



Department of Health

and Human Services Maine People Living Safe, Healthy and Productive Lives

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LD 1291, Resolve Establishing a Study Commission on In Utero Narcotic Drug Exposure

January, 2010

Prepared by:

Maine Department of Health and Human Services

For

The Joint Standing Committee on Health and Human Services

Background:

Illicit drug use during pregnancy is an important public health issue, with the potential for severe negative effects on the newborn and implications for subsequent parenting. This is an international concern with Australia reporting that (8%) of women who were pregnant or breastfeeding used illicit drugs, in the United Kingdom, research found that 15% of test samples from pregnant women were positive for illicit drugs. Survey data from the U.S. show that 4% of pregnant women report illicit drug use, suggesting an under reporting of illicit drug use in the United States. Drug use during pregnancy is associated with poor obstetric and perinatal outcomes, with exposed infants being more likely to be born preterm, having lower birth weight and head circumference, requiring resuscitation after delivery, being admitted to special care nurseries, and having longer stays in the hospital.ⁱ

Infants who are born to mothers who use illicit drugs are at risk for multiple challenges to their health and well being including:

- Neonatal abstinence or withdrawal syndrome (NAS). The extent of withdrawal symptoms depends on the type of drug, dosage and frequency of use during pregnancy. The risk for NAS is greatest with opioids, such as heroin and methadone. The neurologic symptoms of withdrawal include irritable and inconsolable crying, jitteriness, muscle twitchiness and shaking of the extremities and at worst, seizures. The gastrointestinal symptoms include poor feeding, vomiting, diarrhea and dehydration. Subacute symptoms of prolonged colicky crying and feeding difficulty may last for 6 months. These infants can be very challenging to care for by professionals and parents.
- Developmental delay. Few studies have followed these children long term and it may be that their risk for delay is no greater than other children from backgrounds high in adverse childhood experiences.ⁱⁱ, ⁱⁱⁱ, ^{iv} Whether the cause is nature or nurture, many of these children (21% in Maine) will require developmental services before entering kindergarten.
- Behavior problems in later childhood. Studies suggest that this is the result of both the prenatal drug's direct effect on the child's brain and the effect of exposure to social challenges.^v
- Child neglect. The association between maternal drug abuse and child abuse and neglect was first described more than 30 years ago.^{vi} Parents impaired by substance abuse may have great difficulty attending to their child's needs.
- Physical and emotional child abuse.^{vii},^{viii} Methadone programs may mitigate this risk, as mothers that were compliant with a methadone program were at lower risk of neglecting or abusing their children than were mothers who continued to use illicit drugs.^{ix}
- Sudden unexplained infant death, especially if the infant is bed sharing with caregivers, including mothers in methadone programs or parent/caregivers actively engaged in alcohol and/or illicit drug abuse (or use).

Scope of the problem:

In 1999, all infants in Maine symptomatic from narcotic exposure in utero were transferred to a level 3 Nursery (NICU) for further care. In 2008, a total of 215 newborns experienced drug withdrawal symptoms (a 16-fold increase since 2000, when only 13 births were noted to involve drug withdrawal syndrome).

2001 2002 2003 2004 2005 Year 2006(4/12mos)Cases/year 18 22 32 48 41 23 Avq \$29,638 \$33,478 \$22,854 \$31,269 \$29,853 \$31,209 Charge/Case 36d 23d 20d Avg LOS 27.5d 22d 18d

Records from the NICU at the Maine Medical Center in Portland, Maine show:

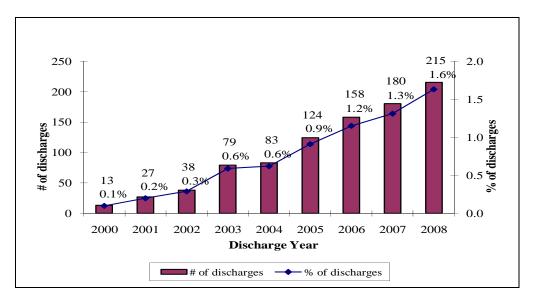
In 2008, drug withdrawal symptoms were experienced by some newborns in every county in Maine, including 11 infants born at Central Maine Medical Center in Lewiston and 16 at the hospitals of MaineGeneral Medical Center in Augusta and Waterville. As the prevalence of symptomatic substance exposed newborns grew, providers at community hospitals increased their skill and willingness to treat these infants at their place of birth. The most symptomatic of these infants continue to be transferred to the NICU at either Maine Medical Center in Portland or the Eastern Maine Medical Center in Bangor.

Not all infants exposed to narcotics in utero will be symptomatic at birth. Of those that exhibit symptoms, most will begin their withdrawal behavior before the 4th day of life. Thus, all infants born to mothers with known narcotic dependency (illicit or prescribed) are observed in the hospital for 4 days after birth rather than being discharged on the second or third day of life.

Also, because of the high rate of developmental delay and the risk for child abuse observed in this population, all newborns exposed to narcotics in utero are referred to child protective services through the federal Child Abuse Prevention and Treatment Act (PL 108-36) (CAPTA) legislation. Data from the Office of Child and Family Services show the number of births of infants known to be **exposed** to substances in utero (Not all infants exposed to substances in utero show withdrawal symptoms) and referred to DHHS:

- 2005 165 highest concentrations Bangor, Lewiston, Portland
- 2006 201 highest areas still the same but include a jump in Ellsworth
- 2007 274 highest in Bangor, Augusta saw big increases
- 2008 343 Caribou, Lewiston, Rockland saw significant increases

Of the 13,604 infants born in Maine in 2008, **2.5% were known to be exposed** to substances in utero and **1.6% experienced symptoms of withdrawal**. The following graph depicts the number of infants showing withdrawal symptoms after birth and as a percentage of all infants discharged from their birth hospital.



Newborns Experiencing Drug Withdrawal Symptoms in Maine

Current Involvement of State Agencies and State and Federal Legislation:

Title 22: §4004-B. Infants born affected by substance abuse or after prenatal exposure to **drugs** states:

The department shall act to protect infants born identified as being affected by illegal substance abuse or suffering from withdrawal symptoms resulting from prenatal drug exposure, whether or not the prenatal exposure was to legal or illegal drugs, regardless of whether or not the infant is abused or neglected. The department shall:

- 1. Receive reports of infants who may be affected by illegal substance abuse or suffering from withdrawal symptoms resulting from prenatal drug exposure;
- 2. Promptly investigate all reports received of infants born who may be affected by illegal substance abuse or suffering from withdrawal symptoms resulting from prenatal drug exposure.
- 3. Determine whether or not each infant reported is affected by illegal substance abuse or suffers from withdrawal symptoms resulting from prenatal drug exposure.
- 4. Determine whether or not the infant is abused or neglected and, if so, determine the degree of harm or threatened harm in each case.
- 5. For each infant whom the department determines to be affected by illegal substance abuse or to be suffering from withdrawal symptoms resulting from prenatal drug exposure, develop, with the assistance of any health care provider involved in the mother's or the child's medical or mental health care, a plan for the safe care of the infant and, in appropriate cases, refer the child or mother or both to a social service agency or voluntary substance abuse prevention service; and
- 6. For each infant whom the department determines to be abused or neglected, comply with section 4004, subsection 2, paragraphs E and F.

Child and Family Services Policy, IV.C-2, Response to Infants affected by Illegal Substance Abuse states:

District Responsibilities^x

All reports from health care providers alleging that an infant has been born that is affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure (legal or illegal substances) will have the report type of "drug affected baby." This type of report is selected even if there are also allegations of suspected abuse. Cases where the infant and/or the mother has had, does have, or is likely to have medical needs should be referred to Public Health Nursing or the visiting nursing program serving the area where the family is residing. No matter who does the fact finding the following determinations must be made:

- 1. That the infant was affected by or addicted to one or more substances
- 2. Whether the infant received appropriate medical care immediately after birth
- 3. That there is or is not a safe plan of care for the infant in the immediate future

The district will clearly communicate to the referral source the requirement to record in their records the above determinations. They will also be informed that:

If a family refuses to work with the CIP or visiting nurse agency, the agency must report that immediately to the District Office. If that occurs the report will be opened by the District and an assessment process will take place and be documented in the narrative log of the report. The assessment requires that enough information be gathered to make the above three determinations.

Collaboration between Maine DHHS and DOE:

The Keeping Children Safe Act of 2003 amending the Child Abuse Prevention and Treatment Act (PL 108-36), (CAPTA) was signed into law on June 25, 2003. This law requires that the Maine Department of Health and Human Services refer to the regional offices of Child Development Services (CDS) within two days a child under the age of 3 who is involved in a substantiated case of child abuse or neglect or who is identified as affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure. Maine Unified Special Education Regulation Birth to Age Twenty requires that the regional CDS site implement Maine's Part C as a component of IDEA (Individuals with Disabilities Education Act). Agencies providing Part C services are required to provide comprehensive, coordinated, multidisciplinary, early intervention for infants and toddlers with disabilities or developmental delays and their families.

This means that all children exposed to narcotics in utero are considered at risk for developmental delay and must be referred to Child Welfare Services and then to CDS for developmental screening. The current regulations do not require that Child Development Services keep a separate accounting of the children reported due to substance exposure from the children referred because of substantiation of abuse. In 2008, 686 children under age 3 were referred to CDS through the CAPTA system and 343 (50%) would likely have been referred due to intrauterine substance exposure. Of the 686 referred, only 322 (47%) were evaluated as the parents were required to consent to the developmental screening. Of the 322 screened, 69 (21%) of these children needed an Individualized Family Service Plan and developmental services. Theinability to gain consent from the parents for the recommended assessment may mean that

we are missing many children in need of developmental services. These missed opportunities for early intervention may add to the number of children that are not ready for school at age 5.

Office of Substance Abuse (OSA):

The 2007 Office of Substance Abuse Annual Report stated that heroin accounted for a slightly higher proportion of treatment admissions than cocaine. Informants suggested that individuals addicted to opiate pharmaceuticals will use heroin if they cannot get access to their drug of choice, but they prefer to use pharmaceuticals instead of heroin because they have more confidence in the level of purity of the drug. The report showed that addiction to opiates continued to rise, particularly among young adults and that OxyContin was the primary drug of abuse. Hospital admissions data from 2005 suggested that admissions related to opioid abuse or dependence were substantially higher than admissions for other types of abuse or dependence. Despite the existence of a statewide Prescription Monitoring Program that tracks all Schedule II, III, and IV prescriptions filled within the state, diversion of opioids and other prescription medication continued to be a problem. Abuse of methadone appeared to be decreasing while abuse of buprenorphine appeared to be an emerging problem, most likely because the supply of buprenorphine increased so quickly in Maine. In the period January 1 – June 30, 2005, there were 240 prescriptions for Subutex and 7,098 prescriptions for Suboxone filled in Maine. During June 1 – December 31, 2006, these numbers rose to 671 and 14,403 respectively.^{xi}

OSA is one of two single state agencies to receive both a Strengthening Treatment Access and Retention (STAR-SI) and Advancing Recovery (AR) grant in the fall of 2006. The STAR-SI program funded by SAMHSA's Center for Substance Abuse Treatment (CSAT) and the Robert Wood Johnson Foundation, is an infrastructure program focused on improving access to and retention in treatment. AR is a collaborative program between the Network for the Improvement of Addiction Treatment (NIATx), the Treatment Research Institute (TRI), and the Robert Wood Johnson Foundation (RWJF). Advancing Recovery promotes the use of evidence-based practices for addiction treatment. OSA has used these grant initiatives to improve access and retention in treatment statewide for individuals with addictive disorders and co-occurring conditions.^{xii}

Community Services, Grant Programs and University Activities:

> <u>The Acadia Hospital Narcotic Treatment Program (Bangor, Maine)</u>

The Acadia Hospital has offered methadone, and buprenorphine therapy for the last 9 years and they have reported a dramatic increase in the number of 18 to 25 year olds addicted to opiates. Their program offers a well child clinic on the site and they provide parenting classes and prenatal care to expectant parents enrolled in the treatment program. They developed a toddler playgroup one hour a week and offer CDS screening and services, public health nurse, CPR training and time with a pediatrician that can answer parents questions and they meet regularly with the Eastern Maine Medical Center NICU staff and breastfeeding consultants. Acadia has treated more than 400 pregnant women in replacement therapy since 2001 and routinely has 20-30 pregnant woman enrolled in treatment at any one time. Also, Acadia was funded this year by the Sadie and Harry Davis Foundation to educate and coach parents of 0-1 year olds in infant massage therapy to enhance attachment and reduce NAS symptoms in newborns.

The University of Maine in Orono and Maine Institute for Human Genetics & Health In collaboration with Mark Brown, MD, Chief of Pediatrics at Eastern Maine Medical Center and the Acadia Hospital Narcotic Treatment Program (NTP), Marie Hayes, PhD, professor of psychology and biomedical sciences, is funded by NIH to study Maine infants with neonatal abstinence and risk of Sudden Infant Death Syndrome. This longitudinal program evaluates neonatal neurocognitive status using EEG at birth and 7 months; neurobehavioral status at birth, and standard assessments such as the Bayley Scales of Infant Development during the first year. The interdisciplinary program currently has 80 high risk infants and mothers. The goal is to develop neonatal and early infancy markers for neurodevelopmental compromise including SIDS risk.

MaineGeneral Medical Center

MaineGeneral Medical Center has a Maternal Child Health "Warm Line" for Augusta and Waterville, a call in number for information about and referral to community services and the Neonatal Narcotic Abstinence Syndrome information for caregiver's pamphlet. They also provide substance abuse services in Kennebec County through their Prevention Center.

Project LAUNCH

The Community Caring Collaborative of Washington County in partnership with the Maine CDC has a multi year grant to improve care for the Washington County population experiencing health disparities, including prenatal, maternal and infant care for those in drug treatment programs. In partnership with Eastern Maine Medical Center (EMMC), they have developed a bridging program where pregnant women in drug treatment travel to EMMC to tour the NICU and meet the nurses and physicians that will provide their and their infants care. The bridging program works with the family to provide supports and services through a family informed wraparound team to increase access to services and to help parents with high need babies. The program is also available for high risk babies who are in the NICU or are affected by other risk factors. Additionally the program offers ongoing services through integrated Infant Family Support Specialists at local health centers and treatment centers when the babies return home to Washington County.

Perinatal Nurse Managers of Maine

Through a grant provided by the Maine CDC, the Perinatal Nurse Managers of Maine hold a quarterly meeting to discuss challenges they face delivering quality care to mothers and newborns and to learn of activities in the State to improve maternal and infant outcomes. Recent presentations include a clarification of the drug affected infant reporting law.

> The Neonatal ICU at Maine Medical Center Follow-Up Program

Dr. Brenda Medlin directs the care of the special group of infants that had withdrawal symptoms while in the NICU. Dr. Medlin provides a link to their ongoing care in the community and uses the Maine CDC Public Health Nurses and/or their contract providers to deliver in-home follow-up care. Dr. Medlin reports that she provided care and PHN referrals for over 100 infants in the Maine Medical Center catchment area in 2009. She also reports that there are 5 narcotic treatment programs in Portland alone and many additional primary care providers available to provide replacement therapy with Subutex.

Summary:

Mothers using illicit narcotics during pregnancy are more likely to deliver their infants prematurely with low birth weight. Children exposed to narcotics in utero are at risk for withdrawal in the newborn period with symptoms of persistent irritable crying, diarrhea, dehydration, malnutrition and seizures. The cost of caring for these children is very high. They can be harder to care for in the first 6 months of life because of feeding difficulties and irritable temperament, and as they grow older, they are more likely to experience delays in development. In Maine, 21% of these children require developmental services before age 3 and studies show that they have a greater likelihood of having behavior problems at age 7.^{xiii} This is a serious problem for the children of Maine and the number of children affected is increasing annually.

Addiction experts suggest that alcohol and drug disorders should be treated as chronic medical conditions and this approach to care may improve cost-effectiveness. In Oregon, the elimination of Medicaid coverage for outpatient mental health and substance abuse treatment benefits, including methadone treatment, led to a decrease in compliance with drug treatment programs and an increase in illicit drug use as well as legal, medical, psychiatric and employment problems.^{xiv} When mothers are compliant with their methadone treatment program, their children are much less likely to experience abuse or neglect than children of mothers that continue to use illegal substances.^{xv}

We have described a number of programs that the State of Maine has in place to attempt to improve outcomes for these babies and their parents. In utero substance exposure is a growing problem, but there are a number of steps that could be taken to improve outcomes for these children.

First, DHHS will actively track the number of children affected, the services they receive and their developmental outcomes.

- a) DHHS/OCFS is developing a memorandum of understanding with DOE to ensure these children receive needed services and are fully accounted for.
- b) The Pregnancy Risk Assessment Monitoring System (PRAMS) is a state-wide representative survey of new mothers conducted on an ongoing basis in Maine by Maine CDC/DHHS since 1987 on maternal experiences and attitudes before, during, and shortly after pregnancy. This survey currently includes a set of questions about alcohol and tobacco use during pregnancy; as funds become available, questions about narcotics and other substances of abuse will be added to the set.

Second, the legislation relating to reporting of drug affected babies should be clarified. Hospital systems and their legal counsel around Maine are not consistent in their interpretation of the rules and this has resulted in variation in reporting and variation in service. Medical professionals caring for these children report that not all children exposed to drugs in utero have symptoms; a child can be drug exposed without being drug affected. Some legal counsels for hospitals interpret this to mean that only drug affected infants need to be reported and referred for services. Children exposed to substances in utero but who are not symptomatic at birth may still benefit from referral to Child Development Services (CDS), but they may not need follow-up by Public Health Nursing.

Third, we could task the Maternal Infant Mortality Review Panel (MIMR) to develop expertise in the systems of care being developed nationally to address this issue. The US Department of Health and Human Services is sponsoring a conference in Old Town Alexandria, Virginia June 23 and 24 in 2010 titled: Substance Exposed Newborns, collaborative approaches to a complex issue. Funds should be sought to send representatives from MIMR to this conference.

Fourth, the Maine DHHS and its Offices could partner with private, not for profit organizations to access federal and private grant funds to help develop a statewide systematic approach to caring for these infants and supporting their families. Many private agencies would be willing to apply for federal grant funds but they may have limited experience in doing so.

Example: The Spurwink Program in Portland recently identified an opportunity to develop a proposal to implement and rigorously evaluate approaches to prevent child maltreatment and to promote family strengths and optimal development among infants and young children (birth-5) who are at high-risk for abuse, neglect, and abandonment, including those impacted by substance abuse and/or HIV/AIDS, and for whom there is no substantiated Child Protective Services report. The granting organization planned to fund a maximum award of \$1,240,000 for a grant period of March 1, 2010 - June 30, 2013. Unfortunately, the time for submission has already passed.

Fifth, discretionary grants from the March of Dimes and programs like Maine Health Access Foundation, the American Academy of Pediatrics and The Bingham Program may be available to fund programs like Project LAUNCH's bridging program described above to help families trust the caregivers enough to allow their child to complete the developmental screening and when necessary, intervention.

Finally, given that the number of narcotic drug affected babies is ever growing, we should consider this population as a priority when reviewing grant opportunities for obtaining funds as well as a priority for directing state funds via RFP's. The Health and Human Services Committee should encourage and support cross department initiatives.

^x IV. C-2. Response to Infants Affected by Illegal Substance Abuse Effective 7/13/04.

http://saprp.org/knowledgeassets/knowledge_detail.cfm?KAID=1. Downloaded by SMeister on December 1, 2009.

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^v Lester, B. Infant Neurobehavioral Dysregulation: Behavior problems in Children with Prenatal Substance Exposure. Pediatrics. 2009; 124:1354-1361.

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^{vii} Black, R; Mayer, J. Parents with special problems; alcoholism and opiate addiction. Child Abuse Negl. 1980;4(1):45-54

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http://www.maine.gov/dhhs/ocfs/cw/policy/index.html?iv_c_2_response_to_infants_a.htm Accessed 12/31/2009 ^{xi} Substance Abuse Trends in Maine: July through December 2006. August 2007

http://www.maine.gov/dhhs/osa/data/pubrpts.htm Accessed 12/28/2009.

^{xii} MAINE GENERAL POPULATION DRUG AND ALCOHOL SURVEY: <u>www.maine.gov/dhhs/osa/data/pubrpts.htm</u>. The Maine Office of Substance Abuse's [OSA/DHHS] statewide quantitative research study on drug and alcohol use and abuse issues. Accessed 12/28/2009.

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^{xiv} Mccarty, D. Substance Abuse Treatment Benefits and Costs Knowledge Asset, Web site created by the Robert Wood Johnson Foundation's Substance Abuse Policy Research Program; September 2008.

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