Substance-Exposed Infants: Current Issues and Responses

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Overview[1]

While the topic has not been on the front pages for quite some time, the issues related to substance-exposed infants still affect at least 400,000 babies born each year—and closer to a million infants, if exposure to tobacco and alcohol are included. When the numbers are expanded to include all children under the age of 18, the fact that more than seven million children were prenatally exposed to alcohol, tobacco, or other drugs is a national health concern of major import.

Yet, considering the total number of births, estimates of substance-exposed births, and births in which exposure has been detected with follow-up assessment and services, it is clear that 90%–95% of all children with prenatal substance exposure are not detected at birth and leave the hospital with their birth parent(s) without follow-up plans or services.

This article suggests a practice and policy framework to provide a comprehensive view of the issues related to prenatal substance exposure, including a brief review of estimates of the prevalence of the issue, a summary of state policies and programs to assist these families, and suggestions of needed interventions in policy and direct practice.

A Policy Framework for Intervention

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

The framework (Figure 1) developed by Children and Family Futures, Inc. (CFF) to organize practice and policy responses to these children asserts that there are five major time frames when intervention could reduce the potential longer-term harm of prenatal substance exposure:

1. **Pre-pregnancy** – This time frame offers the opportunity to promote awareness of the effects of prenatal substance use among women of childbearing age and their family members;

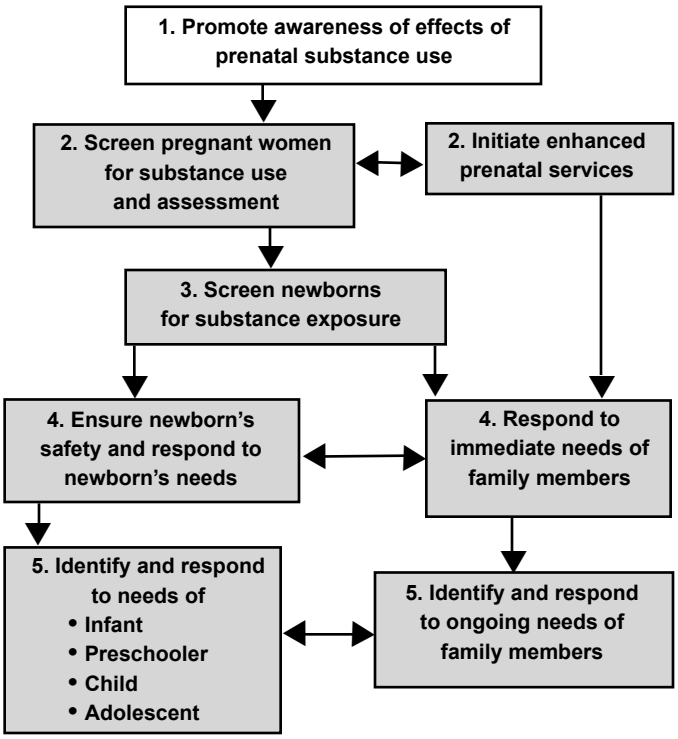
2. **Prenatal** – This intervention point encourages health care providers to screen pregnant women for substance use as a part of routine prenatal care and to make active referrals with follow-up that facilitates access to treatment and related services for women who need those services;

3. **Birth** – Interventions during this time frame incorporate screening newborns for substance exposure at the time of delivery and obtaining needed assessments—including safety assessments—and follow-up care for the family;

4. **Neonatal** – The emphasis includes developmental assessment and the corresponding provision of services for the newborn as well as the family immediately following the birth event; and

5. **Throughout childhood and adolescence** – This time frame calls for ongoing provision of coordinated services for both child and family.

Figure 1: Framework for Analysis of the Five Time Frames for Prenatal Substance Abuse



The Problem

History

The issue of substance-exposed infants 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 cocaine, particularly crack, during pregnancy. Earlier research on fetal alcohol syndrome was first published in the 1970s. National focus on the problem has reemerged over the past few years in response to several developments:

- In 2003, Congress passed amendments to the Child Abuse Prevention and Treatment Act (CAPTA) which require that substance-affected infants be referred to child protective services (see CAPTA side bar); this policy does not specifically mention alcohol, but refers only to illicit drugs, although several states have included alcohol in their testing and referral protocols:

- A growing body of research on fetal alcohol spectrum disorders (FASD) has included longitudinal studies documenting the long-term neurological effects of prenatal exposure to alcohol, leading to the development of new federally funded resource centers and the formation of a congressional caucus to address the issue;

- Concern has grown about the increasing number of pregnant women and children affected by the maternal use of methamphetamines, and households in which children are exposed to the dangers of methamphetamine manufacture;[2]

- Some states have recently enacted or proposed legislation directed at maternal substance abuse, including legislation in some states that has led to the incarceration of mothers of substance-exposed infants.

The focus on prenatal substance exposure is also intensified by increasing evidence that for substance-exposed infants 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.[3]

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

- 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 under the age of 3 years who have substantiated cases of child abuse or neglect to early intervention services, funded under the Individuals With Disabilities Education Act (IDEA). While the CAPTA amendments regarding substance-exposed infants state that the identification of a substance-exposed infant shall not be construed as establishing child abuse or neglect in itself, these infants can be included in the group of children who can be referred for developmental assessments.

Prevalence

Several different studies have estimated substance use by pregnant women and the number of infants exposed. Each of the studies varies in its estimates, due, in part, to differing methods of data collection, focus of the population included in the study, and different approaches used in the analyses. The following are some of the major studies.

National Survey on Drug Use and Health (NSDUH)

The most recent national data available from the NSDUH reports 2004–2005 annual averages of substance use by pregnant women (see Table 1). Prior studies based on this annual survey have found similar rates of substance use.[4] When these percentages are applied to the approximately 4 million infants born each year, the projections result in a wide range of estimated substance-exposed infants, depending on substance and trimester of use.

Table 1: Substance Use by Pregnant Women by Length of Gestation, and Estimated Number of Infants Exposed
(2004–2005 Annual Average)

Substance Used (past month)	*1st Trimester*	*2nd Trimester*	*3rd Trimester*
Any Illicit Drug (3.9%)	7.0% women	3.2% women	2.3% women
Alcohol Use (12.1%)	20.6% women	10.2% women	6.7% women
Binge Alcohol Use (3.9%)	7.5% women	2.6% women	1.6% women

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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.[5]

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 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 Fetal Alcohol Syndrome (FAS) within a geographically defined area. CDC studies from FASSNet showed FAS prevalence rates ranging from 0.2 to 1.5 cases per 1,000 live births in different areas of the United States. Other prenatal alcohol-related conditions, such as alcohol-related neurodevelopmental disorders (ARND) and alcohol-related birth defects (ARBD) are estimated to occur about 3 times as often as FAS.[6]

Screening During Pregnancy
In a study of more than 7,800 pregnant women enrolled in prenatal care clinics in five communities who were 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 continued to use substances after learning of the pregnancy.[7]

The Pregnancy Risk Assessment Monitoring System (PRAMS)
The 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 prior to and during pregnancy is compiled; questions on illegal drug use are included in the survey at the discretion of the state.[8] Seventeen states reported tobacco use in the PRAMS study and found that 6.2% to 27.2% of women smoked during last 3 months of pregnancy, and 1.8% to 8.2% used alcohol in last 3 months of pregnancy.[9]

The need for routine data collection and monitoring remains important, because 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 6.2% in 2003, and it remained steady at 6.2% in 2004.[10]

When these data are analyzed together, the following summary can be made:

- An estimated 10%–11% of the 4.1 million live births (in 2004) 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;
- 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.[11] (This figure differs from the 400,000 stated at the beginning of this article; the 400,000 figure measures only prenatal use that can be detected at a point in time—birth—while the surveys that are the basis for the larger figure cover prenatal substance use during the entire period of pregnancy.[12])

The Practice and Policy Responses

Based on our recent review of state-level documents and in-depth interviews in ten states, we believe that the current system of identifying these infants and responding to their needs is too often fragmented and fails to identify and serve most of these children. State efforts in each of the five areas set forth in the framework above are summarized next.

Pre-pregnancy Awareness

Fewer than half of the states have public education campaigns that emphasize the potential harm done by using alcohol, tobacco, and illicit drugs during pregnancy. Some states 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 pregnant women, especially those who are younger.

Prenatal Screening

To reduce substance exposure during 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. Good model programs for prenatal screening operate in most of the ten states, but no state in the entire nation *requires* prenatal screening for substance use. In fact, few states have developed any policy that supports prenatal screening by private physicians, beyond a handful of pilot projects,

with Washington State a notable exception. At present, infants are tested for a large number of birth conditions, including some with an incidence far lower than prenatal exposure to harmful substances, but no state has mandated either prenatal testing or testing at birth to detect substance exposure. There are some efforts to move toward universal prenatal screening, and in some states and localities, a substantial portion of the most at-risk pregnancies are screened. State use of Medicaid funds provides one example of the disconnection between screening for substance abuse and screening by public programs for other medical conditions. Medicaid covers the cost of 37% of births nationally. Recently, Medicaid regulations were changed to include screening for substance use disorders among its covered benefits. Yet no state has used this as a policy option to ensure that the large percentage of births using this program require screening for substance use among pregnant women.

Further, no state has current prevalence data on substance use during pregnancy that covers the full range of substances. This lack of data regarding prenatal screening, referrals for treatment, and outcomes of treatment makes it difficult to assess the results of the model programs in place, or the states' overall policies.

Testing at Birth

Hospital policies and practices vary widely regarding the testing of newborns for evidence of substance exposure, with very few hospitals using universal screening. Moreover, most testing that is conducted is based on somewhat subjective criteria. Hospitals do not usually provide child protective services (CPS) or other state agencies with data on the total number of infants tested at birth, the results of these 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. Fetal alcohol spectrum disorders have received increased attention in some states. As an example of the variance however, seven of the ten states interviewed considered prenatal exposure to be evidence of child abuse or neglect, while three others do not.

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 ten states studied in depth, only two have strong links between IDEA referrals and child protective services agencies. The lack of uniformity in child welfare-referred developmental assessments that are utilized in most states makes it difficult to assess status in this area.

Services for Children and Families

Ideally, services for an infant or child and the child's parents would be 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 both simultaneously. Some states have strong models of family-centered services. For instance, 19 states fund treatment services for mothers of substance-exposed infants (SEIs) with supplemental funds beyond the funding level required by the federal government. However, waiting lists for treatment persist, and admissions of pregnant women are a disproportionately small percentage of total admissions. Even where adequate treatment resources are available, other agencies may simply lack information or sufficient outreach regarding those resources and may conclude that treatment is not available.

In addition to the five listed areas, cross-cutting efforts are critical to assessing progress in addressing this issue.

Data Systems and Interagency Organizational Efforts

Issues related to substance-exposed infants must be dealt with in a collaborative manner, 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 to be a major barrier to collaboration. The information gaps at each of the hand-off points delineated in the framework are substantial, and these weaken the ability of the systems to work together to track children and families as they move from one agency to another. State policies and practices related to substance-exposed infants tend to develop within a complex system that includes diverse agencies within federal and state government. We found that states' interagency organizational efforts usually subordinate attention to substance-exposed infants in favor of other interagency activities.

Gaps in how substance-exposed infants are tracked by state data systems in terms of screening, assessment, and service delivery inhibit states' ability to measure whether they are making progress on addressing the problem. The need for routine data collection and monitoring remains important. Better tracking of data related to substance-exposed infants would support the case for developing more resources to serve these infants, and their mothers and families.

With respect to alcohol, the Substance Abuse and Mental Health Services Administration (SAMHSA) FASD Center for Excellence summarized state efforts in its 2004 report:

> 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.[13]

As an example, in 2004 the 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.[14] Also in 2004, the Minnesota legislature transferred funds from the Commissioner of Health to a statewide organization focused solely on prevention of and intervention with FASD. Shortly after, 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.

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Options for Further Efforts

The states reviewed and highlighted in this report have shown that policy related to substance-exposed infants can be made effective, and that it can be taken to scale. In addressing the needs of these children, it is apparent that the connections across the five points discussed in this paper are as important as the interventions themselves. The handoffs from one point to the next and the linkages needed to coordinate services must become a comprehensive services framework, rather than a series of fragmented initiatives. The following action steps are needed to provide the proper foundation for this framework to result in better outcomes:

- ✔ States should make the most of Medicaid regulations and resources to influence hospitals and providers to adopt prenatal screening policies in their Medicaid schedules and reimbursements, given that Medicaid pays for 37% of births nationally, and well above that level in several states.

- ✔ 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 policy in a comprehensive and systemic manner as part of their mandates, and to establish and monitor interagency outcomes for programs serving substance-exposed infants annually, guided by a strategic plan that is supported by an inventory of all state programs that affect outcomes for substance-exposed infants.

- ✔ States need to augment the capacity of their existing information systems to collect data regarding how many parents of substance-exposed infants are referred, how many enter treatment, how many complete treatment, and how many succeed in continuing their recovery. This data are crucial to understanding the costs and cost-effectiveness of programs.[15]

- ✔ States must creatively use multiple funding sources to support the implementation and expansion of interventions for this target population. Comprehensive treatment is essential for substance-exposed infants and their 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 due to substance abuse by one or both parents.[16] Likewise, 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.

From this policy framework and model, it is possible to develop some concrete steps for hands-on practitioners in dealing with the problem of substance-exposed births. These include the following:

- ✔ *Work with hospitals, health clinics, and maternal and child health agencies to develop closer ties in serving families that may be affected by substance use disorders.*

In states such as Washington and Rhode Island, exemplary prenatal screening protocols have been developed by maternal and child health agencies and by hospitals. Child welfare workers need to know what their state's procedures are and how to respond to families by providing services rather than with punitive action that may worsen parents' incentives to seek treatment for their problems.

- ✔ *Understand the referral procedures from hospitals to child protective services, and from CPS to agencies that can conduct developmental assessments as required in the CAPTA legislation previously referred to.*

The required developmental assessments under CAPTA should seek to identify the specific neurodevelopmental delays that may be caused in part by substance exposure. Even when children do not assess at levels that ensure they will be admitted to the caseloads of Part C agencies that provide early intervention services for 0–2-year-olds, it is important to follow these children over time so that schools responsible for 3–5-year-olds are prepared to provide any needed special education services and parental support.

- ✔ *Work with medical staff who are familiar with the more subtle signs of fetal alcohol spectrum disorders.*

Considerable publicity has been given to the more visible facial and other aspects of fetal alcohol syndrome, but many children who do not show these visible effects may still be affected by the neurodevelopmental impact of prenatal exposure or the emotional impact of postnatal exposure in a family affected by a family member with a substance use disorder.

- ✔ *Develop an awareness of how to detect and record substance abuse in child abuse and neglect cases.*

The challenge is not to assume that parents are abusing alcohol or illicit drugs; the challenge is knowing how to detect abuse at a level that affects child abuse or neglect. Some states and localities have participated in online training for their front-line employees, using the tools developed by the National Center on Substance Abuse and Child Welfare (available at www.ncsacw.samhsa.gov). These tools have been developed in response to the findings that front-line workers often do not record substance abuse; for example, two adjacent states reported in 2000 that their foster care caseloads were affected by substance abuse in 62% and in 4% of the cases—suggesting strongly that the first state was doing a far better job of preparing its employees to detect and record the problem. The National Center on Substance Abuse and Child Welfare has also prepared a comprehensive review of screening and assessment tools—the SAFERR process—that are used by child welfare staff around the nation. This is available at www.ncsacw.samhsa.gov.

- ✔ *Ensure that child welfare agencies include staff with expertise in multiple funding sources for treatment and children's services, rather than assuming that child welfare funding will be needed for such services.*

Sometimes child welfare agencies are reluctant to diagnose and record problems with children out of fear that limited funding from the child welfare system would be the only way to respond to such diagnoses. But funding exists from multiple systems, and many children and their families are eligible for those funds.

The policy framework for intervention presented in this article along with the research from major studies and the action steps suggested for states, practitioners, and programs offer solutions toward more favorable policy actions in the area of substance-exposed infants.

Notes and References

[1] This article is the result of research and analysis sponsored in part by the federal government through its support of the National Center on Substance Abuse and Child Welfare, but the views expressed are those of Children and Family Futures (CFF) and do not represent those of the federal government of any funder of CFF.

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

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[10] Office of Applied Studies, Substance Abuse and Mental Health Services Administration, National Survey on Drug Use and Health; due to changes in the methodology and data collection procedures for the NSDUH, trend comparisons with figures prior to 2002 are not possible.

[11] Chasnoff, I., & McGourty, R. (2003). *Power beyond measure.* Chicago: National Training Institute Publishing.

[12] A 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. The American College of Obstetrics and Gynecology. (2000, February). *Alcohol and pregnancy.* Danvers, MA: Author. American College of Obstetricians and Gynecologists. (2000, February). *Repeated miscarriage.* [ACOG Education Pamphlet AP100]. Washington, DC: Author. DiFranza, Joseph D., & Lew, Robert A. (1995). Effect of maternal cigarette smoking on pregnancy complications and sudden death syndrome. *Journal of Family Practice, 40*(4), 385.

[13] Fetal alcohol spectrum disorder legislation by state, 2003–2004 legislative sessions. SAMHSA FASD Center, Washington, DC.

[14] The 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 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 childbearing 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 childbearing age to reduce and eliminate the risk of an alcohol-exposed pregnancy and preventing secondary conditions in children already affected by FASD.

[15] National Institute on Drug Abuse. (1999). *Measuring and improving costs, cost-effectiveness, and cost-benefit for substance abuse treatment programs: A manual.* Bethesda, MD: Author.

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The mission of Children and Family Futures is to improve the lives of children and families, particularly those affected by substance use disorders. CFF consults with government agencies and service providers to ensure that effective services are provided to families. CFF advises federal, state, and local government and community-based agencies, conducts research on the best ways to prevent and address the problem, and provides comprehensive and innovative solutions to policy makers and practitioners. CFF is a California-based not-for-profit organization.

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