Substance Exposed Newborns:

Addressing Social Costs Across the Lifespan

Paper prepared by:
Margaret L. O’Brien, JD, MA, Heller School for Social Policy and Management, Brandeis University
Susan M. Phillips, JD, MA, Heller School for Social Policy and Management, Brandeis University

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Executive Summary

The Problem and Associated Costs  Approximately 24,000 substance-exposed infants\(^1\) were born in Massachusetts in 2009, and it is estimated that approximately 10% of those exposed will be measurably affected by this exposure. Thus, an estimated 2,400 substance-affected infants were born in 2009 within Massachusetts. While illegal drugs and the misuse of prescription medication can cause damage, substantial harm also comes from the use of alcohol and tobacco. Although interactions with poor prenatal care, poor maternal nutrition, adverse postnatal experiences, and polysubstance use make it difficult to isolate the adverse impact of any particular substance, the effects of prenatal substance exposure can be profound. Prenatal substance exposure may result in effects that are subtle, such as irritability and emotional reactivity, attention and memory deficits, and difficulties with information processing and decision making, to more severe lifetime physical, cognitive or developmental disabilities, or even miscarriage or death of the newborn.

Societal costs of prenatal substance exposure include those associated with: 1) health, psychological, and behavioral treatment (ranging from possible neonatal intensive care to other care throughout the newborn’s lifetime), 2) developmental supports such as early intervention and special education, 3) residential and/or other institutional care throughout the lifetime, 4) lifetime productivity losses, including lost earnings for caregivers, 5) juvenile and criminal justice involvement, 6) child welfare system involvement such as foster care, 7) entitilements such as Supplemental Security Income, and 8) substance abuse treatment if the child goes on to misuse substances.

Requirements for Intervention  There are five intervention points where state policy and practice can benefit substance-exposed individuals and their families: preconception, during pregnancy, at birth, during infancy, and throughout the lifespan. Regardless of where in this spectrum services are provided, service delivery should minimize judgment and stigma, and should be comprehensive, individualized, gender responsive, trauma-informed, family centered, strength-based and culturally competent.

Current Efforts Within Massachusetts  Massachusetts is fortunate to have a broad range of programs and services for pregnant and parenting women and their substance-affected children at almost every intervention point. Among other things, the Department of Public Health (DPH) has: 1) undertaken a large screening, brief intervention and referral to treatment initiative directed at a broad range of individuals and developed a tool kit for providers to assist in prenatal screening, 2) developed a substance abuse treatment provider guide for medically monitored treatment for pregnant women, 3) begun a study to determine birthing hospital protocols for dealing with prenatally-exposed infants, 4) facilitated specialized treatment for women civilly committed due to dangerous substance use at the Women’s Addiction Treatment Center, 5) developed innovative family residential treatment centers that serve pregnant and parenting women, 6) piloted peer recovery support programs that utilize mothers in recovery to provide recovery coaching, care coordination, and parenting support to pregnant women and new parents with substance use disorders, and 7) piloted in-home services for families not in substance abuse treatment but who are parenting children and are identified as having substance abuse problems.

\(^1\) Substance-exposed, as used herein, entails any prenatal exposure to any amount of alcohol, tobacco, illegal drugs, or misused prescription drugs. Substance-affected is a more ambiguous concept and entails different degrees of disability, ranging from minimally present but undiagnosed to profound.
The Department of Children and Families (DCF) is endeavoring to better coordinate practices throughout the state regarding procedures for screening and investigation of reported prenatal substance exposure.

**Policy Recommendations**  In addition to continuing these existing efforts, there are opportunities for improvement within Massachusetts. We make the following policy recommendations to strengthen the state’s response to the problem of substance-exposed newborns, cognizant of the state’s limited resources and the need to balance many competing demands:

**PRECONCEPTION and DURING PREGNANCY:**

- **Education**: Conduct large scale media campaigns or mass distribution of materials to educate the public about the need for fertility planning and pre-pregnancy cessation of both illegal and legal substance use.

- **Universal SBIRT**: Implement universal screening, brief intervention for those whose substance use is unhealthy, and referral to treatment where indicated (SBIRT) for all women of childbearing age, or, at minimum, for all pregnant women, with quality performance measures adopted to track compliance.

- **Reimbursement**: Add screening procedure codes for Mass Health (Massachusetts Medicaid) to ensure availability of Medicaid reimbursement for both preconception and prenatal SBIRT. Encourage more private insurers to adopt SBIRT reimbursement as well.

- **Geographic availability of services**: Expand services in different areas of the state with demonstrated need, particularly programs like *FRESH Start* that serve pregnant and parenting women and are able to facilitate coordination between the multiple agencies and services with which women with past or present substance use disorders are likely to be involved.

- **Detox**: Equip all detoxification facilities with the knowledge and resources to feel comfortable serving pregnant women.

**AT BIRTH:**

- **Birthing hospital protocols**: Implement consistent written protocols for birthing hospitals to ensure objective non-discriminatory screening when there are concerns that a newborn may be substance-exposed.

- **Evidence-based treatment**: Require use of evidence-based infant treatment when substance-exposure complications surface.

- **Cross-systems coordination**: Consider approaches taken in other states to enhance cross-systems coordination, efficiency and thoroughness in identification, treatment and referral at birth.

- **Electronic health records**: Explore the use of electronic hospital records to identify women who come into contact with substance-related services during pregnancy and whose record
includes substance-related diagnosis or treatment codes, with possible referral to an Early Intervention Partnership Program (EIPP) and/or to Early Intervention (EI).

- **Provider communication**: Facilitate communication between ob/gyns and pediatricians to allow connection of pregnancy issues to the child’s medical record and permit accurate diagnosis of the child.

- **DCF response**: Enhance coordination within DCF to assure consistent, equitable responses throughout the state when substance-exposed children are referred to DCF.

- **EI referrals**: Increase referrals to EI by birth hospitals.

- **EI eligibility**: Establish automatic EI eligibility for any substance-exposed newborn for at least six months following birth.

- **Treatment in correctional facilities**: Explore alternatives to the practices of requiring women in correctional custody to terminate medication assisted treatment after giving birth and to be shackled during transportation for childbirth.

THROUGH INFANCY AND THE LIFE SPAN:

- **EI screening and training**: Integrate universal Fetal Alcohol Spectrum Disorder (FASD) screening into EI programs and increase EI provider training on intervention strategies for all substance-exposed children.

- **Additional treatment options**: Expand treatment options within Massachusetts to additional locations within the state. Ideally, this would include:
  
  - An additional site for civilly committed women in Western Massachusetts
  - Additional residential family treatment programs
  - Supporting the development of comprehensive community based treatment either at single sites or through networks of providers within a community
  - Refining and replicating the best aspects of the peer recovery worker model of *FRESH Start* and *A Helping Hand*

- **Family Treatment Drug Courts**: Direct resources to the piloting of Family Treatment Drug Courts in appropriate areas of the state.

- **Treatment for affected children**: Develop appropriate treatment for affected children throughout childhood and adolescence.

- **Services for families**: Make comprehensive services available for families because parenting substance-exposed children can pose unique challenges.
- **Promising practices**: Ensure ongoing state funding for evidence based and promising practices currently funded through temporary federal grants, including: *Project BRIGHT*, the *Family Recovery Project* and *FRESH Start*.

- **Coordination**: Enhance coordination between state agencies as children who were substance-exposed newborns move through the educational system and into young adulthood.

*The Value of Making a Difference*  
Money spent on pre- and inter-conception education and identification of substance using mothers during pregnancy, and, when appropriate, treatment of both the substance using parent(s) and substance-exposed newborn during the first years of life, will minimize lifetime social service costs. Providing substance abuse treatment to pregnant women can reduce substance use, improve nutrition and prenatal care, and improve birth outcomes. Better birth outcomes lead to lower medical costs and social service costs throughout the child’s life. Moreover, many women who give birth to a substance-exposed newborn may go on to have other children, so that appropriate and effective pre-pregnancy interventions result in even greater savings if subsequent prenatal substance exposure is prevented.

**Goals and Methods for Issue Brief**

This Issue Brief synthesizes what is known about the effects of prenatal substance exposure, as well as programs and policies designed to deal with this problem. It highlights key research on the health and functional challenges that impact substance-affected children and their families, as well as associated societal costs. It presents approaches to help prevent prenatal substance exposure, and to effectively respond to such exposure when it occurs. This includes steps that individuals, communities and the state can take to create a healthier environment for substance-exposed newborns and their families.

We begin by quantifying exposure and by summarizing the known cognitive, physical and developmental effects of substance exposure for the child, as well as the effect such substance exposure has on the family and society. We then turn to a description of the necessary features of effective treatment responses to substance-exposed children and their families and a review of the continuum of treatment options that currently exist in Massachusetts, highlighting ways in which various options or the system as a whole can be made more accessible and effective. We also make policy recommendations.

Although we rely primarily upon research literature to describe the depth and complexity of the issue of substance-exposed newborns, we turn to experts, primarily those within Massachusetts, to direct our review of relevant programs and policy literature. We generally do not quote anyone by name from these interviews, although we sometimes quote without attribution from our notes. The names of people interviewed or who provided substantive information are listed in Appendix A. Acknowledgements of others who assisted in the preparation of this brief may be found in Appendix B.
Quantifying Exposure

The injection, inhaling, or ingesting of certain substances during pregnancy can have harmful effects on the fetus and newborn, as well as on the pregnant woman, her family and society in general. Substances of concern include illegal drugs, such as cocaine, heroin or marijuana, the inappropriate and illegal use of prescription medications, such as pain medication or benzodiazepines, and legal substances such as alcohol and tobacco.

The degree of prenatal substance exposure in Massachusetts may be measured in several ways, none of which are ideal. However, as suggested in Table 1, an estimated 24,000 prenatally substance-exposed infants were born in Massachusetts in 2009. These estimates were obtained by applying preliminary 2009 birth data for Massachusetts (75,104 births): 1) to 2009 national data on prenatal substance use obtained from the National Survey on Drug Use and Health (NSDUH)[5], and 2) for non-binge alcohol and tobacco use, to 2008 data from the Pregnancy Risk Assessment Monitoring System (PRAMS) survey[6], which reports on the use of those two substances during the last three months of pregnancy by state. While Table 1 figures do not account for Massachusetts-specific patterns of use for illicit drugs, for higher binge drinking rates in Massachusetts [7], for infants that may be poly-substance-exposed and double-counted, or for under-reporting by individuals surveyed, it is the best estimate available and suggests that perhaps a third of infants born in Massachusetts have some level of substance exposure. Given that approximately 10 to 12% of substance-exposed newborns are believed to be affected by their exposure [8], between 2,400 and 2,880 infants were born substance-affected in Massachusetts in 2009 alone.

Substance exposure usually does not begin and end during pregnancy. Newborns and young children who live with substance

<table>
<thead>
<tr>
<th>Substance</th>
<th>Percent of Pregnant Women Ages 15-44 Reporting Past Month Use</th>
<th>Total Estimated Number of Exposed Infants in Massachusetts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tobacco</td>
<td>9.8</td>
<td>7,360</td>
</tr>
<tr>
<td>Alcohol</td>
<td>11.0</td>
<td>8,261</td>
</tr>
<tr>
<td>Binge Alcohol</td>
<td>5.4</td>
<td>4,056</td>
</tr>
<tr>
<td>Marijuana</td>
<td>7.6</td>
<td>5,708</td>
</tr>
<tr>
<td>Illicit Pain Reliever Use</td>
<td>1.5</td>
<td>1,127</td>
</tr>
<tr>
<td>Illicit Benzodiazepine Use</td>
<td>0.8</td>
<td>601</td>
</tr>
<tr>
<td>Illicit Use of Stimulants</td>
<td>0.3</td>
<td>225</td>
</tr>
<tr>
<td>Cocaine</td>
<td>0.2</td>
<td>150</td>
</tr>
<tr>
<td>Hallucinogens</td>
<td>0.6</td>
<td>451</td>
</tr>
<tr>
<td>Heroin</td>
<td>0.2</td>
<td>150</td>
</tr>
</tbody>
</table>

[Source: See references 5 (weighted frequencies), 9 (Table 6), 10].
using caretakers may be physically, psychologically and emotionally impacted by the presence of substance use in their environment [3]. There are no national or state data on the number of persons who enter substance abuse treatment who have children, the ages of those children, or whether those children live with the parent who is in treatment. Limited data suggest, however, that approximately 57% of all persons admitted to substance abuse treatment have minor children, with a larger percentage of women than men being parents of minor children (69% vs. 52%) [11].

Effects of Prenatal Substance Exposure

Interaction effects with poor prenatal care, poor maternal nutrition and adverse postnatal experiences, as well as polysubstance use, make it difficult to isolate the adverse effect of any particular substance on children [12-16]. In addition, effects can vary greatly by substance, timing, frequency and quantity of use, with, for instance, binge drinking generally or any substance use at crucial periods of development regarded as particularly dangerous [12, 15, 17-19]. What we do know of potential effects is summarized in Table 2, with some potential ill-effects of prenatal substance exposure ranging from more common subtle effects of irritability and emotional reactivity, attention and memory deficits, and difficulties with information processing and decision making, to rarer but more severe lifetime physical, cognitive or developmental disabilities, or even miscarriage or death of the newborn [12, 13, 20-32].

Potential effects of alcohol and tobacco have been well-documented for years, and Fetal Alcohol Syndrome (FAS) is widely regarded as the leading cause of preventable intellectual disability in the western world [12, 33]. A body of evidence related to

<table>
<thead>
<tr>
<th>Substance</th>
<th>Possible Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol</td>
<td>Preterm birth, spontaneous abortion and stillbirth; Fetal Alcohol Spectrum Disorders, the most serious of which is Fetal Alcohol Syndrome which may include: facial anomalies, growth retardation, below average intelligence, impairment of memory and attention, serious behavioral difficulties, and congenital abnormalities</td>
</tr>
<tr>
<td>Tobacco</td>
<td>Premature birth, miscarriage, increased risk of sudden infant death syndrome (SIDS), impairment of fetal nutrition and growth, reduction in blood flow and oxygen to the fetus, birth defects, pathologic changes in the lungs of the fetus and in the fetal brain, cognitive and neurobehavioral deficits</td>
</tr>
<tr>
<td>Marijuana</td>
<td>Neurological development problems, attention and memory problems, problem-solving deficits</td>
</tr>
<tr>
<td>Methamphetamine</td>
<td>Neurobehavioral patterns of decreased arousal, lethargy, increased CNS stress, poor quality of movement, effect on verbal memory network</td>
</tr>
<tr>
<td>Cocaine</td>
<td>Pre-term delivery, possible low birth weight, small head circumference, growth retardation, possible neurobehavioral deficits, deficits in cognitive performance with differences between genders</td>
</tr>
<tr>
<td>Heroin</td>
<td>Possible low birth weight, prematurity, neurodevelopmental impairment, Neonatal Withdrawal Syndrome</td>
</tr>
<tr>
<td>Prescription Opioids</td>
<td>Neonatal Withdrawal Syndrome, possible impairment of learning and memory, birth defects</td>
</tr>
<tr>
<td>Benzodiazepines</td>
<td>Evidence of birth defects, cognitive deficits in animals, withdrawal syndrome in humans</td>
</tr>
</tbody>
</table>

[Sources: See references 12, 13, 14, 20-29, 31, 32, 38, 39].
illicit drug exposure is currently expanding. While failure to account for factors such as poor prenatal care and poor maternal nutrition led to some exaggeration of the immediate effect of cocaine use on exposed infants during the 1980s and 1990s, studies of cocaine-exposed infants, as they have aged through latency and adolescence, demonstrate that substance effects vary as children develop [e.g., 34, 35-37].

Substance use by the mother can affect the developing fetus and lead to future problems even when such use does not meet the clinical criteria for substance abuse or dependence. Therefore, current recommendations are that women not consume any alcohol, tobacco or illicit drugs during pregnancy [20, 29, 40, 41].

**Correlates of Prenatal Substance Exposure Within the Family**

Prompt identification of unhealthy use, diagnosis of *in utero* substance exposure, and appropriate early intervention can reduce the effects of prenatal exposure to certain substances. Conversely, continuing substance use, or failure to provide appropriate interventions, elevates risk and may lead to adverse outcomes when children are exposed to unhealthy substance use either prenatally or in their early environment [3]. In considering the effect of substance exposure, it is necessary to address correlated difficulties among those parenting substance-exposed newborns.

**Effect on the Mother, Child and Other Family Members**

The birth of a substance-exposed infant can have multiple effects on the birth mother, other family members and on the parent-child relationship. The mother-child dyad, in particular, may be impacted, with the mother possibly experiencing feelings of shame, guilt and/or depression following such a birth, particularly if the birth is accompanied by child welfare involvement. Such feelings can impair the ability of the mother to bond and of the child to develop healthy attachment [34, 42, 43]. When children are removed from biological family care, they also may develop attachment problems if placement entails multiple caregivers in multiple foster homes. It also can be more difficult to parent children born substance-exposed, which may make attachment more difficult for the infant and further separate parent and child [44]. Continued substance abuse within the family can lead to compromised parenting, with some studies estimating that children born to parents with substance use disorders are at three or four times greater risk of incurring abuse or neglect [44].

*The incidence of parental substance abuse does not vary by socio-economic status, although the substances used may vary.*

A comprehensive study of the effects of adverse childhood events, such as parental substance abuse, on adolescent and adult development and health outcomes can be found in the Adverse Childhood Experiences (ACE) Study [2]. It is important to note that the incidence of parental substance abuse...
does not vary by socio-economic status, although the substances used may vary. Thus, adverse developmental outcomes can affect all children exposed to parental substance abuse [2].

As a result of the developmental challenges posed by prenatal substance exposure and/or the adverse impact of substance use in the post-birth environment, individuals parenting substance-exposed children, whether the birth family or substitute caregivers, may need more parenting education and support than those raising a child not prenatally exposed [43]. Evidence shows that substance-exposed newborns raised in nurturing and stable home environments typically have improved outcomes over those who reside in chaotic or neglectful post-natal environments [27, 43, 45].

Additional Risk Factors – Co-morbid Mental Illness, HIV-AIDS, and Domestic Violence

Substance use disorders do not exist in a vacuum and women who abuse substances often grew up in substance abusing families, often have been victims of physical and sexual abuse, and may have begun using substances at a very early age, thus compromising their own developmental trajectories. In light of these common experiences, it is not surprising that women who give birth to substance-exposed newborns may also experience mental illness, be infected with HIV-AIDS, or be exposed to domestic violence.
Understanding the extent of such co-occurrence is important because it fosters recognition of the complexity of the problem of substance use during pregnancy, and it helps determine appropriate treatment for both parents and children.

**Substance use disorders and mental illness among pregnant women**

Substance use disorders often co-occur with mental illness, including mood disorders such as bipolar disorder, depression, or dysthyemia, as well as anxiety, schizophrenia and other disorders. Pregnant and parenting women with substance use disorders may experience mental health issues as well. Depression, in particular, is not uncommon among pregnant women, with research showing high rates of substance abuse among depressed pregnant women [46].

In Massachusetts, 60% of pregnant women in specialty substance use disorder treatment in 2009 reported at least one co-occurring mental health problem at admission beyond the substance problem for which they were being treated [47], and 58% of women reported having received prior mental health treatment [48].

**Substance use disorders and HIV-AIDS among pregnant women**

HIV-AIDS and substance use also have an intertwined relationship, as many individuals infected with HIV also experience substance use problems. The CDC reported that, in 2005, 52% of those with HIV also reported use of alcohol and/or illicit drugs [49]. Women who use substances during their reproductive years have high rates of HIV infection compared to the non-using population [50] and female injection drug users are at very high risk of contracting HIV, either through their own drug use or through sexual contact with another injection drug user. Increasing percentages of prenatally HIV-infected infants have mothers who acquire the infection during pregnancy [51] and drug use during pregnancy may contribute to mother to child transmission of HIV [52]. Women with HIV may, either because of denial of their illness and/or because of on-going substance use, access prenatal care late in pregnancy, or not at all, and may fail to inform delivering providers of their HIV status. This also results in increased likelihood of transmission of the virus to the child [53].

Estimates of domestic violence directed towards pregnant women are limited to certain states, but, as of 2008, between 1.8 and 6.0% of pregnant women surveyed reported being subjected to domestic violence during pregnancy [6]. Nearly 2% of pregnant women in Massachusetts surveyed in 2008 reported experiencing domestic violence [6], a number that is surely low, given the fear many women have of reporting abuse. Domestic violence during pregnancy is a risk factor for prenatal substance use, with evidence that pregnant victims of interpersonal violence are more
likely to smoke, drink alcohol and use drugs [54, 55].

Effect on Society, including Social, Economic and Human Costs

There are two types of costs that must be considered in connection with substance-affected newborns; those related to special medical care during the perinatal period, and those experienced through infancy and beyond to address the developmental effects of substance exposure. Growing evidence of the more subtle and delayed effects of substance exposure may lead to future recognition of other life span costs associated with exposure. Additionally, a large percentage of child welfare costs have been associated with parental substance use disorders generally [56].

Costs Directly Relating to the Birth of Substance-Exposed Newborns

Prenatal exposure to tobacco\(^2\) is estimated to result in neonatal health expenditures of over $458 million annually [57]\(^3\). The Office of National Drug Control Policy [59] estimated medical costs associated with drug-affected infants in 2002 at what would be approximately $751.5 million in 2011 dollars. An estimate of the public health and medical costs associated with neonatal treatment for opioid exposure in 2009 placed costs at between $73.5 million and $117.3 million in 2011 dollars [1].

Costs Through the Life Span

Costs associated with prenatal substance exposure beyond those incurred at birth are even more difficult to quantify but include:

1. treating associated health, psychological, and behavioral impacts,
2. early intervention and special education costs,
3. institutional, residential and/or support costs throughout the lifetime,
4. lifetime productivity losses, costs of supported employment of the affected individual and lost earnings for caregivers,
5. associated juvenile and criminal justice costs,
6. associated child welfare system costs, not only for adoptive, foster or respite care, but also administrative and procedural,
7. Supplemental Security Income and other entitlement payments, and
8. possible substance abuse treatment costs if the child goes on to use substances [60].

Attached to these costs are, of course, uncertain prevalence rates and difficulty in ascertaining the degree of special or extraordinary needs for each individual child. For example, as of fiscal year 2010-2011, even a child not severely affected by prenatal substance exposure, who is determined to be unable to remain in parental care, will incur costs of at least $5,500 for each year of foster care.

\(^2\) These distinctions between different substances and their costs ignore, of course, the fact that many people use multiple substances.

\(^3\) All costs in this and the following section have been updated to 2011 dollars [58].
care or subsidized adoption, which in today’s dollars would be at least $99,000 through age 18. For a child with specialized needs, costs could range from $36,800 a year for intensive foster care to $98,000 a year for residential placement. Such placement costs are distributed between the state and federal government, and additional costs to both the state and federal government include Medicaid coverage for children removed from parental care [61]. Additionally, if a substance-exposed newborn becomes an adult with a substance use disorder, there is a possibility that yet another generation of substance-exposed newborns will be born to those who are currently unidentified or whose needs are not being met.

The lifetime costs of prenatal substance exposure have been most thoroughly explored relative to alcohol exposure. In 2003, the Substance Abuse and Mental Health Services Administration (SAMHSA) FASD Center for Excellence conducted a review of multiple studies of FAS-related costs in the United States. Direct and indirect costs per individual over his or her lifetime have been estimated at $2.484 million or more in 2011 dollars, allocating $1.987 million for medical treatment, special education and residential care for individuals with mental retardation, and $0.497 million per individual for productivity losses [60]. This estimate could be higher for those with the most profound intellectual disabilities. These figures, the best that exist on costs associated with FAS, do not specifically include costs associated with the less severe manifestations of FASD. While those individual costs would be lower, the prevalence of FASD is higher and, because it is frequently unrecognized and untreated, associated costs such as those related to criminal justice involvement may actually be higher.

Overarching Principles Underlying Effective Societal and Programmatic Responses to Prenatal Substance Exposure

Through our interviews with researchers and service providers, a recurrent theme was that services for families of substance-exposed newborns, especially when a substance using parent remains the child’s primary caretaker, should be comprehensive, individualized, gender responsive, culturally competent, strength-based, family centered, trauma-informed and minimize stigma. In our discussion of these necessary characteristics of effective service provision, and through the remainder of the brief, we will largely focus on treatment and services for pregnant and parenting women, because they are the primary caretakers of the majority of substance-exposed newborns.

Key Features of Effective Service Provision:
- Comprehensive
- Individualized
- Family Centered
- Gender Responsive
- Culturally Competent
- Strength Based
- Trauma-Informed
- Minimizes Stigma

4 These are, of course, characteristics of good treatment generally and do not pertain only to pregnant women.
substance-exposed newborns. Without serving these women effectively, we will be unable to either decrease the frequency of substance exposure or ameliorate the individual, social, or economic effects once substance exposure occurs. These same principles apply, however, whether the parent, child, or a substitute caretaker is the focus of treatment.

**Comprehensive, Individualized and Family Centered Treatment**

Effective treatment needs to comprehensively address both the mother’s substance use and other difficulties within the family [62]. Attention to the woman’s needs must be individualized and patient-centered, as “one-size-fits-all treatment” is ineffective. Difficulties within the family may include not only co-occurring mental illness, HIV-AIDS infection or domestic violence, but also the parents’ needs for education, job skills, employment, safe and stable housing, transportation and parenting education. Comprehensive treatment for any pregnant or parenting woman with a substance use disorder also must include attention to the needs of all of her children.

Family centered treatment includes assisting the entire family, including the woman’s partner and older children, and must address the potential for additional children. Mothers with young children, including those who give birth to infants identified as substance-exposed, have particular needs for substance abuse treatment. Logistically, treatment must be geographically accessible for women with young children, with child care and any necessary family treatment included. Residential or inpatient treatment should include appropriate family living quarters. Parenting education and behavioral health services for substance-affected children also need to be available [63].

**Gender Responsive Treatment**

Women face a number of unique challenges that interfere with substance abuse treatment. These include: issues related to parenting; opposition to treatment by people in the woman’s life; the stigma associated with substance use in women; co-occurring disorders more commonly seen in women – such as mood, anxiety and eating disorders; cultural factors interfering with treatment in the company of men; trauma history that affects both follow-through with referrals and comfort in participating in treatment with men; and responsiveness to different therapeutic approaches [64]. The SAMHSA Center for Substance Abuse Treatment (CSAT) Treatment Improvement Protocol (TIP) No. 51 offers research-based suggestions for improving both women’s engagement and treatment success, including:

- Outreach services
- Pre-treatment intervention groups
- Comprehensive case management
- Supportive and collaborative therapy rather than confrontational approaches
- Trauma-informed treatment
- Same-sex groups
• Attention to co-occurring disorders

• Safety planning when there are issues of potential domestic violence [65].

Culturally Competent and Strength Based Treatment

Good treatment acknowledges cultural differences and values and culturally competent treatment improves outcomes in behavioral health treatment. In one study, interventions that were culturally specific proved four times more effective and native language interventions twice as effective as generic English language interventions [66].

Effective treatment builds on a woman’s strengths and uses those to help her transcend current problems. Strength-based treatment puts the individual’s interests and abilities to work in service of recovery. Rather than focusing only on client deficits, a strength-based approach focuses on areas of competence and promotes growth and resilience [67]. This kind of treatment provides hope for clients by identifying realistic building blocks for improvement.

Trauma-Informed Treatment

Women with histories of significant trauma have as much as 12 times the risk of alcoholism and drug abuse as do women without such histories [3]. Trauma includes exposure to or personal experience of domestic violence or childhood physical, sexual and/or emotional abuse or neglect. Effective substance abuse treatment for women, especially pregnant and parenting women, should therefore be trauma-informed, not merely gender specific [68]. Trauma-informed treatment means that the clinician or direct service provider is aware of the likely existence of trauma in a woman’s life and uses this recognition to avoid re-traumatizing experiences. This requires that every person a woman interacts with in the course of obtaining services, such as receptionists or on-site child care providers, be educated about and sensitive to the ways that trauma history might influence treatment.

Treatment That Minimizes Stigma

Both substance abuse and mental illness remain stigmatized, and pregnant women with co-occurrence may be doubly stigmatized. Many people assume that a substance using or mentally ill mother is unfit to raise her child, leading to fears of custody loss if help for either disorder is sought. Almost everyone we interviewed pointed out that people who are uneducated about the substance use/abuse continuum tend to be judgmental and punitive. This attitude is not confined to the public but extends to doctors, nurses, judges, legislators and others. Stigma often stands in the way of treatment because women do not feel comfortable telling people that they have a problem in order to access help. Ways to minimize stigma and negative judgment include educating practicing professionals and policy makers that substance use can be problematic even when addiction is not present, that substance use disorders are brain-based, and that the most effective approaches to unsafe substance use are through a public health approach. Such efforts
should include working to change the content and messages about substance use in medical, nursing and law schools.

Identification, Treatment and Services to Support Pregnant Women and Their Substance-Exposed Children

A number of services and programs are currently available in Massachusetts to prevent, identify and treat prenatal substance exposure and to assist families of substance-exposed children. This section discusses both Massachusetts initiatives and best practices implemented elsewhere, and identifies specific challenges confronting Massachusetts. We start prior to conception, when it may be possible to prevent the birth of substance-exposed newborns, and then explore options for effective services during pregnancy, at the time of birth, during infancy, and through childhood and beyond.

<table>
<thead>
<tr>
<th>INTERVENTION POINTS TO PREVENT PRENATAL SUBSTANCE EXPOSURE AND AMELIORATE THE IMPACTS OF SUBSTANCE-EXPOSURE IN INFANCY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 - PRECONCEPTION</strong></td>
</tr>
<tr>
<td>Promote awareness of effects of prenatal substance use by educating adolescent and adult women about the risks of unhealthy use. Encourage no use (including of tobacco and alcohol) when planning pregnancy and during pregnancy.</td>
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<tr>
<td>Universal screening, brief intervention and referral to treatment during routine medical visits for all women of child-bearing age.</td>
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<tr>
<td><strong>2 – DURING PREGNANCY</strong></td>
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<tr>
<td>Universally screen pregnant women for substance use and make referrals to treatment when appropriate.</td>
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<tr>
<td>Provide enhanced prenatal services, including referral to services in which coordination can occur with all relevant entities (hospitals, DCF, substance abuse treatment providers, etc.) prior to birth.</td>
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<tr>
<td><strong>3 – AT BIRTH</strong></td>
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<tr>
<td>Use consistent and effective protocols for identification of substance-exposed newborns.</td>
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<td>Make referrals for developmental or child welfare services.</td>
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<td><strong>4 – THROUGH INFANCY</strong></td>
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<td>Provide developmental services.</td>
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<tr>
<td>Ensure an environment safe from abuse and neglect.</td>
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<td>Respond to immediate needs of other family members, including treatment of the parent-child relationship.</td>
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<tr>
<td><strong>5 – THROUGH THE LIFE SPAN</strong></td>
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<tr>
<td>Identify and respond to needs of exposed child.</td>
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<tr>
<td>Respond to needs of mother and other family members.</td>
</tr>
<tr>
<td>Provide for appropriate education, screening, and support as exposed children approach adolescence and adulthood to prevent adoption of high risk behaviors such as substance abuse.</td>
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</tbody>
</table>
Reproductive Life Planning and Prevention

Over half of all pregnancies in the United States are unplanned [69], with the highest rates of unplanned pregnancies among women under the age of 24 with less than a high-school education. Thus, while many women report discontinuing the use of alcohol, tobacco, and illicit substances once they become aware they are pregnant [70], this is too late to prevent the birth of a substance-exposed child. Further, women who give birth to one substance-exposed child are at increased risk of delivering another [71]. For this reason, fertility planning and the preconception prevention of substance abuse for all women of reproductive age, beginning in pre-adolescence, is increasingly a focus of public health research, policy development and implementation [72].

The CDC takes a broad approach to preconception care and has issued recommendations and a strategic plan focused on preconception risk factors that adversely affect pregnancy outcomes, including alcohol and tobacco use5 [74]. Although the CDC recommendations and strategic plan focus on alcohol and tobacco, the approach is equally applicable to prenatal use of illicit substances and misuse of prescription medications. The actual recommendations are broad and cover the spectrum of preconception care from a public health perspective, and include:

- Increase public awareness of the importance of preconception health behaviors and care
- Encourage all individuals of reproductive age to have a reproductive life plan and engage in active family planning
- Encourage preventative visits in the form of risk assessment (including screening and educational and health promotion counseling for all women of childbearing age)
- Support inter-pregnancy care for women who had a previous pregnancy that ended in an adverse outcome, including prior delivery of a substance-exposed newborn
- Provide adequate health insurance coverage for women with low incomes [74].

“*If even a fraction of what is spent dealing with the after-effects of prenatal substance exposure were to be devoted to prevention of that exposure, society would save significant amounts of money.”*
It has been argued that, if even a fraction of what is spent dealing with the after-effects of prenatal substance exposure were to be devoted to prevention of exposure, society would save significant amounts of money. However, because many of the negative effects of prenatal substance exposure are not clear until years later, it is difficult for policymakers to make these up-front investments, particularly in times of severe budgetary constraints. Successful policy change requires educating policy makers to the individual and societal costs of not providing these services in a timely and appropriate manner.

**Screening, Brief Intervention, and Referral to Treatment (SBIRT)**

Protocols are available for providers to screen for unhealthy substance use, provide immediate feedback, counsel about behavior change, and refer a patient to specialty substance abuse treatment if appropriate. This process is known as SBIRT or Screening, Brief Intervention and Referral to Treatment.

In the general population in Massachusetts, about 74% of people who are screened are not using alcohol or drugs in ways that put their health at risk and, therefore, simply receive reinforcement for their current behavior and education [75]. Universal screening using validated tools can help find the remaining people and help them cut back or stop their unhealthy use. Thus, SBIRT can be appropriately used for any population but is a particularly important intervention for all women of reproductive age, beginning in adolescence, whether pregnant or not. Universal screening of this population is important for several reasons: First, universal screening that asks about pregnancy status helps to assure that providers will not miss substance use that puts a mother or child at risk and provides an opportunity to educate the woman about the risks of use during pregnancy. Second, it reduces the stigma that occurs when only a portion of the population is screened and normalizes dialogue and education about substance use in the health care setting. Third, it can capture girls and women who may not be dependent but who, nonetheless, could benefit from a conversation about reducing or stopping their use—even for a period of time such as during pregnancy.⁶

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⁶ It has been suggested that screening for substance use also should include screening for other factors such as depression and domestic violence. This has been piloted by DPH at community health centers [76].
States that have launched universal screening initiatives for all pregnant women include Virginia and Washington [71]; Massachusetts has not, but, as shown in the sidebar, the state has instituted the MASBIRT initiative aimed at increasing use of SBIRT in multiple settings and populations. DPH also has developed a provider tool kit designed to assist obstetricians and others as they provide prenatal care to women and facilitate the use of SBIRT.

SBIRT treats addiction as an end point in a continuum of use. Behavior change at any point along that continuum can prevent adverse outcomes, especially when high risk substance use is detected and addressed prior to progressing to substance dependence. The screening process also gives providers an opportunity to learn which patients are in recovery. In the case of pregnant women, this important information can help the health care team support recovery throughout pregnancy and the postpartum period, while avoiding prescribing medications that might lead to a relapse. There are several screening tools for identification of pregnant women engaged in prenatal substance consumption. Despite the existence of practice guidelines and recommendations related to SBIRT for pregnant women, many prenatal care providers do not routinely screen pregnant patients. Further, a large number of practitioners who do screen fail to use instruments validated for pregnant women and feel uncomfortable about their ability to appropriately refer to treatment if needed [18, 77, 78].

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**The MASBIRT Initiative**

The Massachusetts Department of Public Health (DPH) Bureau of Substance Abuse Services (BSAS) is in the final year of managing a five-year SAMHSA SBIRT project that is focused on implementation of SBIRT in health care settings ranging from primary care offices and clinics to inpatient hospital floors and emergency departments. Although MASBIRT reaches beyond pregnant women to a much larger segment of the population, the initiative has screened over 127,000 people including many women of childbearing age.

The MASBIRT project also developed a medical school SBIRT curriculum and is in the early stages of developing an interactive web-based screening tool for use in healthcare settings as a time-saving device for providers. DPH is assisting in the development of a toolkit that, when final, will be made available to all OB/GYNs in the Commonwealth. This toolkit will encompass more than simply substance use and will include screening for the related areas of depression and domestic violence. By distributing the toolkit to all OB/GYNs, the DPH is sending a strong message that unhealthy or problematic substance use and other issues are not confined to women from disadvantaged backgrounds.

Reasons given for failure to provide prenatal SBIRT include: inability to obtain reimbursement, lack of time, lack of familiarity with screening procedures and referral options, lack of information and misinformation about substance use among women generally and during pregnancy specifically, doubts about the benefits of treatment, discomfort with the subject, and cultural and language barriers [18, 78, 79]. With regard to screening for any
substance use in pregnant women, health care providers also may have concern about the implications of mandated reporting requirements in situations that may require a breach of confidentiality [78]. All such impediments to appropriate prenatal screening must be addressed if screening is to be routinely conducted for all women of childbearing age or all pregnant women.

One stumbling block to screening has been the inability to obtain reimbursement, but some reimbursement is now available. In 2007 and 2008, the Centers for Medicare and Medicaid Services (CMS) added procedure codes to Medicaid and Medicare to permit providers to record and seek reimbursement for both Screenings and Brief Interventions (Medicaid) and Brief Intervention Counseling Time (Medicare) [80]. For Medicaid, however, these codes must be implemented individually by each state in order for the provider to obtain reimbursement. Over 20 states have added SBIRT to their Medicaid programs, but Massachusetts has not yet done so [81]. The American Medical Association also has developed codes for the brief intervention counseling and some commercial payers do reimburse. Physicians can also use general patient counseling codes or bill using a higher level code as they would, for example, when counseling a patient about reducing a new high blood pressure reading. As the health care system moves towards global payments, codes such as these may be less necessary. What will become even more important is the continued development and use of quality measures that quantify providers’ use of SBIRT, such as exist for women of reproductive age within the Indian Health Service [82], and which hold providers accountable for this important intervention.

Services for Pregnant Women

Although early and brief intervention can be very useful during pregnancy when many women may have an increased desire to stop substance use [64], not all women with problematic patterns of substance use will be able to interrupt such use on their own. Some women may need intensive specialty treatment, on either an inpatient, residential, or outpatient basis. A number of issues can arise in such treatment settings specific to women during pregnancy, some of which are addressed in a recent BSAS provider guide for medically monitored treatment for pregnant women, including the need for obstetric care and careful detoxification [83].
Any type of residential or inpatient treatment for pregnant women requires additional supports, including but not limited to obstetric care [64]. In most programs, this is accomplished on a case by case basis, with the woman in treatment being transported to an outside medical provider for obstetric care. Although most programs build successful relationships with obstetric groups or individual obstetricians, it may be problematic to rely on such *ad hoc* arrangements. In addition to finding a health care practitioner who will accept the available insurance, some practitioners are reluctant to form what might be a short term relationship, lasting only for the duration of the woman’s stay in the residential facility, particularly with a woman who may also be experiencing a higher risk pregnancy due to substance use.

Although pregnant women typically can participate in alcohol detoxification, there are complications associated with detoxification for pregnant women dependent on opioids or sedative-hypnotics. Sudden withdrawal, as well as repeated relapses, can lead to fetal withdrawal and distress, with resulting pre-term birth and attendant complications, and occasional fetal death. Thus, although the maintenance medications used as part of detoxification, such as methadone or Subutex, may have an effect on the fetus, it is generally considered best practice to start or continue a pregnant woman on substitute medication rather than to withhold it [64, 84].

The needs for consistent obstetric care and continuous medication assisted treatment can be stumbling blocks upon transition from one level of care to another. Obtaining continuous methadone coverage can be difficult if a woman can only obtain treatment or services (such as housing) by relocating to a different community or neighborhood. Locating inpatient or residential facilities, and all other necessary services, where women live alleviates this problem, as may the development of medical homes, where all care is coordinated from a single provider and behavioral health care is better integrated with primary care.

**Identification of Substance-Affected Newborns and Referral to Services at Birth**

Ideally, more pregnancies would be planned so that substance exposure during even the earliest stages of pregnancy is avoided, and universal screening using validated tools by primary care and obstetric providers would lead to abstinence or treatment entry during the remaining months of pregnancy. Until then, identification of substance-affected newborns at delivery is critical in ensuring appropriate treatment and referrals.

At birth, some infants may present with an immediate need for medical management of their prenatal substance exposure. All substance-affected infants, including those not requiring medical management while in the hospital, are considered at risk for future developmental problems or for abuse or neglect. Thus, hospitals must: (1) identify substance-affected newborns; (2) medically manage infants experiencing adverse effects of substance exposure, particularly
withdrawal or “neonatal abstinence syndrome”; (3) notify the state child welfare agency, the Department of Children and Families (DCF), of the birth of a substance-affected newborn for screening of the infant’s risk of experiencing abuse or neglect; and (4) refer newborns for developmental assessment and potential services through Early Intervention (EI). Other states, including Arizona, New Mexico, Rhode Island, Virginia and Washington have undertaken comprehensive approaches to part or all of this process [85, 86].

1. Federal Requirements for Identification and Care

The Child Abuse Prevention and Treatment Act (CAPTA) [87] provides directives for states to identify and treat very young children who have experienced or may be at risk of abuse and neglect. CAPTA, as amended by the Keeping Children and Families Safe Act of 2003 and the CAPTA Reauthorization Act of 2010, requires states to develop policies and procedures to address the needs of infants identified as being affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure, or by FASD, including:

- referrals to child protective services and other appropriate services
- requiring that health care providers involved in the delivery or care of such infants notify child protective services
- development of a plan of safe care for the infant [87].

Taken together, CAPTA and the Individuals with Disabilities Education Act (IDEA) mandate that states also develop procedures for referral of any child under the age of three who is either: (1) involved in a substantiated case of child abuse or neglect, or (2) identified as affected by illegal substance abuse or withdrawal symptoms resulting from prenatal exposure, to Early Intervention (EI) developmental services funded under IDEA. For
2. Identification of Substance-Affected Newborns

Identification of substance-affected newborns can occur in several ways, including verbal screening of the mother using a validated tool (as is done with SBIRT), toxicological screening of the newborn, or through observation of the mother or newborn. Review of the mother’s electronic health records, where available, and communication between the delivering doctor and the child’s pediatrician also may be a resource in the future, if privacy concerns can be alleviated via informed consent. Although none of these methods will independently capture all substance-affected newborns, comprehensive and consistent systems of identification can provide a viable framework. One state that has developed such a framework is Rhode Island, through the Vulnerable Infant Program (VIP), which entails provider identification of newborns who display symptoms of substance-exposure and referral of those newborns for a neurobehavioral exam, with the results of the neurobehavioral exam dictating whether referral to child welfare and EI occur.

The Massachusetts Department of Public Health (DPH) has been examining the issue of identification of substance-affected newborns, and currently is surveying birthing hospitals around the state to determine what practices are being used. Preliminary findings suggest there is little consistency between hospitals, or even within individual hospitals, as to when screening occurs, how it is conducted, and, when toxicological screening does take place, which substances are tested for. Without clear procedures and protocols, many substance-affected newborns may not be identified and fail to receive appropriate treatment or referrals.

Typical reasons Massachusetts birthing hospitals gave for conducting toxicological screening at birth included certain objectively verifiable criteria related to either the infant or the mother. Infant characteristics included prematurity or low birth weight. Maternal characteristics included acknowledged use of either illegal drugs or medications for the treatment of opioid dependency, a history of substance use, or visibly appearing to be under the influence of substances at the time of birth. Other criteria for conducting a toxicological screening of either the mother or the newborn were more subjective, including “clinical suspicion.”

Unfortunately, subjective criteria and the inconsistent application of ostensibly objective criteria often result in toxicological screening being more common for women already disadvantaged by race, class and ethnicity. This problem has existed for years and a recent study demonstrated that, even when...
a hospital had clear criteria to determine whether toxicological screening should occur, minority infants still were screened at three to four times the rate of white infants, and often not in accordance with hospital criteria [91].

3. Screening For and Medical Management of Neonatal Abstinence Syndrome and Other Substance-Related Complications

There are clinical criteria for assessing and treating infants with neonatal abstinence syndrome (NAS) due to opioid and polysubstance exposure [92], for assessing infants born exposed to cocaine [93], and for assessing infants with FAS and FASD [94-100]. Despite the existence of such guidelines for assessment, a national survey of accredited fellowship programs in Neonatal-Perinatal Medicine in the United States revealed that only 55% had a written policy regarding management of NAS. A number of the respondents indicated that they either did not use an abstinence scoring system or did not use validated systems recognized as appropriate by the American Academy of Pediatrics (AAP). Only 70% of those who responded stated that they routinely used a scoring system to determine when to start or terminate treatment of the infant or to determine what dose of medication to use. The survey also indicated wide disparity rather than consistent compliance with AAP guidelines for treatment [101]. Having appropriate screening in place is important, especially with the skyrocketing problem of prescription drug abuse, particularly opioids [102].

4. Notifying the Department of Children and Families

In addition to the requirements of CAPTA, under Massachusetts law hospitals are required to notify the Department of Children and Families (DCF) when any newborn is identified as “physically dependent upon an addictive drug at birth” [103], a requirement more narrow than that of CAPTA and one that does not include most substance-affected newborns, and certainly not most substance-exposed newborns. The Massachusetts DPH preliminary survey of birthing hospitals indicates that although hospitals have different protocols for when screening takes place, when screening does occur, all hospitals seem to report the birth of an infant identified as substance-affected to DCF through the filing of a 51A report. In fact, some birthing hospitals file a 51A report when an infant is born to a mother with a history of substance abuse, even without toxicological screening of either mother or child at the time of birth [89].

Current DCF regulations classify newborns identified as “addicted” at birth as having experienced physical injury [104]. Cases of physical injury are almost inevitably screened in, meaning that a DCF case is opened so that the agency can look at the effect parental substance use has on the care and safety of the child. The procedure typically followed by DCF upon receiving
a report of a substance-exposed newborn is that a case is screened in for investigation. Investigated cases may be closed, or proceed from investigation to assessment. Once a case is opened for assessment, and the infant has been medically cleared for discharge from the hospital, there is a further determination of whether the child should be allowed to go home with his or her mother, with DCF providing protective supervision; or placed, temporarily or permanently, with another caretaker. DCF can also decide, after any length of time with protective supervision, to remove the child from the parent’s custody and place the child with another caretaker.

In Massachusetts, screening for abuse or potential neglect is done by DCF. However, we encountered three distinct models for such screening in other states, specifically: (1) those, such as Rhode Island, where the screening for abuse/neglect potential and recommendations for a service plan was conducted by the hospital; (2) those, such as Missouri, where there is a separate statewide child welfare investigation unit to evaluate all substance-exposed newborns to maintain statewide consistency in response; and (3) those, like the current Massachusetts model, in which the report is made to the local DCF Area Office. Regardless of the model employed, the most important features of any screening and assessment process are objectivity, uniformity, and consistent application.

Interviewees report that there is currently significant variation in how DCF responds to similar factors in 51A reports. Such variation has been reported not only across but also within specific regions and offices, and seems most common in
cases involving exposure to marijuana and/or medication assisted treatment, such as methadone. After receiving a 51A involving a substance-affected newborn, DCF is obligated to screen the case in for investigation, to utilize collateral sources of information, and to use all available information to determine risk and safety issues for the child. This means DCF responds to many facts and circumstances beyond the report by the hospital. This may account for some perceived inconsistencies. DCF continues to strive for statewide consistency in responding to 51As, yet it appears from conversations with providers, particularly birthing hospitals, that such consistency has not yet been attained.

In one effort to improve consistency with respect to treatment of opioid dependency, DCF is looking at adopting a policy of not opening a case when a 51A report on a substance-affected newborn is received and all three of the following are verified as true:

- The only drug affecting the newborn was methadone, buprenorphine (or a related medication such as Subutex) or another appropriately prescribed and used medication;
- The medication was used as part of treatment and was used as authorized (which must be verified by a medical or other provider); and
- There are no other issues of abuse or neglect or risk to the child, as determined by available information, including documentation of any prior DCF involvement.

It is anticipated that this will eliminate DCF involvement in cases where the mother is participating appropriately in treatment for opioid dependency and there are no other concerns, which reportedly currently occurs, and where all stakeholders seem to be in agreement that a different response is necessary.

5. Early Intervention

Federal law requires that all newborns identified as “affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure” be referred to a local Early Intervention (EI) provider to determine eligibility for developmental services [88]. This referral requirement does not, however, automatically capture every child affected by substances, as exposure may not be known and some delays may not manifest until later in the child’s development.

The opportunity to receive EI services is mandated by federal legislation for children aged birth through three who meet certain criteria. Children who are not eligible the first time they are referred may be re-referred at a later time as part of developmental monitoring or as concerns arise. Each state receives federal funding to provide EI services. In Massachusetts, DPH is the lead EI agency, with assessment and services delivered through local EI providers approved by DPH.
Eligibility criteria for EI include that a child is: (1) not reaching age-appropriate milestones in one or more areas of development; (2) diagnosed with a specific physical, emotional, or cognitive condition that may result in a developmental delay (including FAS); or (3) at risk for developmental delay due to various biological and/or environmental factors such as those identified in the sidebar. Thus, even if a child does not present with one of the specific diagnoses in criterion 2, many substance-exposed children do satisfy criteria 1 or 3.

If a child is deemed eligible for EI and the family accepts services, the local provider works with the family to create an Individual Family Service Plan, with goals and services specific to the child’s needs. Depending on those needs, an EI team may include educators/developmental specialists, physical therapists, speech-language pathologists, psychologists, occupational therapists, social workers, nurses, and other specialty service providers. EI is family centered and acceptance of screening or services is voluntary. Thus, an infant’s caretaker may elect not to take advantage of EI, with the result that eligible children may not receive services.

A conservative estimate of the number of Massachusetts children born exposed to controlled substances between 1998 and 2005 (7,350), found that 60% were referred at least once to EI before their third birthday, and 42% multiple times, with only 15% of those referrals being made by hospitals. Of the children referred, 88% were evaluated, out of which 90% were eligible and 93% of those enrolled in services [106]. Multiple EI referrals for substance-exposed newborns are particularly appropriate. Many substance-exposed newborns may develop at typical rates in early infancy. Re-referral, at 6 month intervals, ensures that any latent developmental concerns are rapidly identified and remediated during infancy.

QUALIFYING FOR Early Intervention THROUGH MULTIPLE RISK FACTORS
To be eligible for EI due to known risk factors for developmental delay, children and their families must present with four or more individual or environmental risk factors. Some of these risk factors may be present in substance exposed newborns, including:

*Low birth weight or premature birth
*Maternal age less than 17
*Multiple family traumas or losses
*Substance abuse in the home
*Parental chronic illness or disability affecting care-giving ability
*DCF involvement
*Documented prenatal substance exposure
*Family lack of social supports
*Suspected central nervous system abnormalities

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7 Although FASD is not an identified condition for EI, as FAS is, there is now a screening tool designed specifically for use in EI assessment to identify risk for children prenatally exposed to alcohol. [105]
EI for infants who are “at risk” is helpful in preventing the emergence of developmental delays [107, 108], including those brought about by heavy cocaine exposure [109]. Access to and use of EI can be cost-effective although cost estimates associated specifically with substance-exposed children are lacking. Estimates of total EI costs for children delivered preterm (a common occurrence in substance-exposed newborns) ranged from $1933 to $6611 (2011 dollars) over three years in Massachusetts [58, 110]. This early intervention for those born preterm, however, should be considered in conjunction with figures from another study that estimated average monthly expenditures ranging from $656 to $1318 in 2004, depending on level of disability, with total expenditures per child ranging from $7442 to $26,856 in 2011 dollars [58, 111], which might be more representative of costs associated with children with more severe substance-related disabilities.

Service Provision for Mothers to Minimize the Effects of Substance Exposure Through Infancy

If a woman is identified as in need of substance abuse services, she can be referred to one or more programs that provide services to adults with substance abuse problems. These programs may be residential or outpatient and may or may not be designed to accommodate pregnant or parenting women.

1. Residential Treatment

Residential treatment, which may follow a period in detoxification, can be voluntary or involuntary, the latter of which includes incarceration and civil commitment. Some women also may involuntarily enter treatment in order to satisfy a DCF requirement for retaining or regaining custody.

a. Voluntary Residential Treatment

The Bureau of Substance Abuse Services (BSAS) funds a number of voluntary women’s residential treatment programs, eight family residential treatment programs, and two sober living programs. At each program, treating pregnant women is a priority. Most of the women’s residential treatment programs have up to four slots for pregnant/postpartum women. The women’s residential treatment programs cannot admit the children of the women other than newborn infants up to six months of age. Under these circumstances, some women decline to enter, or chose to leave treatment because of the need for separation, out of concern for older children’s well-being, or due to fears that they will lose custody of children while in residential treatment. For this reason, the comprehensive family residential treatment model is the preferred treatment model. BSAS funds eight family residential treatment programs that provide services to
pregnant and parenting women and their children. These programs can and do admit all children of all ages in the family. Family residential treatment programs serve between 175 and 250 families a year, with an estimated one-quarter to one-third of the women served being pregnant during their treatment. Many families served are homeless and the programs work to find housing, on-going medical care, continuing treatment, day care, and WIC for the families before they leave. The biggest challenges reported include finding post-treatment housing and day care, and finding a treating psychiatrist for the women while they are in the program. These programs often have a waiting list for entry [112].

The parent(s) and children in these programs currently receive trauma-informed treatment through the federal grant funded Project BRIGHT, which treats traumatic stress in children from birth to age 5 and their parents, helping them deal with trauma symptoms and build resilience. Older children are offered the evidence-informed WELL Child group intervention, also designed to deal with the trauma experienced by these children.

The two sober living programs are designed to admit women and their children post-treatment, until they can find permanent housing. BSAS also funds Supportive Case Management in Community Housing Programs, which provides permanent housing for families and children when a family member is in recovery from a substance use disorder.

b. Incarceration as Residential Treatment

Massachusetts appropriately treats prenatal substance abuse as a public health rather than a criminal issue. The state does not incarcerate women for the “crime” of exposing their fetus to illegal drugs. Nonetheless, the penal system still plays a significant role in the residential treatment of pregnant and parenting women with substance abuse disorders and it does provide an opportunity to deliver services to mothers of substance-exposed newborns, which may increase opportunities for positive outcomes for both these mothers and their children.

The Massachusetts Department of Corrections (DOC) provides substance abuse treatment for incarcerated women at the MCI-Framingham facility, and, where appropriate, treatment at the DOC Opioid Treatment Program, which is run by UMASS Correctional Health. The DOC program designed for pregnant and post-partum inmates is known as Catch the Hope and involves weekly prenatal classes, individual counseling, prenatal care, infant custody planning for those who will deliver during incarceration,
and discharge planning, which includes post-release substance abuse treatment or recovery support. Pregnant and parenting women awaiting trial or serving shorter sentences may be detained in county correctional facilities rather than MCI-Framingham. Although it is beyond the scope of this brief to review practices at all facilities, we learned about specific services available at Hampden County Correctional Facility in Western Massachusetts, which include a doula program for pregnant inmates, substance abuse treatment, pre-employment training, parenting classes, supervised parent-child time, domestic violence awareness and education programs, and discharge planning for follow-up services in the community.

Despite these positive practices, non-evidence-based practices continue within Massachusetts corrections, such as reportedly requiring women to discontinue methadone treatment after giving birth. In addition, the Commonwealth remains one of a few states to shackle pregnant women both for transportation and during medical visits, including on the way to give birth [113]. Thus, the correctional system in Massachusetts presents a mixed picture where pregnant women are involved.

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**Hampden County Corrections Doula Program**

At Hampden County Correctional Facility, a program, funded by DPH using short-term federal grant money, pairs pregnant inmates with *doulas*, who become birth coaches accompanying women to prenatal appointments and meeting the woman at the birthing hospital to assist with labor and delivery. This service is particularly important for inmates with substance abuse and histories, who may need support in dealing with the pain of childbirth without inappropriate utilization of pain medication. In the likely event an inmate has a history of trauma, such support can help prevent appointments, transportation and the birth experience from being re-traumatizing.

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c. Civil Commitment at the Women’s Addiction Treatment Center

Massachusetts permits individuals to be civilly committed for no longer than 30 days if their abuse of alcohol or controlled substances “substantially injures [their] health or substantially interferes with [their] social or economic functioning, or [they have] lost the power of self-control over the use of such [substances]” [114]. The Women’s Addiction Treatment
Center (WATC) in New Bedford serves most pregnant and parenting substance abusing women committed for treatment, although some are civilly committed to MCI-Framingham.

The WATC has 84 beds, and treats approximately four or five civilly committed pregnant women each month. The majority of women admitted to the WATC are young and the most frequently used drugs are opiates (both heroin and prescription drugs), cocaine, and benzodiazepines. Women tend not to be in treatment because of alcohol dependence, although they frequently abuse alcohol in addition to opiates. A large number of these women have a co-occurring mental health disorder (51% of those admitted in 2010 had prescribed psychiatric medications), and a number have Hepatitis C and/or HIV. Most of the women admitted already have children (56% in 2010), but because civil commitment is a treatment of last resort, most do not have custody.

Pregnant women are always prioritized for admission to the WATC but still may have to wait for an opening. This all-female facility satisfies gender responsive treatment criteria and the persons we interviewed also recognized the need for trauma-informed services. The WATC has a full-time psychiatrist and a medical doctor. It provides three levels of service: 1) Acute Treatment Services (ATS) or “detox,” 2) Clinical Stabilization Services (CSS) or “rehab,” and 3) Transitional Support Services (TSS) for transition planning and care. Women may stay in the transitional care facility as long as necessary in order to locate a suitable next placement and are not discharged without a suitable placement.

2. Outpatient Treatment

Outpatient treatment is an alternative to residential treatment, allowing women to remain at home, near family or other supports. The greatest drawback to relying on outpatient treatment is the insufficient number of comprehensive programs providing services to pregnant and parenting women beyond substance abuse treatment, such as housing support, education, job training and assistance, mental health services, day care, after school care, and therapeutic services and recreational opportunities for children. Two examples of treatment programs that offer comprehensive outpatient services are the Shields for Families program near Los Angeles and Meta House in Milwaukee. The Vulnerable Infants Program (VIP) in Rhode Island also provides a broad array of services, many of which (e.g., HIV pre/post-test counseling, prenatal and postnatal care, primary medical care, family planning, entitlement assistance) have been successful in moving families towards self-sufficiency [85].
Creating comprehensive community-based programs can be challenging given today's budget constraints. One alternative is to provide effective treatment through a network of independent service providers where case management, referral and coordination provide broader access to a wider range of services for families with substance-affected newborns. The peer recovery worker model, home-based services, and Family Treatment Drug Courts (FTDCs) are three promising models for improving community-based treatment.

a. Peer Recovery Worker Case Coordination – A Helping Hand and FRESH Start

The peer recovery worker model, in which a consumer of behavioral health services becomes part of a treatment provision team [115], was first explored by DPH in the A Helping Hand program, which was piloted at three sites around the state between 2005 and 2009, and is currently being further developed at the FRESH Start program in Hampden County. A peer recovery worker, also called a peer mentor, is provided to a pregnant or parenting mother with a substance abuse problem. The peer recovery worker is another mother in recovery from substance abuse.

The primary services the peer recovery worker provides to clients are recovery coaching, care coordination, and parenting support, while also serving as a role model in recovery and parenting. FRESH Start also has a clinician on staff, to support clients’ clinical needs, and offers parenting and GED preparation groups, which address women’s needs for skill development and social connection. The peer recovery worker assists clients in following through with referrals to the myriad services that are necessary to ensure comprehensive treatment, and supports clients in managing day-to-day issues faced by parents of substance-exposed newborns while navigating DCF and other systems involvement[116]. This is done not only by meeting with clients and responding to emergent concerns, but by making phone calls, providing or arranging transportation, and accompanying the client to meetings with state agency personnel or service providers. Such tasks are often considered cost-ineffective or too time intensive to be conducted by professional case managers or service delivery professionals, but can make an enormous difference in the degree of follow-through with referrals or engagement in services by parents of substance-exposed newborns. The peer recovery worker can alleviate a new mother’s stress of having to navigate multiple services on her own while learning how to parent as a person in recovery.

A Helping Hand and FRESH Start were mentioned by almost every interviewee we spoke to
to in Western Massachusetts, whether affiliated with DPH, DCF, or other service providers, and by many interviewees in other parts of the Commonwealth. These programs and the peer recovery worker model were identified as reflecting a promising practice for increasing service entry and treatment completion by mothers of substance-exposed newborns. Although the promising results of A Helping Hand and FRESH Start are largely anecdotal, they are consistent with the benefits of the peer provided services model identified in research literature [115].

b. Home-Based Services – Family Recovery Project

The Family Recovery Project is another pilot project underway in Hampden County, serving families referred by DCF where parental substance abuse is an issue and children are at imminent risk of removal from the home or have been placed outside the home with the goal of reunification. Services, which can include parenting support, care coordination, and substance use disorder and mental health treatment, are provided in the home to all members of the family who need services.

Unlike the peer recovery worker model, the Family Recovery Project relies on masters level clinicians for service delivery. The intensive home-based services provided are not otherwise available in the Hampden County area and are not reimbursed by any third-party payers. The five year grant from the federal Administration for Children and Families which currently funds the program will end in the summer of 2012.

c. Family Treatment Drug Courts

With the exception of treatment during civil commitment or incarceration, most services to improve outcomes for substance-exposed newborns are voluntary. If, however, DCF opens a case in connection with a substance-affected newborn, the mother may be expected to participate in certain programs as a condition of DCF closing its case. Court involvement sometimes can help ensure that mothers participate in services, including substance abuse treatment, obtaining an assessment of the child’s needs for EI, or necessary medical follow-up to the child’s substance exposure.

In Massachusetts, the Juvenile Court Department accommodates all families with issues of abuse and neglect. When parental substance abuse is one of the presenting problems, Family Treatment Drug Courts (FTDCs), which do not exist in Massachusetts, provide an alternative model of court intervention. FTDCs typically incorporate the following:
• A team approach to case management, including representatives from the judicial system, the child welfare system and treatment systems;

• Frequent, perhaps weekly court appearances;

• Treatment systems including, but not limited to, substance abuse services;

• Frequent drug testing;

• A system of rewards and sanctions linked to service compliance [117, 118].

One of the primary ways in which FTDCs differ from adult drug courts is that the ultimate incentive for the parents is not avoiding jail time, but the hope of reunification with, or retained custody of, their children [119].

As of July 2010, there were 267 FTDCs in 38 states and an additional 31 programs were being planned [120]. Evaluations of FTDCs show successful substance abuse treatment outcomes for parents and successful outcomes related to child custody [117, 119]. FTDCs can be more effective than traditional courts within the Juvenile Court Department in overseeing children in out-of-home care, in obtaining parental compliance with substance abuse treatment and in increasing the number of children reunified with their parents. These positive outcomes have been documented in many states, including California and Rhode Island.

Beyond Infancy – Services Through the Life Span

As children grow and develop and, in particular, as they enter school and then adolescence, evidence of disabilities linked to prenatal exposure may surface [12, 27, 34, 121]. There are multidisciplinary programs in several states that offer comprehensive services, including diagnosis by clinical geneticists, counseling, family therapy and education, behavioral therapy, speech and occupational therapy, and treatment by developmental pediatricians. Examples include the Fetal Alcohol Syndrome and Drug Exposure Center in Atlanta, Georgia, and the Brown Center for the Study of Children at Risk in Providence, Rhode Island. Two practitioners at Boston Children’s Hospital have established a virtual clinic that draws on their areas of expertise, specifically as a clinical geneticist (Dr. Joan Stoler) and as a developmental behavioral pediatrician (Dr. Lisa Albers-Prock), with the goal of eventually expanding into a more comprehensive program. As is true of treatment for women with substance use disorders, the importance of having comprehensive, coordinated services for substance-affected children at a single location might be ideal, but strong networks among existing service providers can be effective and are likely more feasible in the current health care funding climate.

Although parental substance abuse is not a per se reason for placing a substance-exposed newborn in out-of-home care,
many children born with prenatal substance-related disabilities are appropriately removed from parental care. One provider views such separations as an opportunity to work effectively with an entire family system (i.e., the adoptive or foster family) where the caregivers are not “in the trenches in terms of substance use” while simultaneously trying to deal with the child’s impairments. This may be particularly appropriate for children who present with complex medical or behavioral needs, which may or may not relate directly to substance exposure, or in situations where birth parents are limited in ways that may or may not relate to substance use. On the other hand, children placed in foster care, especially those with behavioral problems, frequently cycle through many placements, impeding normal development and attachment processes. Thus, permanent out of home care, whether institutional or in a foster or adoptive home, carries a large price tag, and must be carefully weighed against the alternative of providing services in the parental home, including services to assist children with ongoing parental substance use.

One major challenge is that there is no comprehensive algorithm for how to treat individuals who were born with substance-related disabilities. Unlike diabetes, for example, where there are clear diagnostic criteria and evidence-based interventions, that is not the case with many substance-related disabilities. Evidence for science-based interventions is weak, many individuals are polysubstance-exposed with complicated repercussions, and many live in a challenging environment where substance abuse continues and other problems exist. Moreover, some individuals born substance-exposed may have other non-substance-related disabilities.

Although certain sequelae of prenatal substance exposure can be treated (e.g., anxiety, mood disorders) or accommodated (e.g., learning disabilities), problems associated with executive functioning deficits such as attention, impulse control and aggression may remain [121-123]. In the most extreme cases, these may necessitate around the clock intervention and supervision. Nor do individuals grow out of these disabilities. Many individuals with FASD, and some exposed to substances other than alcohol, have executive functioning-related issues of behavior and judgment. In adolescence and adulthood such deficits may lead to unplanned pregnancies, legal problems, and substance abuse [e.g., 123, 124].

EI services are more easily accessed than are the services that are needed after children reach age three. Many substance-exposed newborns will qualify for EI services due to the existence of multiple risk factors, but there is no similar qualification for special educational services. Both federal and state laws require either a documented developmental delay or other disability before a child is eligible for special education services. Thus, most children who were substance-exposed in utero must first attempt school without specific supports. Only if they begin to demonstrate academic delays or serious emotional or behavioral difficulties will they become eligible for special education services. This means that parents raising children
who were substance-exposed should remain vigilant in monitoring academic progress and seek help as soon as the need for support emerges.

There are resources designed to help caregivers educate school systems on how to manage the often challenging behaviors of substance-exposed children, as well as specific resources for educators. Examples include resources from the CDC [125] and SAMHSA [126].

After children “age out” of the educational system, and, sometimes even before, they may qualify for services such as those provided by the Department of Mental Health (DMH) if they have a significant mental health diagnosis, or by the Department of Developmental Services (DDS) if they are found to have significant cognitive impairment with functional disabilities. As state resources are stretched however, these services cannot be guaranteed. One provider interviewed noted that she has seen children with even Moderate Intellectual Disabilities (those with an IQ between 35 and 55) found not to qualify for DDS services. She also noted that, because the disabilities associated with prenatal substance exposure do not fit neatly into one category, parents are not able to apply to a single agency for help.

As individuals enter adulthood, the challenge of knowing where to go for services becomes even more difficult. Lack of coordination in this regard is a major challenge for families and providers in Massachusetts and better coordination, especially as young people transition into early adulthood, is crucial. At this point, the connection to prenatal substance exposure may not matter in terms of treatment. All children with disabilities should receive appropriate care, including transition to adulthood and adult services.

Priorities for the Commonwealth

Returning to the five intervention points for preventing the birth of substance-affected newborns, and ameliorating the individual and social costs of substance affected children, we make the following recommendations, cognizant of the state’s limited resources and the need to balance many competing demands:

PRECONCEPTION and DURING PREGNANCY:

- Although health warnings caution women of the risks of using alcohol and tobacco during pregnancy, there have been no large scale media campaigns or mass distribution of materials to educate the public about the need for fertility planning and pre-pregnancy cessation of both illegal and legal substance use. Such efforts, as well as peer to peer, culturally appropriate grass roots messaging are important to alter behaviors before conception and during pregnancy.

- Universal screening, brief intervention for those whose substance use is unhealthy, and referral to treatment
where indicated (SBIRT) is not routinely performed for all women of childbearing age, or even for all pregnant women, but should become a universal practice in medical care in Massachusetts, with quality performance measures adopted to track compliance.

- Add screening procedure codes for Mass Health (Massachusetts Medicaid) to ensure availability of Medicaid reimbursement for both preconception and prenatal SBIRT. Encourage more private insurers to adopt SBIRT reimbursement as well.

- Effective service delivery models for pregnant and parenting women with substance use disorders can include inpatient treatment, voluntary or involuntary residential treatment, or community based treatment of varying intensity, including medication assisted treatment (such as methadone). Massachusetts currently has an appropriate variety of substance abuse treatment programs, but should work on expanding the number of such programs in different areas of the state with demonstrated need, particularly those like FRESH Start that serve both pregnant and parenting women and are able to facilitate coordination between the multiple agencies and services with which women with past or present substance use disorders are likely to be involved.

- Equip all detoxification facilities with the knowledge and resources to feel comfortable serving pregnant women.

**AT BIRTH:**

- Birthing hospitals in the Commonwealth follow a variety of inconsistent practices when a woman delivers a substance-exposed newborn. All hospitals should have consistent written protocols in place to ensure objective non-discriminatory screening when there are concerns that a newborn may be substance-exposed. The state should provide guidance on the content of the protocols.

- As DPH establishes criteria for identification of substance-affected infants by birthing hospitals, consider including requirements for use of evidence-based infant treatment when substance-exposure complications surface.

- As Massachusetts seeks to enhance or reform its processes for ensuring appropriate identification, treatment and referral at birth, consider approaches taken in other states to enhance cross-systems coordination, efficiency and thoroughness.

- Explore the possibility of using electronic hospital administrative records to identify women who come into contact with substance-related services during pregnancy (inpatient, emergency, and observational stays) and whose record includes substance-related diagnosis or treatment codes; such identification could trigger referral to an Early Intervention Partnership Program (EIPP) and/or to Early Intervention (EI) to support the mother and developmental needs of the child.
- Explore ways to facilitate communication between ob/gyns and pediatricians to allow connection of pregnancy issues to the child’s medical record and permit accurate diagnosis of the child as he/she ages.

- Federal law requires that all newborns identified as affected by illegal substance abuse or withdrawal symptoms resulting from prenatal substance exposure, or by FASD, be reported to DCF to allow assessment of the risk of neglect or abuse. No law requires DCF to open a case or to remove an infant from the parents’ care. Many parents, even those who might struggle with substance use, can parent effectively, especially if they and their children are identified and provided with appropriate supports. In other situations the most appropriate response to the birth of a substance-exposed newborn is placement with substitute caregivers on a temporary or permanent basis. Decisions as to when and how to become involved following the birth of a substance exposed newborn are complex and multifaceted. Present variation between DCF workers, offices and regions, might be responded to by enhanced coordination to assure consistent, equitable responses.

- Increase referrals to EI by birth hospitals rather than continuing to rely primarily on DCF for EI referral.

- EI eligibility should be automatic for at least six months for any substance exposed newborn.

- Explore alternatives to the practices of requiring women in the custody of the Department of Corrections (DOC) or county correctional facilities to terminate medication assisted treatment after giving birth and to be shackled during transportation for childbirth.

THROUGH INFANCY AND THE LIFE SPAN:

- Alcohol is the substance known to have the most severe potential impact on child development and, with the exception of tobacco, is the substance to which prenatal exposure is most common. The Commonwealth should integrate universal Fetal Alcohol Spectrum Disorder (FASD) screening into EI programs and increase EI provider training on intervention strategies for all substance-exposed children.

- Expand the comprehensive, family centered, trauma informed treatment options currently existing in Massachusetts to additional locations within the state. Ideally, this would include:
  - An additional site for civilly committed women in Western Massachusetts
  - Additional residential family treatment programs
  - Supporting the development of comprehensive community based treatment either at single sites or through networks of providers within a community
  - Refining and replicating the best aspects of the peer recovery worker model of Fresh Start and A Helping Hand in additional programs or at additional locations around the state
• Direct resources to the piloting of Family Treatment Drug Courts in appropriate areas of the state, perhaps targeting geographical areas where the highest percentages of child welfare cases present with issues of parental substance abuse.

• Support the development and coordination of comprehensive, family-centered, trauma-informed treatment for children who were substance-affected newborns throughout childhood and adolescence.

• The range of possible effects of *in utero* substance exposure, including subtle effects on temperament and cognitive, social and academic functioning, parenting substance-exposed children can pose unique challenges for families. Both the child and his or her primary care-givers may require a variety of services throughout childhood, adolescence, and the transition to adulthood. Massachusetts should make comprehensive diagnostic and treatment services available for these children and their families.

• Ensure ongoing state funding for evidence based and promising practices that are currently funded through temporary federal grant money, including: Project BRIGHT, the Family Recovery Project, and FRESH Start.

• Enhance coordination between state agencies such as the Department of Education (DOE), the Department of Mental Health (DMH), the Department of Developmental Services (DDS), DPH and DCF as children who were substance-exposed newborns move through the educational system and into young adulthood.

Prenatal exposure to alcohol, tobacco, misused prescription medications, and illegal drugs can seriously affect the child and family and result in substantial cost to society. Massachusetts and other states have undertaken initiatives to reduce the effect of prenatal substance exposure but many opportunities remain. Even in a time of significant budgetary constraints, it is essential to consider options that will, over time, save taxpayer money, improve lives, and build a healthier and more productive Commonwealth.
Appendix A

List of Individuals Interviewed and Other Sources

Lisa Albers-Prock, MD, MPH, Developmental Behavioral Pediatrician, Childrens’ Hospital Boston

Debra Bercuvitz, MPH, Program Director, Fresh Start

Hermik Babakhanlou-Chase, MPH, Epidemiologist, Office of Data Analytics and Decision Support, Bureau of Substance Abuse Services, Massachusetts Department of Public Health

Judith Bernstein, RNC, Ph.D., Professor, Dept. of Community Health Sciences, Boston University School of Public Health, Professor, Dept. of Emergency Medicine, Boston University School of Medicine

Kim Bishop-Stevens, MSW, LICSW, Substance Abuse Manager, Massachusetts Department of Children and Families

Lynn Bissonnette, Superintendent, MCI-Framingham, Massachusetts Department of Corrections, Letter of January 31, 2011

Marjorie Bloom, MSW, MPH, LICSW, Clinical Social Worker, Baystate Medical Center, Maternal and Child Health in High Risk Maternity and NICU

Tracey Burton, Family Services Lead Counselor/Lead Counselor for Hampden County Correctional Facility

Taletha M. Derrington, MA, Lurie Institute Doctoral Fellow, The Heller School for Social Policy and Management, Brandeis University

Karin Downs, RN, MPH, Asst. Director for Clinical Affairs, Division of Perinatal, Early Childhood and Special Health Needs, Bureau of Family Health and Nutrition, Massachusetts Department of Public Health

Norma Finkelstein, Ph.D., LICSW, Executive Director, The Institute for Health and Recovery, Cambridge, MA

Carol Girard, MA, SBIRT Coordinator, Bureau of Substance Abuse Services, Massachusetts Department of Public Health

Karol Kaltenbach, Ph.D., Professor of Pediatrics, Psychiatry and Human Behavior, Director of Maternal Addiction Treatment Education and Research (MATER), Department of Pediatrics Jefferson Medical College, Thomas Jefferson University, Philadelphia, PA

Ruth Karacek, RN, MPH, CCM, Public Health Nurse Advisor II, Division of Perinatal, Early Childhood and Special Health Needs, Bureau of Family Health and Nutrition, Massachusetts Department of Public Health

Barry M. Lester, Ph.D., Professor of Psychiatry and Human Behavior, Professor of Pediatrics, Director of The Brown Center for the Study of Children at Risk, Warren Alpert Medical School at Brown University
Walter N. Leutz, Ph.D., Associate Professor, The Heller School for Social Policy and Management, Brandeis University

Neil Michaels, MSP, Director of Early Intervention and Special Projects, Massachusetts Department of Children and Families

Daniel S. Mumbauer, MBA, MA, President & CEO, Southeast Regional Network, High Point Treatment Center, New Bedford, SEMCOA

Mary Pfister, CADAC, LADC1, MA, Substance Abuse Specialist, Massachusetts Department of Children and Families, Region IV

Karen Pressman, MS, LCSW, CADAC, Director of Planning and Development, Bureau of Substance Abuse Services, Massachusetts Department of Public Health

Teri St. Pierre, Program Director, Women’s Addiction Treatment Program, High Point Treatment Center, New Bedford

Amy Price, MPA, Associate Director of National Abandoned Infants Assistance (AIA) Resource Center at UC Berkley

Marnie Rieber, Facility Director, Angel House, Hyannis, MA

Joan M. Stoler, MD, Clinical Geneticist Childrens’ Hospital Boston, Assistant Professor of Pediatrics, Harvard Medical School

Enid Watson, M.Div., Director, Screening and Early Identification Programs, MA FASD State Coordinator, Institute for Health and Recovery
Appendix B

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Michael Doonan, Ph.D., Assistant Professor, The Heller School for Social Policy and Management, Brandeis University; Executive Director of the Massachusetts Health Policy Forum and Director of the Council for Health Care Economics and Policy

John L. Eadie, MPA, Director Prescription Monitoring Program Center of Excellence, The Heller School for Social Policy and Management, Brandeis University

Constance M. Horgan, Sc.D., Professor and Associate Dean for Research, Director, Institute for Behavioral Health, Schneider Institutes for Health Policy, The Heller School for Social Policy and Management, Brandeis University

Mark Parrino, MPA, President of the American Association for the Treatment of Opioid Dependence

Marji Erickson Warfield, Ph.D, Senior Scientist and Lecturer, The Heller School for Social Policy and Management, Brandeis University
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