issue that requires the involvement and support of multiple public agencies and private groups. The lack of critically needed data that could be shared across agencies was noted as a major barrier to collaboration.

Information gaps undeniably hamper the capacity of States to implement SEI policy in a coordinated fashion. Baseline data on any aspect of the issue are rare. For example, none of the States interviewed had current statewide prevalence estimates of substance-exposed births, other than the data provided to those States that participate in Federal Pregnancy Risk Assessment Monitoring System (PRAMS) data collection. (PRAMS focuses only on alcohol, with two exceptions.) Some States do have historic SEI baseline data, but these data are based on a point-in-time survey that has not been regularly renewed or updated. In general, States' experiences with these intermittent prevalence surveys have not been frequent enough to support the use of these data as a baseline to monitor progress or seek expanded support.

SEI initiatives seeking to work across agency boundaries have been bogged down by funding dilemmas, including a dearth of innovative funding strategies that might support putting good policy into practice. Even the potential leveraging of Medicaid resources has not been widely exercised, despite the logical connection to that resource based on the substantial number of birth-related costs paid for by Medicaid.

INTERAGENCY COORDINATING BODIES

Each State reviewed had one or more interagency entities that were charged with addressing one or more facets of the SEI issue. In some cases, such as Hawaii's interagency council, the entity is mandated by State legislation, whereas in other States, the coordinating body was created by administrative action. The four sets of generic interagency bodies that exist in most of these States included:

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1. An interagency body reviewing the State's Program Improvement Plan (PIP) under the Child and Family Services Review (CFSR) requirements, with a focus on child welfare outcomes;
 2. An interagency group of treatment providers who meet regularly on a statewide basis, or a policy and planning group who focuses on the State's treatment policies, primarily addressing access to treatment;
 3. An interagency coordinating group, such as the Early Start coalition, is focused on early intervention programs for developmentally disabled children and/or children affected by early mental health issues; and
 4. An interagency group defined by perinatal outcomes and primarily oriented to maternal and child health agencies.

Regardless of whether they originated legislatively or administratively, these entities tend to be housed in a single agency. They also tend to have SEI issues as a focal point under a broader mission, such as child welfare reform, or at the intersection of child welfare and substance abuse. Because SEI issues are related to, but not the primary focus of, the work of these coordinating bodies, the SEI issue typically goes unmentioned and unprioritized in the larger agency strategic plans. None of the 10 States included SEI issues as part of their CFSR PIPs. Furthermore, none of these groups that address SEI policy as part of their mandates had developed interagency outcomes for SEI programs that are monitored annually by an interagency group, based on a strategic plan for SEI issues, or guided by an inventory of all State programs that affect SEI outcomes.

THE ISSUE OF REPORTING GAPS AND DATA SYSTEMS

The extent of interagency organizational capacity in the States is entwined with the issues related to reporting requirements and implementation monitoring. Most States lack the systems to provide regular reports summarizing and analyzing their own data collection efforts. From initial hospital reporting of SEI births, to child protective services (CPS) recording referrals from hospitals, to the drug and alcohol treatment system capturing referral sources and the presence of prenatally exposed children, and on to the early childhood and developmental disabilities systems recording developmental assessments of SEIs—the information gaps at each of these hand-off points are substantial. Such gaps weaken the ability of the systems to work together to track children and families as they move from agency to agency.

Most States do not break out SEI referrals by CPS as part of the overall intake to publicly funded treatment. (Washington and Hawaii are exceptions.) None of the States sampled track total referrals of SEI parents into treatment or the outcomes achieved by those parents in treatment. States monitor their own pilot projects, especially the results of their prenatal programs, but only for the clients enrolled in these programs. No State has an information system that can track the full range of SEI-involved or prenatally targeted parents into and out of the entire treatment system.

Data on how many SEI parents are referred, how many enter treatment, how many complete treatment, and how many succeed in continuing their recovery are needed. These data are crucial to understanding the costs and cost-effectiveness of programs (Yates, 1999). Only the strongest programs can map these “drop-off points” where clients fail to enroll or drop out of treatment or recovery; no States require that such data be collected by their treatment grantees serving SEI parents. Thus, the data on treatment for pregnant and parenting mothers are restricted to those who make it into treatment, not the presumably larger group who need treatment or the group who enter but do not sustain their enrollment.

The client information data systems are limited because some data elements are required, whereas others are optional or ignored. In the Federal and most State child welfare information systems, recording use of alcohol or illegal substances by parents is not a required data element. Another data gap exists in the Medicaid information system, which does not require any data on substance exposure or prenatal screening results. In the current Federal information system for treatment (as well as in the proposed data elements for new treatment outcome monitoring reflected in the National Outcomes Measurement System—NOMS), information on child abuse or even the presence of children related to the parent in treatment is also not required. In both cases, some States and counties have believed this information is so critical that they have added new data fields that include these items.

Data issues in the States include the efforts they have made to monitor the prevalence of pregnant women and births impacted by alcohol and drug use. Although several States have carried out studies to determine prevalence estimates, none do so on a regular basis. Federal surveys, as discussed earlier, can provide some support for State-level estimates, but States that have done their own detailed surveys have produced more targeted information.

These data issues and information gaps make up a major part of the organizational challenge for States seeking to give SEI issues greater visibility and priority. Such issues and gaps are a challenge because what cannot be counted—or simply is not counted at present—cannot be assessed for its ultimate effectiveness and impact.

FUNDING

Funding is a constant constraint, but some States have begun to more creatively use multiple funding sources to support the implementation and expansion of SEI-related interventions. At the Federal level, several different funding streams exist that can be leveraged to provide services for both women and their children. These include, but are not limited to (Dennis, Young, & Gardner, in press):

- Substance Abuse Prevention and Treatment Block Grant (SAPTBG);
- Temporary Assistance to Needy Families;
- Medicaid and the Early and Periodic Screening, Diagnosis, and Treatment Program (Medicaid’s child health benefit package);
- Maternal and Child Health Services Block Grant (Title V);
- Child Abuse and Neglect State Grants;
- Community-Based Child Abuse Prevention Program;
- Title IV-B—Foster Care and Title IV-E—Adoption Assistance;
- Child Welfare Services—State Grants, Title IV-B, Subpart 1;
- Promoting Safe and Stable Families, Title IV-B, Subpart 2;
- Chafee Foster Care Independence Program;
- Child Care and Development Fund and the Child Care and Developmental Block Grant;
- Individuals with Disabilities Education Act Grant Programs (Part B, Section 619—Special Education Preschool Grants and Part C—Special Education Grants for Infants and Families with Disabilities);
- Developmental Disabilities Basic Support and Advocacy Grants;
- Community Mental Health Services Block Grant; and
- Social Services Block Grant.

The National Governors Association (NGA) has documented efforts by a number of States to expand Medicaid coverage for pregnant women, including substance abuse treatment (NGA Center for Best Practices, 2004). States also can take better advantage of Medicaid to finance mental and behavioral health assessments, therapies, wraparound services, and other interventions for children who are at high risk of emotional problems because of substance abuse by one or both parents (Johnson, Knitzer, & Kaufmann, 2002).

Several of the States interviewed described using Medicaid coverage in concert with Federal SAPTBG funding to cover residential and outpatient services for mothers who have delivered SEIs, as well as for women referred from prenatal clinics. However, because SAPTBG sources represent only about 40% of the documented funding available for publicly funded treatment (and an even smaller percentage of funding for child welfare clients, given use of child welfare funding for some of these slots), a wider approach is needed than reliance on the SAPTBG as the primary target.

In addition to Federal funding, there are also resources at State and local levels, primarily in the form of State General Revenue Funds and private funding. A substantial research base documents the effectiveness of treatment programs for pregnant and parenting women in enhancing the well-being of the mother (e.g., reduced substance use and improved functioning), as well as that of the infant or child (e.g., positive birth outcomes and increased parent-child attachment). Increasingly, States are beginning to comprehend the need to upgrade their treatment programs to incorporate the lessons and findings of these evaluations.

A Washington State-based study of its prenatal programs summarized the components of a comprehensive program:

. . . characteristics of a comprehensive program that would most likely yield positive outcomes include family-focused services, a continuum of services from pregnancy through early childhood, coordinated services, individually tailored chemical dependency treatment, and parenting skills training and family relationship enhancement (McGee, Rinaldi, & Peterman, 2002).

Innovation continues in weaving together multiple funding sources, but each State (and, in many cases, each program) tackles these tasks on its own, without the cross-cutting authority to move funding across different streams of categorical finance. Waiver authority in child welfare programs has enabled some innovation, but has not yet affected SEI policy beyond Illinois (DHHS, 2005b; *Synthesis of Findings*).

The various agencies whose support is needed for comprehensive SEI funding may be more likely to team up on this issue when they consider that in addition to the physical, social, and emotional impacts of drug-exposed births, there are also substantial financial costs. Estimates of total lifetime costs of caring for a medically complex SEI range from \$750,000–\$1.4 million (Kalotra, 2002). Investing funds in prevention and early intervention services to women provides significant cost-savings opportunities to the child welfare, health care, education, and criminal justice systems.

SAMPLE STATE INITIATIVES

Table 9 summarizes the policy initiatives that States have launched related to improving system linkages. See the narrative in the Appendix for further detail.

Table 9: Summary of State policy initiatives on improving system linkages			
	Multiagency Funding Streams	Interagency Efforts	Reporting Gaps and Data Systems
<i>California</i>	X	X	X
<i>Hawaii</i>		X	X
<i>Illinois</i>	X	X	X
Missouri		X	
Rhode Island	X		
<i>South Carolina</i>			X
<i>Virginia</i>		X	X
<i>Washington</i>		X	X

(States in italics were part of the in-depth review sample.)

SECTION 5: SUMMARY AND OPTIONS FOR POLICY CHANGES

As this review of State policy and practice has shown, State policy regarding substance-exposed infants (SEIs) is varied and evolving. The State and local models of SEI policy and practice that have been discussed are evidence of how far some States have progressed in developing responses to the SEI issue. At all five levels of intervention identified as the framework of SEI policy, States have innovated and broadened their responses to the SEI problem. They have:

- Worked in the pre-pregnancy arena of public awareness;
- Developed prenatal screening efforts;
- Addressed problems that can be identified at birth; and
- Developed specific services that address the needs of both infants and their parents in the postnatal environment.

States have also developed innovative financing approaches, and have worked in collaborative efforts with the wide array of public and private agencies whose cooperation and resources are essential to addressing the SEI problem.

At the same time, it is clear that States have not yet developed comprehensive policy that addresses the entire spectrum of the framework with strategies that have yielded positive results at each intervention point. To move toward comprehensive policy, State agencies and their respective interagency bodies are challenged with building on the achievements of specific programs, as they seek to widen the scale of efforts to solve the SEI problem. And it should be underscored again that the policy spotlight on that problem is brighter as a result of the passage of the Child Abuse Prevention and Treatment Act (CAPTA) amendments of 2003, as well as the continuing Substance Abuse and Mental Health Services Administration (SAMHSA) mandate for timely services for pregnant and parenting women.

With basic information lacking in so many areas of SEI policy, stronger information systems are fundamental to ensuring accountability for results. The foundations of current policy in each of these separate levels of policy can provide a base for expanded resources and improved results across all five levels.

INTERVENTION POINT 1: PRE-PREGNANCY

Although several States have developed public education campaigns focused on pre-pregnancy messages to women of child-bearing age, a critical minority of pregnant women, especially younger women, do not appear to be influenced by the messages, based on recent data on substance use. The messages may not be widespread enough or penetrating the audience well enough to effect changes in first trimester substance use by this group of women.

The expanded messages in recent years regarding the effects of fetal alcohol exposure have resulted in overall decreases in the use of alcohol in second and third trimesters, which is encouraging. But the reported use levels of alcohol, tobacco, and illicit drugs in the first trimester and by the youngest pregnant women are both cause for concern and an ideal area for intensified prevention efforts. Ongoing efforts at both State and Federal levels to improve the targeting and effectiveness of the pre-pregnancy messages are a continuing priority within the broad array of SEI policies. In particular, Federal and university assessment of message effectiveness may help to refine the targeting and content of pre-pregnancy information campaigns.

INTERVENTION POINT 2: PRENATAL SCREENING

Those States that have made the greatest investments over the longest periods, most notably Washington, have demonstrated that near-universal screening has been achieved and that universal prenatal screening is an achievable goal. Yet a wide range of physician behavior remains with regard to screening. No States require universal prenatal screening for substance use, and few States have screening policy that supports private physicians' efforts beyond pilot project scale. Priority status in entering treatment is given to pregnant women, in accord with Federal requirements, but referrals to treatment from prenatal screening and progress in treatment are not monitored on a statewide basis, and the total number of pregnant women entering treatment from referrals based on screening efforts is a very small percentage of total admissions. States could review their prenatal screening activities because of the very thorough efforts already under way in States such as Washington.

INTERVENTION POINT 3: TESTING AT BIRTH

States have varying policies concerning whether prenatal exposure to drugs is viewed as child abuse and neglect, which leads to wide variations in practices in hospitals and child protective services (CPS) agencies. Hospitals' policies and practices vary widely; some test and refer more extensively than others. But very few hospitals are able to annually track their total testing relative to total births, the results of their testing, or their referrals based on positive results. And no States had data systems able to capture treatment outcomes for women referred from prenatal screening, except for small groups of women in discrete projects.

Recent legislation in some States has expanded requirements for referrals when drug exposure is detected. At the time of the survey undertaken for this report in 2005–2006, this requirement appeared to be in response to concerns about increases in methamphetamine use in some States. Since that time, some increases in referrals may be due to Federal CAPTA requirements. Issues with Fetal Alcohol Spectrum Disorders have received increasing attention in some States, notably in Hawaii and Minnesota, in the form of recent State legislation and a national spotlight resulting from congressional interest. However, some State staff see the detection of Fetal Alcohol Syndrome as a problem, as noted previously in discussing Virginia's 2002 report on SEIs. It pointed out that drug exposure is easier to detect than alcohol exposure.

INTERVENTION POINTS 4 AND 5: POSTNATAL SERVICES FOR INFANTS, CHILDREN, AND PARENTS

Since most drug exposure is not detected prenatally or at birth, postnatal services for both parents and children are important, regardless of how clients come to the attention of the several systems in which these services may be provided.

OPPORTUNITIES FOR ADVANCING POLICY: STATE SELF-ASSESSMENTS

At all five intervention levels, the policy question that States must address is whether the current array of services available to children and families—screening, admissions to treatment, family support for parents, and screening and services for children—is an appropriate response to the potential effects of drug exposure. Each State needs to weigh the adequacy of its response to both parents and children, from the percentages of pregnant women entering treatment to the very low percentages of children entering the caseloads of agencies that respond to developmental disabilities.

There is no “right level” of services; each State needs to assess needs and responses to the problems of these parents and children, along with competing needs and resources. But the overall level of these services is low. This finding suggests that most States may not assess the very high potential for later financial and human costs in sufficient depth. Such an assessment might ensure an adequate response to the problems that led to the passage of the CAPTA amendments in the first place—as well as the Federal treatment priority for pregnant and parenting women.

It would not be appropriate to assess current policy against an ideal standard or a level of service that met all need. But it is fair, and necessary, to assess current programs against current policy. The two clearest expressions of that policy are contained in the CAPTA amendments and the SAMHSA priority for treatment for pregnant and parenting women. Neither of those policies specifies a required level of services or admissions, but both set a standard that encourages States to annually review how these overlapping groups of parents and children are faring in treatment agencies and child-serving systems. States could undertake such a review by using the five-level framework to inventory current efforts at all five levels, by comparing their efforts with similar States, and by determining appropriate outcomes that would enable measuring progress against the State’s own baselines. Although no States were found that are currently undertaking these tasks in a comprehensive manner, the progress made in several of these States provides a strong foundation for linking the initiatives under way at each level of the framework.

States have shown in each of the five levels that substantial progress can be made in responding to these policy and programmatic challenges. Getting started with a broad review of where the State is at all levels could involve at least four steps:

- Conducting an inventory of current statewide and community efforts that address each of the levels, with the inventory ideally including data on funding streams, level of funding, number of clients, and current results as measured by the agency or program;
- Comparing the State's outcomes and resources to those of similar States;
- Collecting data on current levels of need, demand, and treatment capacity relevant to the population affected by the CAPTA and SAMHSA mandates:
 - Need assessment should include a compilation of all available data on prevalence of SEIs;
 - Demand assessment should include a review of the effectiveness of special efforts to engage pregnant and parenting women in the treatment population;
 - Capacity assessment should include State versions of National Survey of Substance Abuse Treatment Services (N-SSATS) data on facilities' capacity to respond to the needs of children as well as to those of their parents. These data would compare admissions to treatment against the current capacity of the system to provide treatment services that build on the principles of family-centered treatment; and
- Considering supporting interagency councils with broad membership and the authorization to collect data across systems. These councils could develop strategic plans for SEI policy that include annual review of progress in meeting goals developed on an interagency basis. Interagency councils would help States and communities that are trying to link multiple funding sources for SEI programs to review and spotlight the models of those sites that have done the best job in achieving multifunded projects (Dennis, Young, & Gardner, in press).

CONCLUSION

Existing policies, strategies, and activities that compose the national response to the problem of prenatal substance exposure are considerably stronger than they were in the late 1980s and early 1990s when the cocaine epidemic was at its peak. But if these tools are still used in fragmented ways in small-scale programs, States and communities may be missing the opportunity to increase the impact of policy on the SEI problem. The nature of the SEI problem requires close ties across the boundaries of public and private systems serving children and their families. To measure the effectiveness of those ties, it is necessary to have robust information systems and a willingness to use those systems to support accountability in achieving interagency missions. The SEI problem also requires greater attention to the gaps between policy as it is stated and policy as it is actually carried out at State and local levels.

The States reviewed in this report have shown that SEI policy can be made effective, and that it can be taken to scale. Now it must also be shown that policy can be coherent, connecting previously separate activities in a continuum of better-linked programs serving children and parents affected by substance use disorders as they move through developmental milestones at the several possible points of intervention. From better-linked programs can come more effective policy and better outcomes for those children and families, and that is the task that lies ahead.

APPENDIX: SAMPLE STATE INITIATIVES

I. PRE-PREGNANCY

- As of January 1, 2005, 22 States had enacted policies requiring mandatory warning signs about alcohol use during pregnancy at the point of sale (e.g., bars, restaurants, and other licensed establishments that sell alcohol). Two of these States also require physicians and/or other health care providers to post such warnings, and three States require that warnings be posted in languages in addition to English.¹
- *Missouri* has enacted two laws. One requires that warning signs about the harmful effects of alcohol use during pregnancy be displayed at retail establishments selling alcohol. The other mandates physicians to advise their patients (verbally and by providing written materials) about the effects of prenatal use of tobacco, alcohol, and controlled substances (DHHS, SAMHSA, n.d.).
- In compliance with the Drug-Free Schools and Communities Act, the University of Massachusetts Alcohol and Drug Policy addresses the hazards of parental substance use by providing this warning message to all students: “Mothers who drink alcohol during pregnancy may give birth to infants with fetal alcohol syndrome. These infants have irreversible physical abnormalities and mental retardation. In addition, research indicates that children of alcoholic parents are at greater risk than others of becoming alcoholics (University of Massachusetts, 2002).
- Since 1995, the Minnesota Department of Health (MDH) has developed and disseminated several public awareness campaigns to reduce the risks associated with drinking during pregnancy (MDH, n.d.). The overall goal is to educate all Minnesotans that “There is no known safe level, time, or type of alcohol to use during pregnancy” (interview on March 21, 2005).
- Statewide campaigns in Minnesota in 1995 and 1998 distributed information to the general public through radio and television ads, print materials, and poster placement in restaurants and bars and on buses. Post-campaign survey findings found that Minnesotans’ understanding of the adverse effects from prenatal alcohol exposure improved (interview on March 21, 2005).
- In 2003, MDH launched a Fetal Alcohol Syndrome (FAS) prevention media campaign specifically designed for populations of color. The campaign focused on urban and rural African-American, Latino, and American Indian women of child-bearing age, as well as their partners, family, and friends, and health and social service providers. In addition to broadcast ads, print materials, and posters, the campaign included pocket cards with tips and resources, tip sheets to encourage providers to ask about alcohol use and refer women to assessment and treatment services, a mailing of campaign materials to 4,000 providers, a toll-free telephone line for the public and providers, and a Website portal page (interview on March 21, 2005).

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- California has both statewide and local/regional efforts under way to educate women and the general public about the risks of substance use during pregnancy. At the State level, California established a Mass Media Communications Account for public education on subjects that include the prevention of tobacco, alcohol, and drug use by pregnant women (California Health and Safety Code Section 130100-130155, 2007). This large-scale media effort is funded by 6% of the California Children and Families Trust Fund. The Trust Fund includes all revenue—an estimated \$700 million annually—generated by Proposition 10, a publicly supported cigarette and tobacco tax to provide early intervention services to children ages 0–5. See <http://www.cffc.ca.gov/press/prop.asp>
 - At the local/regional level, the University of California, Los Angeles (UCLA) is one of three sites receiving funding from the Federal Centers for Disease Control and Prevention (CDC) to refine and test pre-pregnancy substance abuse prevention messages. (The other two sites are St. Louis University and the University of Iowa.) UCLA is evaluating a social marketing campaign using a “narrowcasting approach”—i.e., directed to a highly specific segment of the public—that warns women about the dangers of drinking alcohol during pregnancy. The purpose of the project is to change norms and perceptions of women who are light or moderate drinkers both before and during pregnancy. Print materials have been developed and disseminated, saturating specific neighborhoods in two Southern California communities over a 12-month period; a third community serves as a comparison group (CDC, n.d.)
 - Four of the 10 States were surveyed through interviews (California, 2004 and 2005; Hawaii, September 19, 2005; Maryland, February 10, 2005; and Minnesota, March 21, 2005). These States said that they currently had pre-pregnancy public education efforts under way. These various public education efforts are occurring at both statewide and local/regional levels; and States may include public awareness as one component of a broader maternal and child health strategy, such as Kentucky’s Early Childhood Initiative. Others focus on a single facet of substance abuse, such as Maryland’s FAS efforts.

II. PREGNANCY AND THE PRENATAL PERIOD

- *Virginia* passed legislation more than 10 years ago that requires all licensed prenatal care providers to screen all pregnant women for substance use. The State subsequently developed a perinatal substance use guide for health care providers (Virginia Department of Health, 2003). However, a 2004 survey of perinatal providers in Virginia indicated that only 35% screen for substance use (Virginia Department of Health & Department of Mental Health, Mental Retardation and Substance Abuse Services, 2004; *Perinatal Practice Survey Regarding HIV and Substance Use in Childbearing Age Women*).
- Other States, including *Washington*, encourage and explicitly highlight the benefits of universal screening in their guidelines for health care providers (Washington State Department of Health, 2002), but are still seeking to expand the impact of these policies.

- *Kentucky* uses a hybrid *4P's Plus*[®] that includes questions about intimate partner violence, and their obstetrical/gynecological staff are extensively trained to ensure that they are qualified to make referrals and develop a safety plan when needed (Kentucky Medical Association, n.d.).
- *Massachusetts's* Alcohol Screening Assessment in Pregnancy program (Kennedy, Finkelstein, Hutchins, & Mahoney, 2004) also uses a modified *4P's Plus*[®]. A positive response to any of the interview questions triggers a brief intervention developed as the modification of a model created by the National Institute on Alcohol Abuse and Alcoholism. Currently, however, overall data on the total number of pregnant women screened and on the number of positive results are not compiled (interview on September 14, 2005).
- Of the 10 States surveyed, *Washington* provides the fullest implementation of statewide prenatal screening. In addition to developing and issuing prenatal screening guidelines (as required by State legislation), Washington also operates two broadly based intervention programs for women and children affected by substance use disorders (interview on January 18, 2005).
- At the local level, some cities and counties have invested resources in prenatal screening programs. A number of California counties have adopted the Screening, Assessment, Referral, and Treatment (SART) mode, using Proposition 10 tobacco tax funding dedicated to early childhood programs. SART, developed by Children's Research Triangle in Chicago, is a comprehensive prenatal screening approach that involves:
 1. Raising public awareness about the consequences of substance use during pregnancy;
 2. Creating a multidisciplinary team;
 3. Developing an action plan;
 4. Building public support; and
 5. Motivating and assisting health care providers in screening pregnant women for substance use.

Follow-up takes place at two levels: (1) when mothers are initially referred to treatment services; and (2) in the "Pediatric SART" program, which is a second set of linked interventions that focus on continuing screening and developmental services to children affected by parental substance abuse (McGourty & Chasnoff, 2003).

- To further expand treatment capacity for pregnant and parenting women, *California* has allocated State General Funds in amounts well above the required Federal Substance Abuse Prevention and Treatment Block Grant (SAPTBG) women's set-aside for pregnant and parenting women. Further, California has allocated additional amounts of Temporary Assistance for Needy Families (TANF) funding for women with substance use disorders involved in the TANF system. In accord with the Federal SAPTBG requirements, pregnant women who are not able to enter treatment within 48 hours must be provided interim services (Center for Substance Abuse Treatment, 2007).

In California's Perinatal Services Network Guidelines (California Department of Alcohol and Drug Programs, 2004), interim services are defined as:

1. Human immunodeficiency virus and tuberculosis education and counseling and referrals for testing;
 2. Referrals for prenatal care;
 3. Education on the effects of alcohol and drug use on the fetus; and
 4. Referrals based on individual assessments that may include, but are not limited to, self-help recovery groups; pre-recovery and treatment support groups; housing, food, and legal aid support; case management; children's services; medical services; and TANF/Medi-Cal services.
- In *Minnesota*, the Circle of Women Project, modeled after Seattle's Fetal Alcohol Syndrome-Birth to 3 Project, provides intensive in-home visitation and advocacy services for women who are engaging in heavy alcohol and/or drug use during pregnancy and have no involvement with other community services. The Circle of Women Project provides services for the pregnant women and their children for 3 years. The Minnesota Department of Human Services funds two sites for the Circle of Women Project, one serving women in Minneapolis and one serving women of the Leech Lake Reservation in Cass County (interview on March 21, 2005).

III. TIME OF BIRTH

- In *Massachusetts*, testing policy is stated as follows: "Neonates will be administered toxicology screens upon delivery, with the permission of the mother, if: 1) maternal alcohol or other drug use has been revealed to obstetrical staff during prenatal visits and noted on the obstetric 'problem list'; or, 2) maternal behavior raises concern amongst prenatal staff (many missed appointments, late prenatal care, etc.); or, 3) pre-term delivery or early abruption" (interview on September 14, 2005).
- In *Washington*, new legislation resulted from a child death related to substance abuse. Under this legislation, women testing positive for drugs would be assessed for other risk factors, such as single parent status, no prenatal visits in first trimester, and so on, and referred to early intervention programs, with higher-risk cases opened for child protective services (CPS) investigation (interview on January 18, 2005). Legislation has passed in Colorado that addresses similar issues (Washington State Fetal Alcohol Syndrome Interagency Work Group [FASIAWG], 2007).

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- In *Colorado*, new legislation allows a newborn's testing positive for controlled substances to be considered evidence of child neglect (Child Welfare Information Gateway, 2007). The original draft of the bill would have allowed for termination of parental rights if an infant tested positive for controlled substances. Prior practice would have required the case to enter and proceed through the child welfare system's regular investigation and assessment processes (Colorado Department of Public Health and Environment, 2006).
 - In *Arkansas*, statewide associations of physicians supported a bill redefining neglect. The bill requires babies born exposed to illegal drugs or with health problems resulting from the mother's use of an illegal drug during pregnancy to be reported to the State for child neglect (Thompson, 2005). A test of the mother's or child's bodily fluids or bodily substances may be used as evidence to establish neglect. The bill was intended to protect doctors who report babies affected by prenatal exposure from liability for violating patient confidentiality. New Arkansas legislation also requires the child welfare agency to develop and maintain statewide statistics of the incidents of neglect reported or investigated and to make annual reports of those incidents.
 - *Louisiana's* legislature in 2005 expanded the definition of child neglect to include prenatal substance abuse. Health care providers are required to report to the State when a newborn is affected by prenatal drug use (Child Welfare Information Gateway, 2007a).
 - *Nevada* enacted a measure in 2005 that will amend the State's child abuse statutes. The measure will require health professionals and anyone who reasonably believes an infant has been harmed to report to the State when an infant shows signs of withdrawal or indications of prenatal substance abuse. The measure also will establish that prenatal substance abuse *may* be a reason to remove the infant from the parent (Child Welfare Information Gateway, 2007a).
 - At least two States (*California and Virginia*) have required the development of prenatal substance exposure protocols in hospitals. In California, Senate Bill (SB) 2669 was enacted in 1990, requiring the "health and welfare agency to develop needs assessment protocol for pregnant and postpartum substance abusing women and a review of referral systems." Virginia's House Bill 813, enacted in 1992, requires the "State secretary of health to develop treatment protocols and prenatal care providers to adopt screening protocols for substance abusing pregnant women; requires providers to inform patients about the effects of drug use on the fetus and to refer pregnant substance abusers to appropriate care." But in neither State has this provision led to systematic patterns of reporting or hospital practice, as indicated by studies in both States (Albert, Klein, Noble, Zahand, & Holtby, 2000; Zellman, Fair, Houbé, & Wong, 2002; Virginia State interviews). Virginia is currently assessing the effectiveness of these provisions. The State is also reviewing information systems intended to capture data on how widely these systems are implemented.

- An assessment of *California's* SB 2669 legislation that encouraged hospitals to develop screening protocols with a detailed description of an ideal health assessment process concluded that the legislation was not enforced, and as a result, hospitals' practices varied widely (Albert et al., 2000). Further interviews suggested that policy varied from doctor to doctor and from one nurse or hospital social worker to another (Simmes, 2004). A 2002 assessment of perinatal programs in 31 of California's 58 counties concluded that protocols are routinely implemented in only one-third of the hospitals in these counties (Aved, 2002, p. 30).
- *Illinois* legislation requires a CPS referral to local prenatal care providers, the development of a case management plan, a requirement that treatment be provided to any pregnant woman referred through this network, and monitoring by the prenatal provider of the woman's progress in treatment (Child Welfare Information Gateway, 2007b).
- In *Maine*, new legislation in 2004 developed in response to Child Abuse and Prevention Treatment Act (CAPTA) requires the State to act to protect newborns identified as affected by illegal substance abuse or suffering from withdrawal symptoms resulting from prenatal drug exposure, *whether or not the prenatal exposure was to legal or illegal drugs*, and regardless of whether or not the infant is abused or neglected. The State agency is required to receive reports, investigate, determine whether the infant is affected, determine whether the infant is abused or neglected, and develop a plan for safe care (Child Welfare Information Gateway, 2007a, 2007b).

IV. POSTNATAL SERVICES FOR INFANTS, CHILDREN, AND PARENTS

- *Maryland* is addressing the requirements of the CAPTA legislation through statewide policies and procedures implemented by its local departments of social services (LDSSs). Hospital social workers refer drug-exposed newborns considered to be at high risk for abuse and neglect to the local department's Child Protective Services screening unit, and the referral is accompanied by the Drug-Exposed Newborn Reporting Form. The reporting form provides a uniform and consistent format to document risk and safety factors as identified by hospital staff. All Maryland hospitals have been provided with the Drug-Exposed Newborn Risk Matrix to assist hospital staff in making comprehensive assessments of the risk and protective factors in a family. However, staff report that there still is considerable variation among physicians and hospitals regarding whom to screen and when to screen.

Each local department identified a Drug-Exposed Newborn Care Plan Coordinator within child welfare to form a team of experienced staff to work with these families. This team collaborates with staff from partnering agencies and meets on a regular basis to update the status of referrals and to coordinate services for the newborns, the mothers, and families. The group also identifies resources, barriers to care, and gaps in services.

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- The Heller School for Social Policy and Management developed the *Massachusetts* Early Childhood Linkage Initiative. By establishing a strong relationship between the Department of Social Services, which focuses on family investigations of child abuse and neglect, and the Department of Public Health, which ensures developmental evaluations for children, MECLI aims to enhance and expand early intervention services for at-risk children (Heller School for Social Policy and Management, n.d.). Under the program, the child welfare system refers all children younger than 3 with a recently opened case to receive support services through early intervention systems designated under Part C of the Individuals with Disabilities Education Act (IDEA) (ZERO TO THREE Policy Center, 2004). MECLI program goals include expanding service integration, increasing State capacity to offer early intervention services, and advocating for policy change.
 - *Colorado* has done a more detailed assessment of likely caseload increases than most States. The data compiled indicated that in a sample of children in the child welfare caseload in one county, 12.2% were presumptively eligible for Part C services under IDEA, but only 16.9% of those children were actually enrolled (113 of 668 eligible). Of the entire State child welfare population, only 4.8% were enrolled in Part C; through extensive Child Find efforts, this percentage was raised to 7.9% (Robinson & Rosenberg, 2004).
 - *Wisconsin* has also developed a detailed procedure for a plan of safe care for drug-exposed infants. CPS will accept reports of an infant identified at birth as having controlled substances or controlled substance analogs in his or her system and will assess the safety of the infant. CPS will develop a plan of care that reduces risk to the child and supports a safe environment, either an agency-managed safety plan or a referral to appropriate preventive community services. Or CPS will determine that the family has in place a plan of safe care for the infant. After a referral is accepted for assessment, information on family functioning, parenting practices, home environment, and individual child and parent functioning is used to assess and document safety in the Wisconsin version of the federally mandated child welfare client tracking system (Wisconsin Department of Health and Family Services, 2004).
 - Blank Children's Hospital (Child Abuse Program) in *Des Moines, Iowa*, emphasizes the importance of implementing a postnatal plan of care for substance-exposed infants (SEIs) (Shah, 2000). The plan focuses on providing developmentally sensitive and age-appropriate interventions for these infants. It also emphasizes early recognition of potential developmental challenges and obtaining specialized care to facilitate improved health outcomes. The care plan is delineated into three categories based on the infant's age.

During 0–6 months, the care plan stresses providing appropriate sensory stimulation for neuromotor development; creating opportunities for bonding and attachment through physical, visual, and verbal interaction; and responding appropriately to potential stress and anxiety. From 6 months–2 years, substance-exposed children typically enter a dormant phase in which they are symptom-free. Children 3 years and older have a greater risk of having school-related problems such as being able to stay on task, maintain focus, and manage emotions. Successful implementation of this developmental care plan requires careful collaboration of parents, health care professionals, early childhood educators, and community support.

- *California* has invested in residential treatment programs for pregnant and parenting women with its own general funds, a major portion of its TANF services funding, and a new tobacco tax dedicated to 0–5 early childhood programs. Yet, waiting lists for residential care for women with their infants remain significant. A 2002 survey indicated that in the 31 counties responding, the average waiting time for treatment for 81% of pregnant and parenting clients was “less than 1 month” to 3–6 months; only 19% of clients with children living with them had immediate access to treatment (i.e., no wait time). For those who entered treatment without their children, only 31% had no wait time (Aved, 2002).
- In Illinois, the Department of Children and Family Services (DCFS) and the Department of Alcoholism and Substance Abuse developed the Project SAFE model in response to the problem of substance-abusing mothers showing a substantiated history of child abuse and neglect (Lighthouse Institute, n.d.). Project SAFE is linked with a sister program that provides enhanced services, including case management and early intervention under the heading of the Family Intervention Substance Abuse Treatment (FIRST) program. FIRST allocates funds for both enhanced services and Project SAFE and is specifically designed for children identified as SEI.

In 1986, Project SAFE was initially piloted in four diverse communities. Currently, nineteen programs operate throughout the State, and have served approximately 5,700 women. Recent trends concerning the children in the program indicate a rise in the number of referrals for drug-exposed infants and children and identification of emotional and/or behavioral disabilities. In order to address the negative effects of substance-abusing women and their children, Project SAFE provides a wide range of support services including intensive outreach and advocacy, comprehensive case management, residential and outpatient substance abuse treatment involving a clinical services component, onsite and offsite day care, in-depth parent training developed by DCFS, linkage with critical support groups, and aftercare programs. Program findings showed that outreach workers serve as a key program ingredient that motivates substance-abusing women to enroll in treatment because of their ability to engage, support, and connect with the women (Lighthouse Institute, n.d.). Project SAFE promotes positive, healthy family functioning by offering direct treatment services for chemical dependency in addition to addressing the multiple barriers that impede the fragile recovery process.

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- Since 2001, Rhode Island’s Vulnerable Infants Program (VIP) has provided services to drug-exposed infants, serving 150 babies and their parents annually. As summarized by Dr. Barry Lester of Brown University:

A special Family Treatment Drug Court designed specifically for the families of drug-exposed infants has been established for VIP clients based on the “treatment with teeth” concept. The program allows mothers the opportunity to get the appropriate treatment to be reunited with their infants and to provide the kinds of ancillary services including mental health, to make reunification effective and facilitate the development of the mother-infant attachment relationship. In this voluntary program, the VIP treatment plan is court ordered and sanctions are used for noncompliance, the ultimate sanction, of course, being loss of custody of the infant. (Lester, 2000)

With VIP, mothers get more comprehensive services including drug treatment, mental health treatment, and parent training. The mothers have shown a significant reduction in mental health symptoms. Fathers participate, and services are also provided for other children in the family. A VIP liaison with the State Early Intervention Program ensures that these drug-exposed infants receive early intervention services. Permanency within 1 year has been achieved for 62% of the children in keeping with the Adoption and Safe Families Act guidelines (Lester & Jeremiah, 2003).

Procedure in this hospital, one of the largest birthing hospitals in Rhode Island, relies significantly on the professional judgment of care providers. Reporting is described as “mandated” if a positive toxicological screen exists and the judgment of the professional is that a report is necessary; interviewees agreed that different professionals could interpret this discretion differently. If the mother reported having used substances at any point during her pregnancy, but no toxicological test was done, then reporting is left to the judgment of the professional.

- At the local level, in *St. Louis, Missouri*, the Linkages program was developed by the Missouri Division of Family Services and Catholic Community Services to offer support to mothers of drug-exposed infants (Loman & Sherburne, 2000). Funded by Prevent Child Abuse Missouri (the Missouri Chapter of the National Committee to Prevent Child Abuse), the program provides home visitation from birth–2 years for mothers and their infants. Home visitors are paraprofessionals who identify needs and provide referrals for housing, food, transportation, financial assistance, and enrollment in substance abuse treatment programs. Services are also provided by the Department of Family Services (DFS) on an ongoing basis.

Mothers participating in the Linkages program reside in St. Louis and are identified as high-risk candidates by a statewide infant reporting system. The referral process begins when hospitals screen for risk levels by testing the newborns for the presence of drugs and alcohol in their system. Hospitals will report all instances of prenatal substance exposure to the Missouri Child Abuse and Neglect Reporting Unit. The reports are subsequently sent to DFS, which is responsible for follow-up on these high-risk mothers and infants. The DFS worker interviews mothers to assess the situation and determine whether court involvement, child removal, or additional services are necessary. Since the program accepts only cases in which the infant remains in the home with the mother, DFS refers cases that meet this eligibility criterion.

- In 1997, the Sobriety Treatment and Recovery Teams (START) program was developed and implemented as a response to the dramatic increase of referrals resulting from substance-abusing parents in *Cuyahoga County, Ohio*. In fact, 75% of all child welfare intakes involved drug abuse as a contributing factor (Kinney, 2001). The program views addiction as a disease rather than a lifestyle choice involving potential relapse and varied levels of support services to abstain from drugs. The initial focus of START revolves around treating the parents' addiction upon thorough assessment. After the intake is complete, drug treatment is accessible within 72 hours. The program adheres to a team decision-making process, ensuring regular communication with the parents and other support services. An important program goal is to assist parents in overcoming their substance abuse addiction through a collaboration of partners, which include health care providers, drug treatment centers, housing assistance, family, friends, and the surrounding community.

START accepts women, 150 per treatment group, who gave birth to babies at one of five hospitals located in Cuyahoga County, Ohio (Kinney, 2001). To be eligible, the women must have had a positive drug screen. For staffing, START comprises 10 teams who are managed by two supervisors. An advocate and child welfare social worker is assigned to each team, overseeing a caseload of fifteen families. Since most advocates have been in recovery for a minimum of 2 years, they are able to empathize with the obstacles and hardships associated with achieving abstinence. Advocates and social workers also make referrals to the drug treatment centers, physically escorting the mothers to their first three appointments. This approach directly links the mother and provider, helping to facilitate a positive relationship. Beyond escorting the mothers, START teams continue to follow up and consult with the treatment providers on a regular basis to monitor progress.

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- Under the jurisdiction of Judge Leonard Edwards, former President of the U.S. National Council of Juvenile and Family Court Judges, *Santa Clara County, California*, established one of the first Family Treatment Drug Courts in 1998 (National Abandoned Infants Assistance [AIA] Resource Center, 2005). As a result of Judge Edwards' request, the *Celebrating Families!* Program (CFP) commenced in 2002 to help recovering families acquire the basic knowledge and skills for effective parenting while offering support services to their children. Funded by a grant from the Substance Abuse and Mental Health Services Administration, CFP's main goal is to "foster the development of whole, fulfilled, addiction-free individuals by increasing resiliency factors and decreasing risk factors in participants' lives" (National AIA Resource Center, 2005). Overall curriculum objectives include breaking the cycle of addiction and decreasing participants' use of alcohol and other drugs through educating families about chemical dependency and healthy life skills.

CFP's unique curriculum is based on current research regarding brain chemistry, risk and resiliency factors, asset development, life skills education, and community service. The model consists of 15 weekly, 90-minute sessions, followed by a structured family activity. Examples of session topics include goal setting, feelings-defenses, anger management, chemical dependency as a disease, and healthy boundaries. The curriculum incorporates interactive and experiential learning that is individually tailored for substance-abusing parents and their children. Evaluation results from a study conducted on the Drug Court and CFP's effectiveness revealed a decrease in the length of time children are in the Child Welfare System (CWS) to 6–12 months, compared with 13–18 months in Drug Court without participating in the program. Family reunification rates for Drug Court and CFP were 72%, compared with 37% in CWS without CFP services (Quittan, 2004). This program is currently offered at three test sites in California. Other community-based sites in New Jersey, New York, and Idaho are replicating the program model.

V. IMPROVING SYSTEM LINKAGES

Multiagency funding streams

The States that have been most active in SEI policy have been able to tap multiple funding sources. For example:

- *Illinois* uses Federal SAPTBG funding, Title IV-E Child Welfare funding, Medicaid, Maternal and Child Health (Title V) funding for outreach, and general funds for its SEI programs. Other interviewees from the 10 States indicated that some of these sources had been used, as well as TANF funding for screening pregnant women in the TANF program and for residential treatment for eligible women, Part C Early Intervention funding, funding from CDC for fetal alcohol screening and treatment, and adult and dependency drug court funding for the portion of drug court populations that include parents of SEIs (interview on September 14, 2005).
- *California* uses funding from its statewide Proposition 10 tobacco tax funds for county-level prenatal screening in seven counties. See <http://www.ccfc.ca.gov/press/prop.asp>

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- In *Rhode Island*, skillful negotiation, and a leadership position taken by the insurance industry, appears to have succeeded in allowing private insurance coverage of many of the women in the *Project LINK* program (interview on March 10, 2005).

Interagency efforts

- *Virginia*, which has an especially decentralized service delivery system, has statewide interagency efforts in place as well as links with local Community Service Boards (CSBs) that address treatment issues and local child welfare services. Some of these local entities have worked together to serve hospital-referred postpartum substance-using women and their infants. In 1998, legislation required that annual reports be made of SEI totals; the final report was submitted in 2002. In 2002, the CSBs were awarded funds to support education and collaboration efforts with local hospitals, community medical providers, and child welfare offices regarding perinatal substance use and the SEI legislation. At the statewide level, in response to its 2001 study of a sample of cases, Virginia State agencies formed an interagency work group to assess implementation of this legislation, including the Departments of Health, Social Services, and Mental Health, Mental Retardation and Substance Abuse Services (interview on March 23, 2005).
- *Hawaii's* 22-member statewide interdepartmental council began in 1991 and addresses perinatal issues through five different programs, including Baby S.A.F.E. (Substance Abuse Free Environment). This council works closely with the Healthy Mothers, Healthy Babies program, which operates and provides oversight for several perinatal initiatives, including the Baby S.A.F.E. program (interview on September 19, 2005).
- An *Illinois* law established the Committee on Women's Alcohol and Substance Abuse Treatment of the Illinois Advisory Council on Alcoholism and Other Drug Dependency in 1997. This committee addresses women's treatment and provides for child care for women in treatment (interview on September 14, 2005).
- *California* has a county-based system of perinatal councils that began in 1991. As with many of the perinatally oriented bodies, they address a wide range of issues, including SEI topics (interview in 2004 and 2005).

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- In 1995, *Washington* passed legislation requiring the formation of a Fetal Alcohol Syndrome Interagency Work Group (FASIAWG). The legislation charged the Department of Social and Health Services, the Office of Superintendent of Public Instruction, the Department of Health, and the Department of Corrections to devise an agreement as a way of coordinating the many programs that target children born exposed to alcohol and women at risk of giving birth to children exposed to alcohol (Washington State FASIAWG, 2007). FASIAWG also included representatives from several agency and advocacy groups that play an integral part in the planning, expansion, administration, and review process. FASIAWG members recommend further exploration and implementation in three general areas: (1) providing services for children and adults with Fetal Alcohol Syndrome Disorders (FASD) by institutionalizing a “no wrong door” approach; (2) providing FASD education and training to professionals and to parents of children with FASD; and (3) supporting public agencies, professional and educational organizations, and family-run advocacy groups that will enable them to provide effective services and programs (Washington State FASIAWG, 2007). Washington also has a senior-level steering committee on substance abuse and child welfare. And interviewees believed that discussions about possible consolidation of prenatal programs and the new urgency given to links between substance abuse and child welfare were leading to consideration of expanding SEI efforts to a broader scale. (This new urgency is as a result of recent court orders and Child and Family Services Review follow-up.)
 - For more than 15 years, *Kansas City, Missouri*, has worked through a Metropolitan Task Force on Drug Exposed Infants to address the numerous issues resulting from SEIs. Key topics of concern focus on lack of followthrough within the medical community, varying interpretations of child protection laws, the role of the community in the family’s case management, and the State’s function regarding supervision and custody (Missouri Metropolitan Task Force on Drug Exposed Infants, 2003; *Fact Sheet*). Physicians and health care providers, social workers and child protection personnel, early childhood educators and professionals, court staff, and substance abuse treatment providers joined efforts to address obstacles preventing mothers from receiving treatment and ensuring that the necessary safeguards are in place for SEIs. In 1990, eight prosecutors representing city, county, State, and Federal levels signed an agreement to refrain from indicting substance-abusing pregnant women if they agreed to participate in drug treatment. SB 190 was signed into law in June 1991, requiring health care providers to educate and counsel all pregnant women about the effects of substance use during pregnancy. It also identifies pregnant women as a priority in receiving drug treatment. In 1992, SB 90 was enacted designating the Missouri Department of Health as the local Disciplinary Team. Recently, the Task Force has helped to coordinate family drug court activities with treatment efforts (Missouri Metropolitan Task Force on Drug Exposed Infants, 2003; *Fact Sheet*).

Reporting gaps and data systems

- In *Washington*, the treatment system attaches a code to cases referred by CPS, so there is a record of those referrals coming *into* treatment. However, there is no total of prenatal or hospital screenings, the results of those screenings, or referrals to treatment made *from* the CPS side, so that the gaps between referrals and enrollment could be assessed over time (Washington State FASIAWG, 2007).
- In *Virginia*, a statewide total of 278 referrals during 2000–2001 was cited in a 2002 report, but no annual totals of substance-exposed births (SEBs) are currently collected (interview on March 23, 2005).
- *California* reports the total number of women treated in the statewide perinatal programs, but not the number of referrals received by treatment agencies from hospitals or CPS agencies (interviews in 2004 and 2005).
- *Illinois*, as cited previously, reported 1,060 substantiated SEBs in 2003–2004 (interview on September 14, 2005).
- *Washington* is a good example of a State that does do follow-up on both parent recovery and child outcomes with mothers and babies in the Safe Babies, Safe Moms program until the children are 3 years old (interview on January 18, 2005; Washington State FASIAWG, 2007).
- In response to the growing public concern on the issue of cocaine-exposed infants in the early 1990s, *California* conducted a statewide perinatal prevalence study of alcohol and drug use. In 1992, the Department of Alcohol and Drug Program's Office of Perinatal Substance Abuse funded this study in an attempt to develop better estimates of SEBs, focusing on maternal substance use documented at the time of delivery. Anonymous urine samples were obtained at the time of birth from 29,494 pregnant women throughout 202 maternity hospitals in California. Significant findings were that 69,000 (11.35%) infants were born to mothers who had consumed alcohol and/or drugs and that 41,000 (6.72%) infants were born to mothers abusing alcohol within hours or a few days before delivery. On the basis of self-report, 53,000 (8.82%) infants were born to mothers who used tobacco preceding delivery (Vega, Kolody, Hwang, & Noble, 1993).

These numbers are viewed as conservative since they specifically measured alcohol and drug use at time of delivery that would indicate substance use in a range of 24–72 hours prior to birth. Thus, this study (and any study focused on testing at birth) fails to capture statistics on women who used substances throughout the duration of their pregnancy, but not just prior to birth. It also does not capture use during the first trimester before pregnancy is verified. Although this study provides critical population estimates of substance use at an isolated point in time, it does not provide comprehensive data measuring the extent of SEIs.

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- Negotiations in *Monterey County, California*, between the county public health staff and local hospitals recently reached an agreement to update the statewide perinatal prevalence study of alcohol and drug use for the county's three birthing hospitals. Replication of this survey is currently under way, using the county's Proposition 10 (tobacco tax) funding and based on extensive negotiations with the birthing hospitals around privacy and Health Insurance Portability and Accountability Act of 1996 issues. A second California county is committed to replicating the Monterey survey in 2006, based on a 2005 report on SEI issues in that county (interviews in 2004 and 2005).
 - In 1996, *Hawaii's* Alcohol Drug Abuse Division conducted a blind screening across Maui, Kauai, Hawaii, and Honolulu counties in order to accurately assess the prevalence of substance use and treatment needs for women of child-bearing age. Data measuring substance use were extrapolated through an anonymous questionnaire and coded urine samples from pregnant women. Study findings showed that 12.7% of the women tested positive for illicit drugs (testing was only for major illicit drugs). Given the sample of pregnant women, 3.5% of those tested met *Diagnostic and Statistical Manual of Mental Disorders*, third edition, revised, diagnostic criteria for alcohol dependency, and 3.9% met criteria for marijuana dependence (Hawaii Department of Health, 1996). Utilizing both urine toxicologies and questionnaires enabled data to be collected on recent use as well as frequency, prior treatment history, and other critical information.
 - In 1991, *South Carolina's* State Council on Maternal, Infant and Child Health authorized a substance abuse prevalence study among pregnant women. Results indicated that 12.1% of delivering women used alcohol or drugs based on urine testing which detects more recent use and 22.4% used alcohol or drugs based on meconium testing, which detects more long-term use. The rate based on both testing methods combined was 25.8%. The study measured substance use toward the latter stage of pregnancy, thus potentially omitting data on early and middle stages. In contrast with these numbers, which would result in a range of 14,000 SEBs if the 1991 levels remain accurate, South Carolina indicated that there were 207 reports of drug-impaired infants in 2000 and 163 reports of drug-impaired infants in 2004. Contacts in the State suggested that there may be a problem with under-reporting, due to the increasing numbers of pregnant women giving birth with midwives (South Carolina Department of Health and Environmental Control, 1991).

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ENDNOTES

¹The Child Abuse and Prevention Treatment Act (CAPTA) language requires State policies and procedures for hospitals that assure CPS is notified of all children born affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure; requires CPS to develop a plan of safe care for every such drug-exposed infant referred to it; and mandates CPS to make a Part C referral (to special education agencies handling developmental disabilities) in all cases involving substantiated victims of child maltreatment younger than 3 years (DHHS, ACYF, 2005a).

²Although the CAPTA legislation is silent on fetal alcohol effects, the work of the Interagency Coordinating Committee on Fetal Alcohol Syndrome, Federal Websites on fetal alcohol problems, Federal funding for fetal alcohol-related initiatives, and congressional language regarding resources for fetal alcohol problems make clear that both the executive and legislative branches of the Federal government recognize the issues of alcohol as they relate to SEIs. Congressional initiatives, including the leadership of Congressman Jim Ramstad of Minnesota, a co-founder of the Congressional Caucus on Fetal Alcohol Spectrum Disorders, have added earmarked Federal funding for a variety of fetal alcohol-related projects. In addition, Congress in 2002 requested the Centers for Disease Control and Prevention to update and refine diagnostic criteria for fetal alcohol syndrome (Bertrand, Floyd, & Weber, 2005; see <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5411a1.htm>).

³In a 2003 study, Ebrahim and Gfroerer estimated that in 1998 there were 202,000 pregnancies exposed to illicit drugs; 1,203,000 pregnancies exposed to cigarettes; and 823,000 pregnancies exposed to alcohol. The study used data from the 2000 National Household Survey on Drug Abuse.

⁴The five States participating in FASSNet were Alaska, Arizona, Colorado, New York, and Wisconsin. The seven States currently participating in the FAS Prevention Program are Colorado, Michigan, Minnesota, Missouri, Oregon, South Dakota, and Wisconsin. See <http://www.cdc.gov/ncbddd/fas/whatsnew.htm>

⁵Among the set of ten States in this sample, seven—Hawaii, Illinois, Maryland, Minnesota, Rhode Island, South Carolina, and Washington—are included in PRAMS. For the U.S. map on page 3 of this document that highlights several States, including the seven, see <http://www.cdc.gov/prams/2002PRAMSSurvReport/PDF/2k2PRAMS.pdf>

⁶A significant number of incidents of prenatal exposure to alcohol or illegal drugs take place in pregnancies that do not lead to a live birth (which totals 37% of all pregnancies). It should not be assumed, however, that the ratio of prenatal exposure in births is the same as that in pregnancies, given the harmful prenatal effects that lead to a disproportionate number of terminations of pregnancies and unintended pregnancies resulting from use of illegal and legal drugs (ACOG, 2000; DiFranza & Lew, 1995).

⁷Jones, K. L., & Smith, D. W. (1973, November 3). Recognition of the fetal alcohol syndrome in early infancy. *Lancet*, 2(7836), 999–101. Retrieved November 13, 2005, from Medline.

⁸There has been an overall increase in the methamphetamine/amphetamine treatment admission rate in the United States, from 10 admissions per 100,000 to 57 admissions per 100,000 population aged 12 or older from 1992–2003 (Office of Applied Studies [OAS], 2005).

⁹The bill called for (1) public awareness aimed at the general public, including awareness targeted at high-risk populations, as well as public education on how to prevent FASD; (2) professional education to teach professionals about FASD so that they can recognize and identify FASD for referrals to diagnose, treat, and intervene, and teaching professionals to diagnose and screen and intervene using effective techniques; (3) screening high-risk populations, including both women of child-bearing age and children already affected; (4) diagnosing high-risk populations, including children already affected and women at risk; (5) surveillance and data, including collecting and analyzing prevalence and incidence statistics to help define and describe the problem; and (6) intervening with high-risk populations, including treating women of child-bearing age to reduce and eliminate the risk of an alcohol-exposed pregnancy and preventing secondary conditions in children already affected by FASD.

¹⁰The sources, which have been very helpful to NCSACW in developing this report, include:

S. Christian. (September 2004). Substance-Exposed Newborns: New federal law raises some old issues. See <http://www.ncsl.org/print/cyf/newborns.pdf>

Alan Guttmacher Institute. (September 1, 2007). State policies in brief: Substance abuse during pregnancy. See http://www.guttmacher.org/statecenter/spibs/spib_SADP.pdf

Child Welfare Information Gateway. (2006). Parental drug use as child abuse: Summary of state laws. State statutes series 2006. See http://www.childwelfare.gov/systemwide/laws_policies/statutes/drugexposedall.pdf

Alcohol Policy Information System, National Institute on Alcohol Abuse and Alcoholism. Its Website, <http://www.alcoholpolicy.niaaa.nih.gov/>, includes mapping capacity and tables with detailed legislative citations indicating which States have adopted different reporting policies on pregnancy and alcohol use.

A prime example of the differences in interpretation is the issue of whether any States require prenatal testing or testing at birth. One widely cited source indicates that four States (Iowa, Minnesota, North Dakota, and Virginia) require health care professionals “to test some or all pregnant women or newborns for prenatal drug exposure” (Alan Guttmacher Institute, 2005). Another source says “no State requires systematic detection policies such as toxicology screens for all pregnant women” (Jacobson, Zellman, & Fair, 2003.) And a third source says that “A national survey of State policy directors (Chavkin, Breitbart, Elman, & Wise, 1998) regarding perinatal substance abuse revealed that 12% of respondents’ States in 1995 had mandatory drug testing policies for pregnant women (up from 2% in 1992), and 7% indicated that their State also required testing of all neonates (up from 0% in 1992)” (Ondersma, Malcoe, & Simpson, 2001). Even allowing for the different periods covered by these three reviews, the disparity is too wide to permit confidence in using any of these without further investigation. What appears to be the problem is that some of these sources define testing to be required if prenatal use is suspected—which is far from a universal screening policy, since it is still triggered by a professional’s judgment. Minnesota’s language is illustrative: “A physician shall administer a toxicology test to each newborn infant under the physician’s care to determine whether there is evidence of prenatal exposure to a controlled substance, if the physician has reason to believe based on a medical assessment of the mother or the infant that the mother has used a controlled substance for a non-medical purpose prior to birth. If the test is positive, the physician shall report the result as neglect” Minn. Stat.626.5562 Section 6 (2007).

¹¹ The CAPTA language requires State policies and procedures for hospitals that assure CPS is notified of all children born affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure; requires CPS to develop a plan of safe care for every such drug-exposed infant referred to it; and mandates CPS to make a Part C referral (to special education agencies handling developmental disabilities) in all cases involving substantiated victims of child maltreatment younger than 3 years.

¹² This figure was derived from an analysis of the 2005 NSDUH public use file. The number of pregnant women aged 15–44 classified as needing treatment is 182,013, and the number who received treatment is 10,944. 10,944 divided by 182,013 equals 0.0601 or 6%. The number of those receiving treatment may be very low, so weighted estimates may be less than reliable. Treatment admission data are from the Treatment Episode Data Set (TEDS), whereas data on the numbers needing treatment are from NSDUH. TEDS shows 18,759 pregnant women aged 15–44 admitted to publicly funded treatment in 2003 (excludes missing data), whereas NSDUH reports an estimated 211,678 pregnant women aged 15–44 classified as needing treatment for alcohol or illicit drug use in that same year, and 17,804 who received treatment (8.4%).

¹³ When it comes to prior treatment admissions, nationally, more than half of pregnant women (56.3%), non-pregnant women (57.9%), and men (56.6%) admitted to treatment in 2003 had been previously admitted for treatment. Of the States interviewed and captured in TEDS, the percentages of prior treatment admissions for pregnant women ranged from a low of 46.8% in Illinois to a high of 93.8% in Rhode Island. For non-pregnant women, it ranged from a low of 44.8% in Virginia to a high of 99.8% in Rhode Island (the percentages for men were similar). Of the 10 study States, Massachusetts, South Carolina, and Washington did not have data in TEDS in 2003 on the number of prior treatment admissions for pregnant women; South Carolina and Washington also did not have these data for non-pregnant women.

¹⁴ States may collect additional or more detailed information beyond the minimum data set required by the Federal government. Treatment providers, child welfare agencies, policymakers, and others should contact the appropriate State agencies in each of these fields to find out what data are available.

¹⁵ For further information on the Federal Substance Abuse Prevention and Treatment Block Grant, see <http://womenandchildren.treatment.org/policy.htm#sapt>

¹⁶ The Parent-Child Assistance Program is part of the Fetal Alcohol and Drug Unit at the University of Washington. For a brochure, see http://depts.washington.edu/fadu/PCAP_Brochure_8_28_06.pdf

¹⁷ In Illinois, for example, the 2004–2005 reports and “indicated” (i.e., substantiated) reports of SEIs declined consistent with a 12-year decline in reports, from a high in 1993–1994 of 3,342 indicated SEI reports to 897 in 2004–2005. In California, there was a decline in 0–1-year-old substantiated reports (which is a weak surrogate for SEI reports) in 2004, consistent with an overall decline in reports statewide for all ages.

¹⁸ The United States has a relatively small percentage of the world’s children living with human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS). From the beginning of the epidemic through the end of 2002, 9,300 American children younger than age 13 had been reported to the Centers for Disease Control and Prevention (CDC) as living with HIV/AIDS. Most HIV-infected children acquire the virus from their mothers before or during birth or through breast feeding. Only 92 new cases of pediatric AIDS were reported in 2002. All children born to infected mothers have antibodies to HIV, made by the mother’s immune system, that cross the placenta to the baby’s bloodstream before birth and persist for up to 18 months. Because these maternal antibodies reflect the mother’s but not the infant’s infection status, the test for HIV infection is not useful in newborns or young infants (National Institute of Allergy and Infectious Diseases, 2004).

¹⁹ Phenylketonuria (PKU) is an inherited disorder of body chemistry that, if untreated, causes mental retardation. Through routine newborn screening, almost all affected newborns are now diagnosed and treated early, allowing them to grow up with normal intelligence. About 1 baby in 25,000 is born with PKU in the United States, according to the March of Dimes (March of Dimes, 2007). For more information on newborn screening, see National Newborn Screening and Genetics Resource Center (2007) and <http://genes-r-us.uthscsa.edu/nbsdisorders.pdf> for the National Newborn Screening Status Report.

²⁰ In a survey in Michigan, 77% of responding physicians “agreed that screening for acquired immunodeficiency syndrome during pregnancy should be mandatory. Almost as high a percentage (61% to 75% depending on subspecialty) was also in favor of mandatory screening for alcohol abuse; agreement for screening for illicit drugs was much lower (43% to 55% depending on subspecialty). Despite their consensus (61%) that fear of prosecution would deter pregnant abusers from seeking prenatal care, most were in agreement that existing laws regarding child abuse and neglect need to be redefined to include alcohol (54%) and drug abuse (61%) during pregnancy; 52% were in favor of enacting a statute that includes drug or alcohol use during pregnancy as ‘child abuse’ for purposes of removing that child from maternal custody. Physicians were highly in favor of compulsory treatment for illicit drug use and alcohol abuse for women already in the criminal justice system (82%-83%)

. . . and opposed to criminal prosecution for either alcohol abuse (18%-31% depending on subspecialty) or illicit drug use (23%-34%) during pregnancy.” The conclusion drawn was that “other than criminal prosecution, physicians are not opposed to involvement of the legal justice system in preventing alcohol and drug abuse during pregnancy” (Abel & Kruger, 2002).

²¹ Testing positive for controlled substances is assumed to be substance abuse in most of the legislation. Illinois refers to a “pregnant person who is addicted” as defined by other State legislation, which makes a distinction between use and addiction. Maryland refers to a child “born exposed” without any distinction about amounts; other States refer to “trace amounts” of drugs in the infant’s blood or urine.

²² “Substance Exposed Infants Identified and Served Under §63.2-1509B and §32.1-127.” Department of Mental Health, Mental Retardation and Substance Abuse Services, Richmond, VA. Cynthia Bearer cites one study in which researchers missed the diagnosis of FAS in 100% of newborns who were diagnosed later in childhood (Bearer, C., 2001, citing Little, Snell, Rosenfeld, Gilstrap, & Gant, 1990).

²³ “A particularly appealing aspect of the Part C portion of IDEA is that FAS is considered a “presumptive eligibility” diagnosis. Presumptive diagnoses allow children “at risk” of later developmental delay to be served without meeting particular eligibility criteria. That is, children who are at risk for later developmental problems can receive services, even if they test in the normal range or do not meet other eligibility criteria. This is very important for children with FAS because only about 25% score in the significantly developmentally delayed range” (CDC, 2004).

²⁴ “Children at environmental risk include those whose caregiving circumstances and current family situation place them at greater risk for delay than the general population. As with biological/medical risk, states are not required, but may choose to include children at environmental risk under the optional eligibility category of at risk. Examples of environmental risk factors that states have listed include parental substance abuse, family social disorganization, poverty, parental developmental disability, parental age, parental educational attainment, and child abuse or neglect” (Shackelford, 2006). Hawaii, Massachusetts, New Hampshire, New Mexico, and West Virginia were the only States using the environmental at-risk designation starting in July 2006 (see <http://www.nectac.org/%7Epdfs/pubs/nnotes21.pdf>).

²⁵ The Arizona estimate was made in a teleconference with the Mountain Plains Regional Resource Center, funded by the Federal Office of Special Education Programs. For information about the Center, see <http://www.rfcnetwork.org/mprrc>

²⁶ Only 25 States reported information on wait times to TEDS (OAS, SAMHSA, 2005). This analysis included only those 18 States whose data on wait times were at least 75% complete: Arkansas, Arizona, Florida, Georgia, Hawaii, Iowa, Kansas, Louisiana, Maine, Maryland, Michigan, Mississippi, Montana, Nebraska, New Hampshire, South Carolina, Texas, and Utah.

HHS Publication No. (SMA) 09-4369
Substance Abuse and Mental Health Services Administration
Printed 2009

