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THE EDUCATIONAL NEEDS OF CHILDREN AGES 0-5 BORN WITH NEONATAL
ABSTINENCE SYNDROME IN MAINE

by

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A Thesis Submitted in Partial Fulfillment
of the Requirements for a Degree with Honors
(Political Science)

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ABSTRACT

The goal of this study is to better understand the educational needs of children born with neonatal abstinence syndrome (NAS) in Maine. This study will consider two questions. First, what is currently being done to help children born with NAS in Maine? To answer this question, I looked into previous studies that evaluate the needs of children born with prenatal drug exposure. I also looked into Maine's Strategic Action Opioid Plan to determine what initiatives the state is taking towards helping these children. Second, what should Maine be doing to help the children born with NAS? To answer this question, I interviewed thirteen professionals that have knowledge in the subject area. I evaluated the interviews using content analysis to find trends amongst the interview data. Based on this analysis, I found the primary educational challenges of children born with NAS are cognitive or developmental delays, speech and language delays, dysregulation and impulsivity, social-emotional issues, and behavioral issues. Other challenges include attachment concerns and issues with the environment a child is in. From there, I found that children face barriers to receiving educational services such as difficulty with identification and referrals as well as a lack of providers. Because it is important for a child to have a supportive environment, it is important for parents with substance use disorder to have access to treatment, but stigma, limited support, and limited resources are barriers adults face when attempting to receive treatment. Services and treatment for both children and adults lack funding as well. In conclusion, this study found that more education, awareness, research, and funding are needed going forward in order to support the educational needs of children born with NAS in Maine.

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Though challenging and stressful, completing my Honors Thesis is the most rewarding accomplishment of my academic career. I want to thank the Honors College at the University of Maine for providing me with the opportunity to complete and write about my own research. This has truly been a learning experience that has well prepared me for my future academic endeavors.

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CHAPTER 1: INTRODUCTION

Bethany, a 34-year-old mother of four, told her tale of recovery to one of the employees at The Women’s Project, a service in seven of Maine’s counties for individual recovery planning for pregnant women or women parenting young children who are impacted by substance use.¹ She grew up in Maine, experiencing physical, emotional, and sexual abuse from a very young age. Though she tried to leave Maine by going to school in Florida, she ended up back in Maine and became pregnant. She transferred to online courses, had her child, and completed her degree while living in shelters, but she stayed away from drugs. She met her first husband and had her second child, but when her marriage fell apart, he kept her kids from her. Now alone, she began driving taxis, sliding into a depression. She began drinking heavily and when she sought treatment, she was rejected because she didn’t fit the criteria. She began using painkillers, eventually switching to heroin. She even started driving for crack dealers to earn extra money, eventually accepting crack as payment so she could sell it. She was living with an emotionally abusive boyfriend when she unexpectedly became pregnant. She sought help once again, fearing that completely stopping her heroin use would cause more damage to her and the baby. The emotional abuse got worse to the point where her boyfriend would lock her out on the street during the night, forcing her to her old habits, usually leading to her using crack. However, she continued to go to the clinic because she desperately wanted to be sober. This child was born with mild withdrawal symptoms, and she and her boyfriend began to raise it together. She had a second child with her boyfriend, and again

¹ Opportunity Alliance, “Adult Mental Health Services.”

the child was born with mild withdrawal symptoms due to crack use during pregnancy. Finally, she left her boyfriend and moved into a hotel room with her four kids. She worked for the owners in order to pay for the room. “She was determined to give her children a better life.”² One of her children was diagnosed with cancer, but she stayed sober while also caring for a school aged child, a toddler, and a baby.

Bethany, a name given to protect the identity of this woman, suffered from the lowest of lows. Time after time, she ended up in a situation where she turned to drugs to help her through while always hoping for a better life. Her kids were the motivation for her sobriety. She still works for the motel owners, but she now has her own apartment and her own car. Though there have been hard times in the past four years, she has remained sober. She ends her story with this advice: “It gets hard, but it goes up. No matter how bad it is, your kids are worth it. It’ll always get better.”³

Bethany’s story is inspiring, but it leaves us wondering about her last two children who were both born with mild withdrawal symptoms due to drug use during her pregnancies. Though the entire community is impacted by opioid use, a population that is quite vulnerable to its effects are children, specifically children who are born drug affected. Children who are born drug affected are diagnosed with neonatal abstinence syndrome (NAS), which is defined as “a postnatal drug withdrawal syndrome that can occur after intrauterine opioid exposure.”⁴ Although many drugs can lead to NAS, such as benzodiazepines, barbiturates, and alcohol, the most common cause today of NAS is

² Opportunity Alliance Community News & Notes. “Maine’s Opioid Crisis.”

³ Ibid.

⁴ Fill, et al. “Educational Disabilities Among Children Born With Neonatal Abstinence Syndrome.”

opioid use.⁵ NAS is a treatable condition, but it typically requires intensive care after birth.

The number of infants born with NAS is growing nationwide. In 2004, there averaged 1.5 drug affected births out of 1000 hospital births in the US. That number increased to 8 births out of every 1000 by 2014. In other words, as of 2014, there is a child born drug affected in the United States every 15 minutes.⁶ Maine's average of children born with NAS is much higher than the national average. To compare, the national rate of children born with NAS in 2015 was 6.4 cases out of every 1000 hospital births. In the same year, Maine experienced 34.7 cases for every 1000 hospital births, over five times higher than the national rate.⁷ As of March of 2019, 1 in 12 babies in Maine were born drug affected.⁸ The average of drug affected infants in Maine between 2013 and 2017 was 975 each year, which further averages to about three per day. That number peaked at a high of 1,024 in 2016.⁹ The number of children in the state's custody increased from 928 to 1,322 between July 1, 2018 to June 30, 2019, an overall increase of 42%. Additionally, Maine saw the largest number of infants in state custody in 2018 it had seen in the past five years.¹⁰

While we know that the number of children born with NAS has increased tremendously over the past decade, we do not know the “long-term effects these

⁵ National Association of State Alcohol and Drug Abuse Directors, Inc. “Neonatal Abstinence Syndrome.”

⁶ National Institute on Drug Abuse. “Maine Opioid Summary.”

⁷ Pendharkar, Eesha. “What We Know and Don't Know about How Maine's Opioid Crisis Has Affected Kids.”

⁸ Wgme. “Report: One in 12 Maine Children Born Exposed to Drugs.”

⁹ Pendharkar, Eesha. “What We Know and Don't Know about How Maine's Opioid Crisis Has Affected Kids.”

¹⁰ Walsh, Barbara. “10,500 Maine Children Impacted by Opioid Epidemic.”

newborns endure, such as developmental, behavioral, and emotional problems.”¹¹ A study in Tennessee found that children born with NAS are more likely to face educational challenges by linking health and education data. The study concluded children with NAS are “more likely to be referred for evaluation of an educational disability, to meet criteria for an educational disability, and to receive special education therapies or services.”¹² We can assume that because Maine has had increased numbers of children born drug affected since the beginning of the opioid crisis, more and more children will need to access special education services in Maine. This thesis will investigate what Maine has already done or plans to do to address the educational needs of children born with NAS through literature review and will explore what Maine should be doing by interviewing experts that directly have a stake in the educational needs of children born with NAS.

¹¹ Walsh, Barbara. “More Maine Babies Are Born Exposed to Opioids as Hospitals Struggle to Treat Them.”

¹²Fill, et al. “Educational Disabilities Among Children Born With Neonatal Abstinence Syndrome.”(4)

CHAPTER 2: LITERATURE REVIEW

Introduction

It is easy to think that a child's education starts when they enter kindergarten around the age of five. However, the first few years of life contain countless opportunities for learning and growth. Research recognizes the first five years of a child's life important for brain development, the first three years being especially important for the brain's architecture.¹³ The early years are when children learn the fastest in their lifetime, so "they need love and nurturing to develop a sense of trust and security that turns into confidence as they grow."¹⁴ Simply put, the first five years are "the foundation that shapes children's future health, happiness, growth, development and learning achievement at school, in the family and community."¹⁵

Opioid use by parents can heavily impact the first years of a child's life, particularly if a mother uses opioids during her pregnancy. In utero drug exposure can lead to neonatal abstinence syndrome, or NAS, which is opioid withdrawal.¹⁶ Additionally, continued drug use by one or both parents influences the early experiences of a child, which "have a direct impact on how children develop learning skills as well as social and emotional abilities."¹⁷ Children need "affection, attention, (and) encouragement," all of which can be interrupted by the implications of parental drug use.

¹³ "Child Development and Early Learning." Facts for Life - Child Development and Early Learning.

¹⁴ Ibid.

¹⁵ Ibid.

¹⁶ Opportunity Alliance Community News & Notes. "Maine's Opioid Crisis." Spring/Summer 2018.

¹⁷ "Child Development and Early Learning." Facts for Life - Child Development and Early Learning

Because opioid use has increased in Maine, it is important that we look into the implications for children directly impacted. This literature review will explore the research that has been done on neonatal abstinence syndrome, the educational implications of drug exposure in utero for young children, and the impact of a child's environment on their educational success. It will also evaluate Maine's opioid crisis, the amount of children born with NAS in Maine over the past decade, and Maine's Opioid Response Strategic Action Plan.

Opioid Use in Maine

Prescription opioids such as oxycodone, hydrocodone, morphine, and methadone are prescribed by doctors to alleviate severe pain.¹⁸ Fentanyl, another pain relieving opioid, is several times stronger than the opioids previously mentioned and is only used to treat very severe pain, such as pain caused by cancer.¹⁹ Heroin is an example of an illegal opioid that is commonly used in the US. Additionally, nearly all heroin users use at least one other drug in addition to heroin.²⁰ All opioids cause physical and psychological dependence after prolonged use.²¹ In addition to pain relief, opioids have acute effects from use, including sedation, euphoria, and respiratory depression.²²

¹⁸ Centers for Disease Control and Prevention. "Opioid Basics."

¹⁹ Ibid.

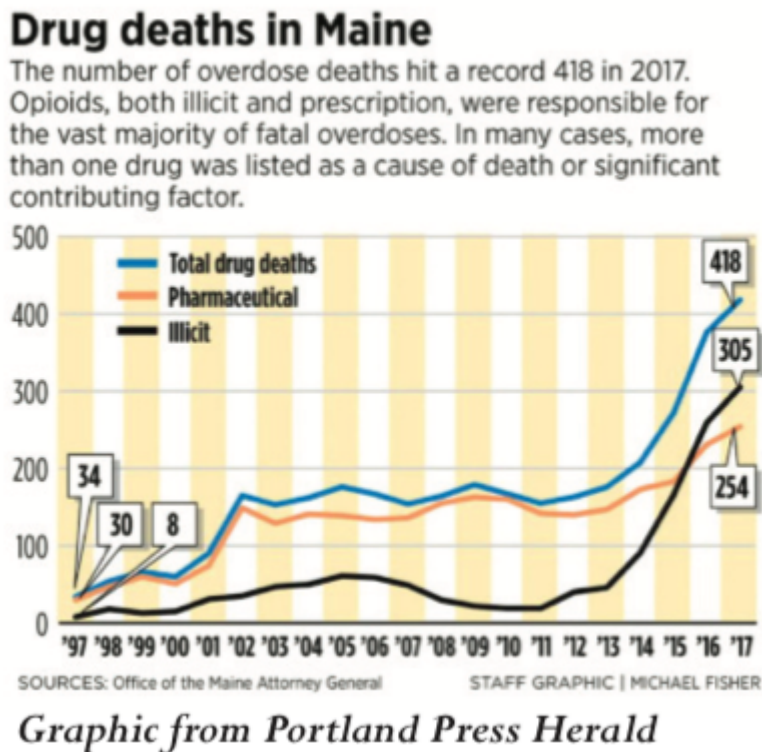
²⁰ Ibid.

²¹ American Academy of Pediatrics, "Neonatal Drug Withdrawal."

²² Ibid.

In Maine, almost 75% of opioid addictions start by using prescription painkillers.²³ Out of the 418 drug-related deaths in 2017, 354 of them, 84.6%, were due to opioids.

Figure 2.1: Drug deaths in Maine in 2017



Further, about 2/3 of deaths in the first quarter of 2018 were due to fentanyl. Although there are 2.5 male overdose deaths for every one female overdose, women are more likely “to be prescribed prescription pain relievers, to be given higher doses, and to use them for longer periods of time.”²⁴ According to the CDC, 28% of women ages 15 to 44 on private insurance and 39% of women ages 15 to 44 on Medicaid “filled a prescription written by

²³ Opportunity Alliance Community News & Notes. “Maine’s Opioid Crisis.” Spring/Summer 2018.

²⁴ Opportunity Alliance Community News & Notes. “Maine’s Opioid Crisis.” Spring/Summer 2018.

a healthcare provider for opioid medication.”²⁵ When women of childbearing age become pregnant while using opioids, the infant is at risk of going through withdrawal, or NAS.

Drug Use and Pregnant Women

When a mother uses drugs while pregnant, the drug is transferred to the fetus through the placenta. The fetus can then become dependent on the substance the mother is using during her pregnancy. During birth, the transplacental passage is interrupted, which causes the newly born infant to develop withdrawal symptoms, leading to NAS. While many types of drugs can cause NAS, opiates tend to cause “a longer and more threatening withdrawal.”²⁶ Opioid withdrawal in an infant can result in a variety of symptoms: hyperirritability; GI dysfunctions such as excessive sucking, poor feeding, regurgitation, and diarrhea; tremors; high-pitched cry; increased muscle tone; seizures; nasal congestion; hyperthermia; tachypnea (abnormally rapid and sometimes shallow breathing).²⁷ The presentation of NAS varies due to the following: “the opioid, the maternal drug history (including timing of the most recent use before delivery), maternal metabolism, net transfer of drug across the placenta, placental metabolism, infant metabolism and excretion, and other factors.”²⁸ Most symptoms occur within 72 hours after birth, but symptoms can also occur right away or a few weeks after. For example, heroin withdrawal in an infant usually begins within 24 hours of birth and methadone

²⁵ Opportunity Alliance Community News & Notes. “Maine’s Opioid Crisis.” Spring/Summer 2018.

²⁶ MacMullen, Nancy J., Laura A. Dulski, and Paul Blobaum. “Evidence-Based Interventions For Neonatal Abstinence Syndrome.”

²⁷ Ibid.

²⁸ American Academy of Pediatrics, “Neonatal Drug Withdrawal.”

withdrawal in an infant usually begins between 24 hours and 72 hours of age. However, for both opioids, withdrawal can appear 5 to 7 days after birth, which is typically after hospital discharge.²⁹ Symptoms can last from 1 week to 6 months.³⁰

The infant may be given medication to treat or manage the symptoms. Once these symptoms are managed, the dose of medication gets smaller over time to wean the infant off of the medication. The three medicines used to treat withdrawal are morphine, methadone, and buprenorphine. During treatment, babies typically receive fluids to keep them hydrated because dehydration is a side effect of diarrhea and throwing up excessively, two symptoms of withdrawal. They are also fed higher-calorie formula because slow growth and trouble feeding are symptoms of withdrawal.³¹ Infants with NAS are typically fussy. Helpful strategies for the mother include rooming with her baby in the hospital, skin-to-skin contact, gentle rocking and swaddling, keeping the baby's room quiet and dim, breastfeeding on the baby's demand, and using a pacifier.³² After the baby is treated and has gone home, it is important to follow up with doctor's appointments so a pediatrician can check for issues associated with NAS, including problems with nutrition and growth, problems with health and vision, problems with drug use in the home, and, most pertinent to this study, developmental delays and problems with motor and learning skills and behavior.³³

²⁹ American Academy of Pediatrics, "Neonatal Drug Withdrawal."

³⁰ March of Dimes, "Neonatal Abstinence Syndrome (NAS)."

³¹ Ibid.

³² Ibid.

³³ Ibid.

Neonatal Abstinence Syndrome Risk Factors

Several factors impact whether the drug exposure a child experiences prenatally will result in withdrawal symptoms, causing neonatal abstinence syndrome. One particular study looked at how “duration and timing of prescription opioid use during pregnancy” impact the risk of NAS, along with four main additional risk factors.³⁴ These four risk factors include “documented history of opioid misuse or dependence,” “documented history of alcohol misuse or non-opioid drug misuse,” “use of prescription psychotropic medications in the third trimester,” and “tobacco use.”³⁵ Five mutually exclusive study groups were created based off the four additional risk factors: women who “had a documented history of opioid misuse or dependence,” “had a history of alcohol or non-opioid drug misuse or dependence,” “had at least one prescription for a non-opioid psychotropic medication during the 3 months prior to the delivery,” “had a history of smoking,” and “had none of the four hypothesized risk factors for NAS.”³⁶ These groups are listed from the group hypothesized for the greatest risk of NAS to the smallest risk of NAS. Further, the study identified prescription opioid exposure during pregnancy based on the duration of the opioid use, the timing of the opioid use during pregnancy, and the cumulative total of opioids used during the pregnancy.

This 2015 study found that the risk of NAS was “greater among long term users of prescription opioids compared with short term users overall and in each of the five

³⁴ Desai, et al. “Exposure to Prescription Opioid Analgesics in Utero and Risk of Neonatal Abstinence Syndrome: Population Based Cohort Study.”

³⁵ Ibid.

³⁶ Ibid.

study groups.”³⁷ As predicted, the group with the lowest risk of NAS was the group that had no risk factors and the group with the highest risk of NAS was the group with documented history of opioid misuse. Additionally, the study found that late use of opioids, which is opioid use through the third trimester, resulted in a “significantly higher risk” of NAS than early use, which is opioid use only in the first two trimesters.³⁸ Lastly, the study found that there is an increased risk of NAS with higher opioid doses, however the risk plateaued at “higher cumulative doses.”³⁹ In conclusion, this particular study found that there is a higher risk for NAS for women who have a history of opioid misuse, for women who use later in their pregnancy, and for women who use higher doses during their pregnancy. Though the study evaluates what contributes to higher risk of NAS, it also mentions that the use of prescription opioids with no additional risk factors leads to a low risk of NAS.⁴⁰

How Environment Impacts Learning Outcomes

A major factor playing into the educational needs of a child born with NAS is the environment in which the child grows up. Children born with NAS can experience one of four environments - they may stay with their biological parents, they may stay with other family members such as grandparents, they may stay in one or multiple foster homes, or they may be adopted. There are several postnatal risk factors that can occur due to a

³⁷ Ibid.

³⁸ Desai, et al. “Exposure to Prescription Opioid Analgesics in Utero and Risk of Neonatal Abstinence Syndrome: Population Based Cohort Study.”

³⁹ Ibid.

⁴⁰ Ibid.

child's environment. These risk factors include "continued parental substance abuse, poor prenatal care, adverse perinatal events, community violence, crime, child abuse and neglect, and poverty."⁴¹ One of the biggest postnatal risk factors if a child remains with their parents is continued parental drug use by one or both parents because drug use impacts parental behavior in terms of consistency and predictability. Additionally, heavy drug use is associated with increased child neglect and abuse, ranging from poor postnatal nutrition, medical care, and learning environment, to accidental drug ingestion of the child.⁴² If a child is placed with a foster family, they can often experience several placements. Oftentimes foster parents are overwhelmed by the needs of children born with NAS.⁴³ Lastly, a child may be adopted. Typically when a child is adopted, they are in a stable environment with little to no postnatal risk factors present.⁴⁴

A study conducted in 1986 by the National Association for Perinatal Addiction Research and Education followed the developmental progress of over 300 children, either cocaine-exposed or polydrug-exposed. Aside from prenatal drug exposure, this population represents the "best case scenario" for children, meaning that all postnatal risk factors are not present.⁴⁵ Additionally, the mothers of the exposed children had good prenatal care, the children had good postnatal care, and they were in "a stable caretaking environment."⁴⁶ This helped researchers attempt to isolate the impacts from the prenatal drug exposure. This study used the Bayley Scale of Infant Development to assess both

⁴¹ Sinclair, Esther. "Head Start Children at Risk: Relationship of Prenatal Drug Exposure to Identification of Special Needs and Subsequent Special Education Kindergarten Placement."

⁴² Griffith, Dan R. "Prenatal Exposure to Cocaine and Other Drugs: Developmental and Educational Prognoses."

⁴³ Ibid.

⁴⁴ Ibid.

⁴⁵ Ibid.

⁴⁶ Ibid.

drug-exposed and non-exposed children at 3, 6, 12, 18, and 24 months. The Bayley Scale is a widely used tool that is designed to test cognitive, language, motor, adaptive, and social emotional development in infants and toddlers between one month and 42 months old.⁴⁷ The study compares the results of the drug-exposed children to non-exposed children. It finds that there was little difference in the scores between the two groups by the time both groups reached the age of three, suggesting that a supportive environment can result in typical development despite a child being born with NAS.

A study published in 1992 that focuses on cocaine use during pregnancy highlights how the parent-child relationship can be impacted by parental drug use. For example, substance abuse “undermines the normal patterns of interactions between parent and child.”⁴⁸ Additionally, “these infants do not experience the normal processes of mother-child attachment,” which are incredibly important to an infant’s development. Though this study offers insight into the importance the environment has on a child, it contains bias towards the topic of addiction, stating that the primary concern for parents who are addicted to drugs is the drug they use, not their children.

In 1993 Princeton University published a study that compared the educational needs of adopted children with prenatal drug exposure to the educational needs of adopted children without prenatal drug exposure. The study found no differences between “children’s behavior, temperament, health, or school adjustment” and parent satisfaction was high for both groups. Parents who adopted drug-exposed children reported it was much more difficult to raise them than experts had expected and “potential adoptive

⁴⁷ Bayley Scales of Infant Development - “Bayley Scales of Infant Development, an overview.”

⁴⁸ Bauer, Anne M. “Drug and Alcohol Exposed Children: Implications for Special Education for Students Identified as Behaviorally Disordered.”

parents are fearful of the long-term effects of drug exposure.” Again, this study advocates looking into the relationship between a child and their environment to understand a child’s development. Many drug-exposed children did not require special education services once they were adopted, indicating that these children can be successful in school without formal services if a stable environment is in place. That being said, it is difficult to research prenatal drug exposure: “... this study cannot answer fundamental questions about what would happen to drug-exposed children given the enriched environments typical of foster homes.”⁴⁹

Studies about Educational Outcomes, Diagnoses, and Placements

In 1990, experts suggested there would be a significant increase in “the number of children who challenge the educational and social services systems with their variations in learning styles, behaviors, and program needs” due to in utero exposure to drugs.⁵⁰ Neurological impairments at birth can range from neurobehavioral abnormalities to chemical dependence. The study looks specifically at children born exposed to cocaine. The study states low birth weight as the most common effect from cocaine exposure. Further, low birth weight is related to “cognitive, motor, and perceptual performances.”⁵¹

A 1998 study conducted in California looked at the relationship between “prenatal drug exposure, emotional and behavioral disorder identification in Head Start, and

⁴⁹ Barth, Richard P. “Adoption of Drug-Exposed Children.”

⁵⁰ Bauer, Anne M. “Drug and Alcohol Exposed Children: Implications for Special Education for Students Identified as Behaviorally Disordered.”

⁵¹ Ibid.

subsequent special education kindergarten placement.”⁵² The study explains that there is “no typical profile of a drug-exposed child,” emphasizing the need for assessment and evaluation of each individual child to identify their strengths and challenges.⁵³ The study states that there are “profound implications of prenatal drug exposure for later educational needs.”⁵⁴ Between the varied drug exposure and postnatal risk factors, the “continuum of impairment can range from minimal to severe across all domains.”⁵⁵ However, “high-quality educational intervention services” significantly help “improve a child’s self-esteem, self-control, and developmental progress.”⁵⁶ It is important to note that prenatal drug exposure alone does not qualify as a disability. Rather, it contributes to the risk of other diagnoses, such as behavioral, social, and learning challenges. The study began with 900 children in Head Start. Out of those 900 children, 142 were identified as eligible for special education services. Out of those 142 children, 30 were identified as having prenatal drug exposure, which was determined by medical records of urine testing at birth.

⁵² Sinclair, Esther. “Head Start Children at Risk: Relationship of Prenatal Drug Exposure to Identification of Special Needs and Subsequent Special Education Kindergarten Placement.”

⁵³ Sinclair, Esther. “Head Start Children at Risk: Relationship of Prenatal Drug Exposure to Identification of Special Needs and Subsequent Special Education Kindergarten Placement.”

⁵⁴ Ibid.

⁵⁵ Ibid.

⁵⁶ Ibid.

Table 2.1: Results of Head Start Children at Risk study

	Drug-Exposed Children	Non Drug-Exposed Children
Emotional/Behavioral Disorders	47% (n=14)	35% (n=49)
Referred for “Special Education Kindergarten”	53% (n=16)	29% (n=32)
Had “associated medical/academic problems”	43% (n=18)	18% (n=20)
Had “speech and language deficits”	Over 50% (n=17)	35% (n=49)

The results of the study suggest prenatal drug exposure is a risk factor and it contributes to a higher frequency of emotional and behavioral disorders in preschool children.⁵⁷ Additionally, the study suggests that prenatal drug exposure correlates with special education placement in kindergarten, which is consistent with the increased risk of emotional and behavioral disorders. The study did not look into the drug exposure of the children that did not qualify for evaluation.

Costs - Healthcare, Foster Care, and Adoption

The National Institute on Drug Abuse reported that “hospital costs for babies with opiate withdrawals were \$66,700 on average, compared with \$3,500 for babies born healthy.”⁵⁸ Further, DHHS reported that of the “250 women who gave birth to a drug-

⁵⁷ Sinclair, Esther. “Head Start Children at Risk: Relationship of Prenatal Drug Exposure to Identification of Special Needs and Subsequent Special Education Kindergarten Placement.”

⁵⁸ Walsh, Barbara. “More Maine Babies Are Born Exposed to Opioids as Hospitals Struggle to Treat Them.”

affected baby between 2014 and 2016 also gave birth to another infant who suffered withdrawal symptoms during the same time period.”⁵⁹ It is important to note that according to healthcare workers, the cost of the birth of a child born with drug exposure could be “reduced dramatically” if these women had access to Medicaid.⁶⁰ The theory here is that women of childbearing age could seek treatment prior to becoming pregnant if they were able to access Medicaid. DHHS reported that two-third of children born drug affected children “were born to mothers with a high school education or less,” which also means these women are “less likely to be married and have private insurance.”⁶¹ Additionally, the Substance Abuse and Mental Health Administration estimates between 25,000 to 30,000 Mainers are unable to get treatment because they either do not have insurance or they cannot find a provider.⁶²

Not only are hospital costs expensive, the costs to both the Child Protective Services system and the foster-care system have increased. When parents have a substance use disorder, they are more likely to become involved with child protection.⁶³ The amount of children in foster care in Maine has increased as well. From 2012 to 2016, the number of children in foster care increased 45%, from 1,268 to 1,842.⁶⁴ In 2018, 52% of the children that went into the state’s custody “entered foster care at least in part because of parents’ drug use.”⁶⁵ Bettie Hoxie of Adoptive Foster Families for Maine

⁵⁹ Ibid.

⁶⁰ Ibid.

⁶¹ Ibid.

⁶² Walsh, Barbara. “More Maine Babies Are Born Exposed to Opioids as Hospitals Struggle to Treat Them.”

⁶³ Pendharkar, Eesha. “What We Know and Don't Know about How Maine's Opioid Crisis Has Affected Kids.”

⁶⁴ Walsh, Barbara. “More Maine Babies Are Born Exposed to Opioids as Hospitals Struggle to Treat Them.”

⁶⁵ Pendharkar, Eesha. “What We Know and Don't Know about How Maine's Opioid Crisis Has Affected Kids.”

explained how the families impacted by opioid use result in a strain on the system as “there are not enough homes to go around.”⁶⁶

The positive side here is that “adoption of drug-exposed children appears to save money.”⁶⁷ An Oregon study from 1986 reported that the cost of adoption was around \$39,000 per child, including “casework, foster care, medical expenses, and adoption and legal costs over a 4-year period.”⁶⁸ Comparatively, at that time in that location, \$39,000 was equivalent to about 18 months of residential treatment for a mother and child. Further, the adoption of children saved the foster care upwards of \$50,000 in long-term foster care alone.⁶⁹ The study concluded that “overall savings may exceed \$5,000 per year or nearly \$100,000 per child over the duration of their minority years.”⁷⁰ Though the numbers here reflect costs from 30 years ago and represent the west coast, the premise applies to the situation in Maine. Adoption eliminates foster care costs, medical expenses falling on the state, and the legal costs of the Child Protective System.

Maine Data on Children Born with NAS

The State Epidemiological Outcomes Workgroup (SEOW) published a short report that looked at the “drug affected babies” by county and public health districts from 2006 to 2014.⁷¹

⁶⁶ Walsh, Barbara. “More Maine Babies Are Born Exposed to Opioids as Hospitals Struggle to Treat Them.”

⁶⁷ Barth, Richard P. “Adoption of Drug-Exposed Children.”

⁶⁸ Ibid.

⁶⁹ Barth, Richard P. “Adoption of Drug-Exposed Children.”

⁷⁰ Ibid.

⁷¹ Office of Child and Family Services (OCFS), Maine Automated Child Welfare Information System (MACWIS). “Drug Affected Babies, by County and Public Health District (2006-2014),” SEOW (State Epidemiological Outcomes Workgroup) Short Report.

Figure 2.2: Average rate of drug affected babies per 10,000 residents, by county (OCFS/MACWIS, 2006-08 to 2012-14)

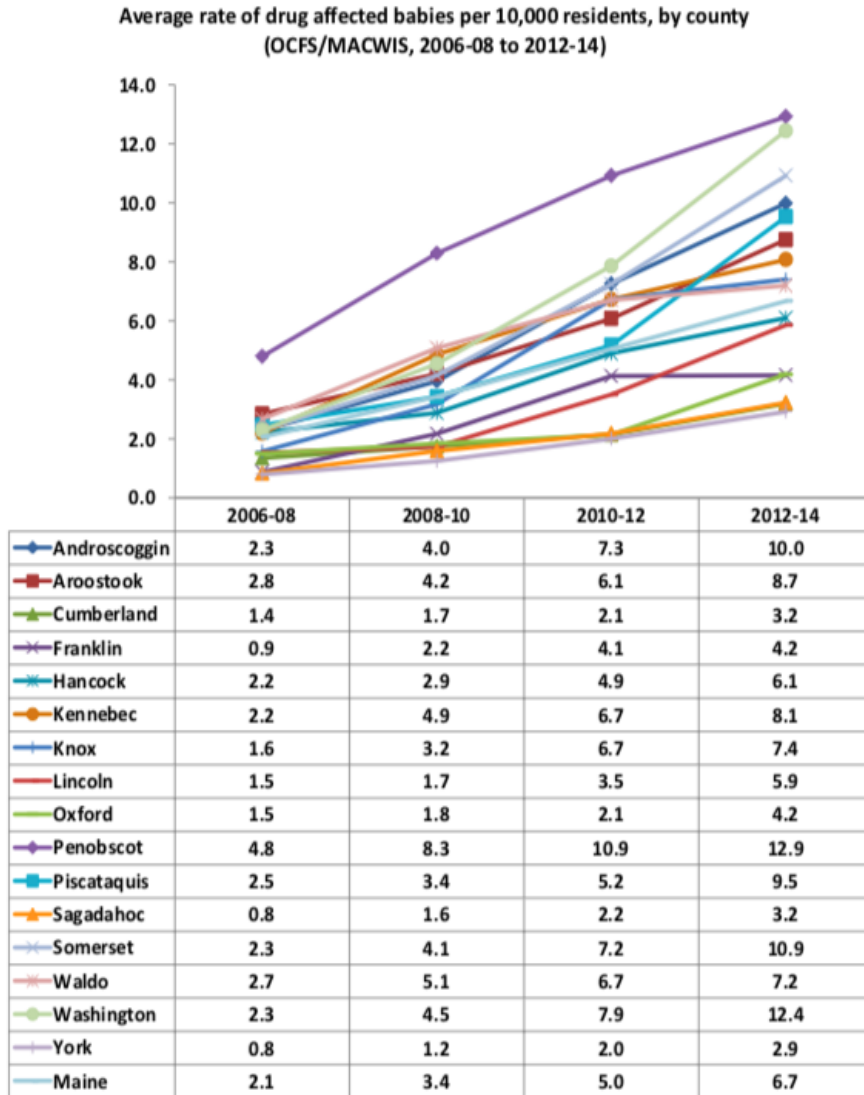
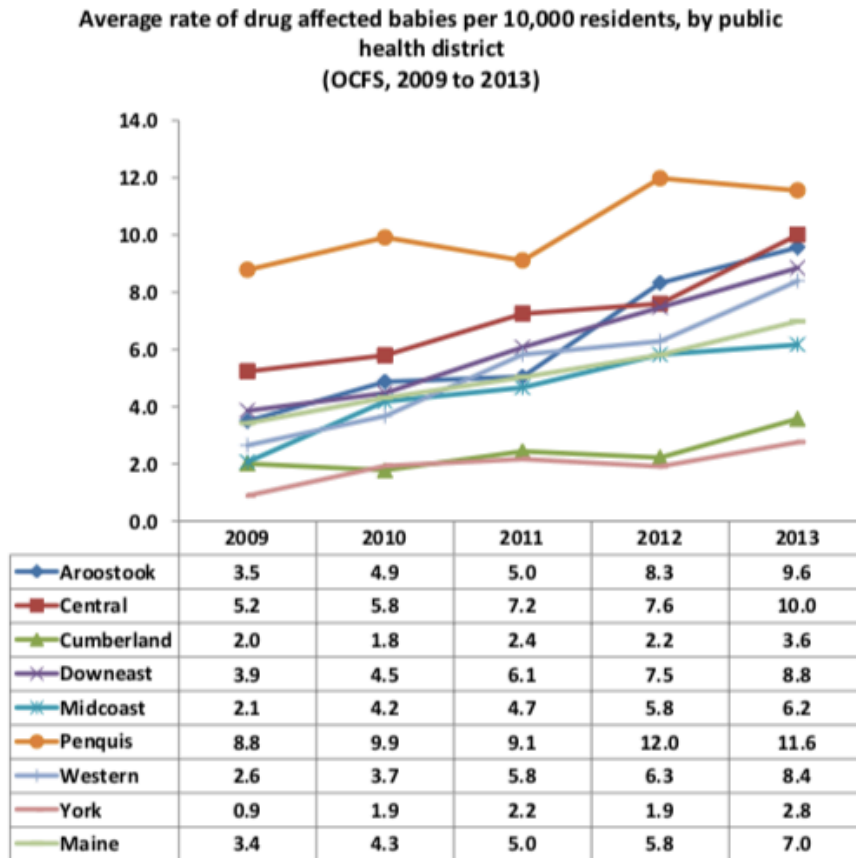


Figure 2.3: Average rate of drug affected babies per 10,000 residents, by public health district (OCFS, 2009 to 2013)



In 2006, Maine’s total of children born drug affected was 201. That number increased to 961 in 2014, a 378% increase over the eight-year span. SEOW used the state database MACWIS to calculate the average rate of children born drug affected per 10,000 residents, by county, from 2012 to 2014. The state average sat at 6.7 per 10,000 residents. Penobscot county had the highest average of 12.9 per 10,000 residents and York county had the lowest average with 2.9 births per 10,000 residents.⁷² Though York’s numbers

⁷² Office of Child and Family Services (OCFS), Maine Automated Child Welfare Information System (MACWIS). “Drug Affected Babies, by County and Public Health District (2006-2014),” SEOW (State Epidemiological Outcomes Workgroup) Short Report.

appear much lower than Penobscot's, it is worth mentioning that each county saw a dramatic increase in cases between 2006 and 2014, Penobscot increasing by 247% from 65 cases in 2006 to 226 cases in 2014 and York increasing by 645% from 11 cases in 2006 to 82 cases in 2014.⁷³ Though York county has the lowest average rate of children born drug affected, the two counties with the least amount of cases in 2014 are Franklin and Sagadahoc with 7 and 8 cases, respectively. Cumberland county follows Penobscot in the number of drug affected children in 2014 at 109; however, due to it being the most populous county in Maine, it ranks slightly higher than York with an average of 3.2 children per 10,000 residents.⁷⁴ Between 2006 and 2014, each county saw a significant increase in children born drug affected.

While 2006 to 2014 saw a significant increase in each county, the numbers between 2014 and 2019 showed smaller increases and even some decreases. In fact, half of Maine's counties (Cumberland, Hancock, Kennebec, Lincoln, Penobscot, Piscataquis, Washington, and York) saw a decrease between 2014 and 2019. The most notable decrease here is Penobscot county, going from 226 cases in 2014 to 124 cases in 2019. While some counties experienced a decrease in numbers, others faced increases. The most notable increases were seen in Androscoggin, Aroostook, Knox, and Oxford, where the percentage of drug affected children increased from below 10% of total births to above 10% of total births. Datacenter.kidscount has the number and percentage of drug affected babies per county in Maine from 2012 to 2019, overlapping with the SEOW report. The source reports that although it looks like there were some decreases between 2018 and 2019, Maine overall had 900 fewer births in 2019 than in 2018, so the

⁷³ Ibid.

⁷⁴ Ibid.

percentage of drug affected children born in Maine actually increased from 2018 to 2019, 7.3% to 7.5% of total births, respectively.⁷⁵ Maine peaked in 2016 when 8.1% of the total births in Maine were children born drug affected, a total of 1,024 children.⁷⁶ The percentage has remained below 8%; however, it did increase between 2018 and 2019.

Table 2.2: Babies born exposed/affected to substances in Maine from 2012 to 2019 by county

Location	Data Type	2012	2013	2014	2015	2016	2017	2018	2019
Androscoggin	Number	97	121	104	128	134	118	144	128
	Percent	7.4%	9.7%	8.4%	10.1%	10.8%	9.5%	11.7%	11.1%
Aroostook	Number	59	67	58	60	76	73	76	79
	Percent	8.7%	10.2%	8.8%	8.7%	11.6%	11.3%	12.1%	12.8%
Cumberland	Number	63	102	109	103	83	114	85	73
	Percent	2.3%	3.6%	3.8%	3.8%	2.9%	4.2%	3.1%	2.7%
Franklin	Number	15	16	7	16	10	11	11	15
	Percent	5.6%	6.0%	2.8%	6.3%	4.2%	4.6%	4.7%	7.1%
Hancock	Number	33	30	37	36	38	28	26	23
	Percent	7.6%	6.1%	7.6%	7.8%	7.9%	6.1%	6.2%	5.9%
Kennebec	Number	89	103	102	83	109	75	72	60
	Percent	7.4%	9.4%	8.3%	6.9%	9.4%	6.6%	6.2%	5.4%
Knox	Number	37	32	19	27	36	33	37	36
	Percent	10.5%	8.6%	5.6%	8.5%	10.2%	10.5%	11.8%	12.1%
Lincoln	Number	17	13	30	23	18	15	24	25
	Percent	6.3%	5.2%	10.7%	8.3%	6.6%	4.7%	8.4%	10.2%

⁷⁵ KIDS COUNT data center: “Babies Born Exposed/Affected to Substances: KIDS COUNT Data Center.”

⁷⁶ Pendharkar, Eesha. “What We Know and Don't Know about How Maine's Opioid Crisis Has Affected Kids.”

Location	Data Type	2012	2013	2014	2015	2016	2017	2018	2019
Oxford	Number	11	27	34	28	32	67	66	55
	Percent	2.2%	4.8%	7.0%	5.6%	6.2%	14.0%	14.0%	11.3%
Penobscot	Number	187	182	226	239	213	167	113	124
	Percent	12.9%	12.4%	15.9%	16.8%	14.4%	11.7%	8.2%	10.0%
Piscataquis	Number	18	15	16	24	21	16	11	14
	Percent	11.3%	10.9%	11.9%	18.5%	12.8%	13.2%	7.9%	12.5%
Sagadahoc	Number	9	17	8	15	10	12	15	12
	Percent	2.8%	5.1%	2.2%	4.5%	3.1%	3.8%	4.9%	3.7%
Somerset	Number	43	70	56	59	58	65	61	65
	Percent	9.4%	13.9%	12.1%	12.6%	12.7%	14.1%	12.7%	15.6%
Waldo	Number	23	29	32	33	54	36	43	34
	Percent	6.0%	8.1%	9.4%	9.3%	16.3%	10.7%	11.9%	9.5%
Washington	Number	32	47	41	42	41	49	47	34
	Percent	10.6%	15.1%	13.8%	13.9%	14.2%	18.3%	15.4%	12.4%
York	Number	38	55	82	96	91	71	72	78
	Percent	2.1%	3.0%	4.5%	5.1%	4.8%	3.9%	3.9%	5.3%

Table 2.3: Babies born exposed/affected to substances in Maine from 2012 to 2019

Location	Data Type	2012	2013	2014	2015	2016	2017	2018	2019
Maine	Number	772	927	961	1,013	1,024	952	904	858
	Percent	6.1%	7.3%	7.6%	8.0%	8.1%	7.7%	7.3%	7.5%

These data show that while some counties are seeing decreases in drug affected children, others are seeing increases, and Maine overall sits around 7.5% of total births. It is important to note here that the number of drug affected children in each county is a reflection of that county's population size. For example, Cumberland county is Maine's most populous county, yet a handful of other counties saw a greater number of children born affected by drugs.

Maine Opioid Response Strategic Action Plan

Maine published its Opioid Response Strategic Action Plan on November 12, 2019 with the following goal: “Reduce the negative health and economic impacts of substance use disorder and opioid use disorder on individuals, families, and communities in Maine.”⁷⁷ The plan is broken up into five focus areas, nine priorities, and twenty strategies. The focus areas include leadership, prevention, overdose rescue, treatment, and recovery. The focus area most relevant to substance-exposed infants (SEI) is Prevention. The first priority under this area is to “prevent the early use of addictive substances by children and youth” and the first strategy under this area is to “support healthy and early childhood development.”⁷⁸ Maine has several current and scheduled activities under this strategy.

The first activity to mention is Maine’s participation in the Maternal Opioid Misuse (MOM) initiative. The MOM model was developed and implemented by CMS, Centers for Medicare and Medicaid Services. Maine is just one of ten states in the US enrolled in the MOM model. The model was developed as a response to the recent increase in substance-use related illness and death, focusing specifically on how this impacts pregnant women. Substance misuse poses risks to both pregnant women, including “preterm labor and complications related to delivery” and postpartum women, including “problems frequently exacerbated by malnourishment, interpersonal violence, and other health-related social needs.”⁷⁹ Infants face risks, too, including “a higher risk of

⁷⁷ “Maine Opioid Response Strategic Action Plan.”

⁷⁸ Ibid.

⁷⁹ CMS.gov, “Maternal Opioid Misuse (MOM) Model.” April 2020. <https://innovation.cms.gov/innovation-models/maternal-opioid-misuse-model>.

being born preterm, having a low birth weight, and experiencing neonatal abstinence syndrome.”⁸⁰ The MOM model recognizes the following as burdens to giving women with opioid use disorders quality care: “lack of access to comprehensive services during pregnancy and the postpartum period, fragmented systems of care, (and) shortage of maternity care and substance use treatment providers.”⁸¹ The shortage mentioned is huge for states like Maine that have rural areas where finding accessible treatment is infinitely more difficult. The three main goals of the MOM initiative are to improve care and access while creating more sustainable coverage. The MOM model has a five-year performance period that indicates when funding will be disbursed to the various states involved. The model begins in January of 2020 with 2020 is the pre-implementation phase, meaning 2020 is focused on funding.⁸² 2021 is the transition period and when care will begin. Full implementation will take place from 2022 to 2024. Maine was awarded \$5.3 million through the initiative. DHHS in Maine added that they would like to see the model include “creating a ‘no wrong door’ system to screening; supporting the treatment and recovery of mothers with group-based medication-assisted treatment; increasing the capacity of integrated care teams; coordinating delivery, hospital, and postpartum care for mothers and infants; enhancing home visiting and community supports; and conducting a public outreach campaign.”⁸³ DHHS Commissioner Jeanne Lambrew expressed her excitement to be participating in a program that will help the wellbeing of mothers and children affected by opioid misuse. Though still very early in the pre-implementation

⁸⁰ Ibid.

⁸¹ Ibid.

⁸² CMS.gov, “Maternal Opioid Misuse (MOM) Model.” December 2019.
<https://innovation.cms.gov/files/fact-sheet/mom-model-fs.pdf>.

⁸³ WCSH, “Maine DHHS Wins \$5.3M Federal Award to Help Mothers and Babies Affected by Opioid Crisis.”

phase of the model, Maine is on the right track to providing better care to mothers with OUD and infants with NAS.

Two evidence-based approaches Maine is promoting are Snuggle ME and Eat, Sleep, Console. Snuggle ME's purpose is as follows: "The purpose of the Snuggle ME guidelines is to give Family Medicine, Obstetric, Pediatric and Addiction Medicine providers' evidence informed tools to care for pregnant women with substance use disorders and their newborns."⁸⁴ The tool emphasizes how best to treat pregnant women with a history of drug use. Eat, Sleep, Console (ESC) focuses on the natural mother-child relationship. The model closely monitors the baby to determine if it should be treated with drugs, depending on the severity of the withdrawal.⁸⁵ More importantly, it keeps the child and mother together. ESC looks at the baby's ability to feed normally, the baby's ability to sleep, and if the baby can be consoled within ten minutes of crying. This approach to NAS has proven to reduce the likelihood of an infant receiving drug treatment and to reduce hospital stays.⁸⁶ ESC empowers mothers as caregivers for their child. They learn how to care for their child by constantly responding to their child's needs. They are able to give the child skin-to-skin contact, which has proven health benefits, as well as undivided attention for all consoling and feeding needs. Telling a mother that *she* is the treatment for her child can build her confidence as a parent early on.⁸⁷ Maine is also promoting the Snuggle ME guidelines. Snuggle ME's purpose is as follows: "The purpose of the Snuggle ME guidelines is to give Family Medicine,

⁸⁴ Maine DHHS, "The Snuggle ME Guidelines: Tools for Caring for Women with Addiction and Their Babies."

⁸⁵ NICHQ, "A Mother-Centered Approach to Treating Neonatal Abstinence Syndrome."

⁸⁶ Ibid.

⁸⁷ NICHQ, "A Mother-Centered Approach to Treating Neonatal Abstinence Syndrome."

Obstetric, Pediatric and Addiction Medicine providers’ evidence informed tools to care for pregnant women with substance use disorders and their newborns.”⁸⁸ The tool emphasizes how best to treat pregnant women with a history of drug use.

In addition to the approaches and initiatives mentioned, Maine plans to create Maternal Substance Use Disorder (SUD) and Substance-Exposed Infant (SEI) task forces, as well as holding an annual SEI conference. The strategic action plan also promotes “early childhood education and social and emotional learning skills for children.”⁸⁹ Additionally, the plan advocates for the development of “effective parenting skills” through educational information and evidence-based programs for parents to engage in.⁹⁰ Further, Maine plans to “provide education and training opportunities for child care providers.”⁹¹ Lastly, Maine is currently promoting education and aware of adverse childhood experiences (ACES) and amending “MaineCare policies to provide education and support for parents.”⁹² Maine’s future activity under the “support healthy early childhood education” strategy is to accelerate the “implementation of social and emotional learning in all schools.”⁹³

Conclusion

While studies on this topic do exist, it is difficult to find studies that focus on opioid use specifically. There are studies that address the withdrawal symptoms in

⁸⁸ Maine DHHS, “The Snuggle ME Guidelines: Tools for Caring for Women with Addiction and Their Babies.”

⁸⁹ “Maine Opioid Response Strategic Action Plan.”

⁹⁰ Ibid.

⁹¹ Ibid.

⁹² Ibid.

⁹³ Ibid.

infants, but the studies about educational outcomes tend to focus on cocaine use or drug use in general. Additionally, several of the studies recognized how difficult it is to isolate prenatal drug exposure when looking at educational outcomes because there are several other factors that play a role in a child’s development and academic success, the most notable of which appears to be a child’s environment. One study deemed it “almost impossible” to “isolate a specific effect of single drug use during pregnancy.”⁹⁴ Not only is it difficult to determine if a child with NAS will experience educational challenges, but it is also challenging to attempt to predict what exactly those educational challenges will be. Though Maine has made great strides in addressing the opioid crisis, there are some gaps when it comes to the children born with NAS. My research attempts to expand on these gaps to further explore what needs to be done to help the educational needs of these children in Maine.

⁹⁴ Jones, Hendree E. “Drug Addiction During Pregnancy: Advances in Maternal Treatment and Understanding.”

CHAPTER 3: METHODOLOGY

Purpose

Maine’s opioid crisis has grown tremendously in the last decade and the implications of this crisis are far-reaching. One of the most serious implications is children being exposed to drugs in utero: “While the nation’s opiate overdoses have dominated the headlines, the devastating and long-lasting effects of the epidemic on children has received little attention,” (Susan Brundage, Director of UHF’s Children’s Health Initiative). The opioid crisis in Maine has taken its toll in several ways, one of those being substance exposed infants, leading to neonatal abstinence syndrome at birth. Though withdrawal can be treated in the NICU, the impacts of prenatal drug exposure can be long lasting and hard to determine. The purpose of this study is to determine the educational needs of children born with neonatal abstinence syndrome from birth to age five in Maine, to learn what Maine is currently doing to serve this population, and to evaluate what Maine should be doing to serve this population going forward. This study attempts to determine the impacts of children born with in utero drug exposure by focusing on educational challenges, the causes of those challenges, and the barriers to receiving services and treatment.

Methodology

I conducted thirteen interviews with professionals and experts that have a stake in the issue of children born with NAS in Maine due to prenatal drug exposure. My target interview population was employees at relevant state agencies and nonprofits, educational specialists such as occupational therapists, speech therapists, and educators, and members of the medical community such as nurses and pediatricians, and policymakers. My goal was to conduct interviews with a wide range of occupations from around the state to complete the full context surrounding children born with NAS. I reached out to participants via email. I found the emails of potential participants on their employer's website, both state websites and private websites. I concluded each interview by asking if my participant knew of any other professionals that I should reach out to and their contact information. I also have connections within the field and was able to acquire emails through professionals I know closely.

I emailed participants between mid January through early April of 2020. We scheduled their interview based on their availability. COVID-19 likely impacted my ability to get more interviews. The medical community was difficult to reach during the pandemic, but the educational community was more available due to the stay-at-home order. I anticipated interviews to last between 45 minutes and an hour. Four interviews were conducted in person and recorded with the voice memo feature on my iPhone. Two of the interviews were recorded on phone call recording apps on my iPhone. The remaining seven interviews were recorded with a digital recording device. Five of those seven were recorded phone calls and the other two were recorded zoom meetings.

All the recordings of the interviews were converted into iTunes tracks on my MacBook Air. I took notes during each interview in addition to the recording. I had an approved list of questions for each interview, however I tailored some questions based on the type of work the professional did. I also asked follow up questions depending on the answers given. The questions covered biographical information, their work or experience with children born with prenatal drug exposure, their knowledge of how services are funded, the policies surrounding providing services to children, both what is in place and what should be in place to help these children and their families (see Appendix A).

I used Trint, a transcription service, to transcribe the interviews. After they were transcribed, my transcription assistant went through each transcription to correct any errors in word interpretation. Once the transcriptions were all complete, I printed them out to begin the content analysis. I reviewed each transcript several times to find trends and commonalities between responses. The first time I read through the interviews I noted biographical information such as where the participant worked and what position they currently have, environmental factors that were mentioned, any policy or funding matters that were discussed, and main findings that I felt were important. The main findings ended up being quite a large category. After a second round of reading through what I had previously noted as important, I was able to break down the main findings to develop three major categories: educational challenges, the causes of those educational challenges, and barriers to treatment. From there, I read through each interview three more times, specifically focusing on one of the three major categories with each read.

After I finished reading the interviews, I was able to further develop the categories I had previously determined into my findings. The first category is educational

challenges, such as cognitive, developmental, speech and language, social-emotional, behavioral, dysregulation, and impulsivity. The second category is the causes of those educational challenges, such as birth history, the child's environment, and attachment issues with caregivers. The third category is the barriers to services or treatment for both children and adults. For children, these barriers are unknown birth history, difficulty with identification and referrals, and lack of providers to give the necessary services. For adults, these barriers are stigma surrounding drug use, accessibility and affordability of treatment, and support to get treatment. A barrier for all services and treatment is the lack of funding through the underfunding and defunding of certain services.

Participants

Participants in this study were adults who work with or have knowledge about children born with NAS. There were thirteen participants in this study.

Table 3.1: Interview length, participant gender, and participant age

Interview Number	Length	Gender	Age
Interview 1	22:58	Female	68
Interview 2	30:41	Female	39
Interview 3	15:26	Male	38
Interview 4	25:38	Female	46
Interview 5 & 6	48:54	Male / Male	51 / 45
Interview 7	18:25	Female	51
Interview 8	13:00	Female	61
Interview 9	31:00	Female	35
Interview 10	22:35	Female	26
Interview 11	23:31	Female	38
Interview 12	34:41	Female	68
Interview 13	35:52	Female	43

Interviews 5 and 6 were conducted at one time in person. Three participants were male and ten were female. Ages ranged from 26 to 68 and the average age was 46.8.

Interviews ranged in length from 13:00 minutes to 35:52 minutes, not including interviews 5 and 6 which took 48:54 minutes together. The recording from interview 3 cut off at 15:26 minutes and the remainder of the interview was not recorded or timed, but notes were taken.

Table 3.2: Participant position and area of the state where the participant works

Interview Number	Position	Area of State
Interview 1	State Senator	Southern Maine
Interview 2	Head Start Employee	Entire State
Interview 3	School Psychologist	Southern Maine
Interview 4	Public Pre-K General Education Teacher	Midcoast Maine
Interview 5 & 6	Child Development Services Administration / Early Childhood Education Administration	Entire State / Entire State
Interview 7	Registered Nurse, Neonatal Intensive Care Unit	Northern Maine
Interview 8	Occupational Therapist	Southern Maine
Interview 9	Patient Social Worker	Southern Maine
Interview 10	Speech Pathologist	Southern Maine
Interview 11	Health Educator	Northern Maine
Interview 12	School Psychologist	Southern Maine
Interview 13	Licensed Clinical Social Worker	Northern Maine

Five of the participants work in Southern Maine, three participants work in Northern Maine, and one participant works in Midcoast Maine. Though representing Southern Maine, the state senator works for the entire state. Three other participants cover the entire state with their work.

Six participants currently work with children - 3, 4, 7, 8, 10, and 12. The participants that currently work with children cover a variety of occupations. The NICU nurse, Participant 7, works with infants in their first days of life, helping to treat any

withdrawal symptoms that result from NAS while they are still in the hospital. All the other participants work with older children once children have left the NICU and are in their home. Participants 3, 8, 10, and 12 are specialists that typically work with children ages three to five. Two participants, 3 and 12, are school psychologists. Participant 8 is an occupational therapist and 10 is a speech therapist. Participant 4 is a public pre-K general education teacher.

Three participants work in administrative roles, each of which represent the entire state with their work. Participant 2 works for Head Start in Maine and Participants 5 and 6 have administration roles for Child Development Services. Participant 2 is the Head Start State Collaboration Director. In this role, she oversees and works with each Head Start program director. Each program serves a lot of families, some of which have children who were born with NAS and some of which have parents in substance abuse treatment programs.

Two participants, 4 and 9, previously worked for CDS. Participant 4, currently a public pre-K teacher in Topsham, previously worked as an educational consultant with CDS. In this role, she would complete educational assessments and consults with regular ed teachers to help them make accommodations in the classroom to better serve the child that was assessed. Participant 9 was an Individual Education Plan (IEP) coordinator. In this role, Participant 9 would screen children ages three to five and make recommendations about further necessary evaluations a child may need, such as psychological evaluation or an evaluation for occupational or speech therapy.

Two participants had relevant past employment experiences. Participant 9 worked at Homeless HealthPartners through Maine Medical Center after working at CDS and

before working as a patient social worker. In her time at Homeless HealthPartners, participant 9 worked as a health guide. This role included checking people in at the front desk, assessing urgency to each individual coming in, and case management for certain individuals. Participant 13 previously worked in a residential treatment program for families and children. This program, called the Infant Mental Health Residential Treatment Program, served the entire family with their family treatment model. She worked for a specific program that served a population significantly impacted by substance use disorder.

One participant represents the medical community. Participant 7, as mentioned, is a registered nurse in the NICU. The medical community is underrepresented in this study. Due to the COVID-19 pandemic, medical personnel were not as available for interviews as educational personnel.

Participant 11 is a health educator in Northern Maine. She previously worked with children, but the children she worked with were primarily ages 12 to 18. That being said, she does know that some of her students were born with prenatal drug exposure based on one on one conversations with those students in her office. Her perspective as a health educator provided insight into the issue of substance abuse as an epidemic in addition to educational approaches to help children be successful in their academic setting.

Though the medical community is underrepresented amongst the thirteen participants due to the COVID-19 pandemic, the educational community is well represented by a variety of professionals. In addition to what they do for work now, some participants had relevant past work experience to supplement their current perspective on

the topic. The educational community provided a full understanding of the situation for children born with NAS. Every interview contained valuable information for further analysis.

CHAPTER 4: DATA ANALYSIS AND RESULTS

Using content analysis to analyze each interview, this section will highlight commonalities and trends found within the interview data to report the findings. First, it will review how an infant born with NAS is treated in the NICU while going through withdrawal and the process through which the state is notified of the birth. Next, it will explain how NAS is an auto-eligible diagnosis for CDS services until the age of three. After discussing these first two introductory points, the data analysis will evaluate what educational challenges children with NAS seem to present, the causes of those educational challenges, and any barriers to children getting the services they need or to adults getting the treatment they need. The data analysis section will conclude with potential solutions to better serve children with NAS in Maine going forward.

Care in the NICU

Participant 7 has been a NICU nurse since 2006 and reports that the way they treat infants with prenatal drug exposure has changed as medical advances have been made. When she first started, infants going through withdrawal were treated with opium, then it changed to fenobarb, then to morphine, and now they are treated with methadone. Though she does not see the infants once they are discharged from the NICU, she is able to describe the physical symptoms they experience with withdrawal. First, infants going through withdrawal experience much higher weight loss than average newborns because going through withdrawal burns many calories. They also experience tremors, difficulty

eating, and difficulty bonding. She explains the discomfort the infant feels by comparing it to having “the worst flu, like where your body aches, you don’t want somebody rubbing you, you don’t want somebody touching you and trying to talk to you.”⁹⁵

She then discussed the scoring tool Northern Light Eastern Maine Medical Center previously used before switching to the Eat, Sleep, and Console Program. The tool they used to use is the Finnegan Scoring Tool. The NICU nurse explained that with this tool, there was actually a higher number of infants being treated for withdrawal because of how the scoring worked. With the Finnegan Scoring Tool, “you can also take a newborn baby not exposed to drugs and you could probably score them.”⁹⁶ Some newborns who were not exposed to drugs have trouble tolerating feedings or cry excessively, so the Finnegan Scoring Tool was able to give any infant a high score, even without drug exposure. The NICU nurse prefers the Eat, Sleep, and Console Program, a much more objective scoring method. In fact, she says that with this program, she’s “seeing a lot less babies being treated.”⁹⁷ She has also seen that “the number of children that have been staying longer has decreased with the new method of treatment.”⁹⁸ That being said, she clarifies that “the numbers have definitely decreased as far as treatment, but not the amount of babies exposed (to drugs), that number isn’t decreasing.”

When a child is born with NAS, they are required to stay in the hospital for five days. The mother isn’t required to stay, so once the mother is discharged, the infant will be moved to the NICU. If the infant ends up not requiring treatment for withdrawal, they are discharged after the five-day period. However, infants stay longer than the five days if

⁹⁵ Participant 7.

⁹⁶ Participant 7.

⁹⁷ Participant 7.

⁹⁸ Participant 7.

they do require treatment and they stay until their treatment is complete. The social worker in the hospital is required to report the infant with NAS to the state. The social worker does an initial assessment on the family, the mother is drug tested via urine, and the meconium of the infant is sent for testing. Meconium “contains the amniotic fluid swallowed by the fetus in the last half of pregnancy and is released as the first stools after birth” and provides a long “window of exposure of up to approximately 20 weeks.”⁹⁹ This is incredibly helpful to know what exactly the infant was exposed to in utero, especially if the mother’s drug test came back negative the day of delivery. Participant 7, the NICU nurse, said the meconium test acts as a baseline because though most mothers do admit to some drug use or they have a history of drug use, they are not always completely honest about the drug use during their pregnancy. Once the social worker completes the evaluation, the social worker reports to the Department of Health and Human Services (DHHS). From there, DHHS can evaluate if this mother has any other cases with other children that may have been removed from her care. Though the social worker can make a conclusion and recommendation regarding the infant’s placement with the family, “under Maine law, only the courts may order the removal of a child from parental care.”¹⁰⁰

⁹⁹ United States Drug Testing Laboratories, Inc., “Meconium Drug Testing.”

¹⁰⁰ Office of Child and Family Services (OCFS). “A Handbook for Parents: OCFS: Maine DHHS - Child Welfare Maine DHHS.”

NAS and CDS

Children born with NAS often qualify for state funded special education services from a young age. Child Development Services (CDS) is broken up into two parts. Part C handles children under the age of three and Part B handles children from ages three to five.¹⁰¹ Each part has a different model of services. Part C is more family based with “an individual family service plan.”¹⁰² Participant 6, who is the Early Childhood Special Coordinator, said that anecdotally, many of the children born with prenatal drug exposure do enter the special education system in Part C. For Part C, NAS is an “auto-eligible diagnosis,” which means that if the infant required treatment for withdrawal at birth, they are “automatically eligible” for services in Part C.¹⁰³ However, eligibility shifts in Part B. If the child does not “demonstrate an adverse effect on their ability to access their education, they may not be eligible.”¹⁰⁴ This means that once a child turns three, they are no longer auto-eligible for services because they have transitioned from the family-based services in Part C to educationally based services in Part B.

¹⁰¹ There is no Part A.

¹⁰² Participant 6.

¹⁰³ Participant 5.

¹⁰⁴ Participant 5.

Table 4.1: Table of main findings

Educational challenges	Cognitive or developmental delays, speech and language delays, dysregulation and impulsivity, social-emotional issues, and behavioral issues.
Causes of educational challenges	Birth history in terms of family history and genetics, the child’s attachment with caregivers, and the child’s environment.
Barriers to children receiving services	Identification, referrals, and a shortage of providers which can result in waitlists.
Barriers to adults receiving treatment	Stigma associated with drug use, access to treatment in terms of location and affordability, and the lack of support to engage in treatment.
Funding concerns	Lack of funding, underfunding, and defunding.

Educational Challenges

To begin, there is no way to predict the educational challenges a child with prenatal drug exposure will face in their future. As Participant 3 stated, “it’s not like a one-to-one correlation with a really specific developmental problem or a developmental outcome.” He elaborates and explains this is because “the types of substances used can affect children and babies differently,” meaning that one child’s outcome can be very different from another child’s outcome, even if they were exposed to the same substances. Several educational challenges can arise due to prenatal drug exposure. Five main educational challenges were mentioned and discussed amongst the thirteen interviews and are as follows: cognitive or developmental delays, speech and language delays, dysregulation and impulsivity, social-emotional issues, and behavioral issues.

Speech and language delays were mentioned by three participants - participants 3, 10, and 13. As a speech pathologist, Participant 10 had the most insight to the speech and language delays she sees in her clients. Though she has only practiced for two and a half years so far, she has already worked with three patients who were born with NAS. She described how their speech delays vary, with one of the children being nonverbal at the age of three and others having delays in “articulation and speech sounds.”¹⁰⁵ Participant 3 elaborated on the cognitive and developmental delays he mentioned by saying those types of delays can also impact a child’s speech. Participant 13 mentioned how language delays arise as well, which is different from speech delays. Speech focuses on the sound and articulation where language focuses on the expression and understanding of language.

Cognitive and developmental delays were mentioned by four of the participants - participants 3, 5, 8, and 9. Participant 3 discussed how short and long term cognitive and developmental problems can occur as a result of prenatal drug exposure. Participant 8 shared how prenatal drug exposure can impact executive functioning. In her role as someone who screened children ages three to five, Participant 9 said her main observation of children born with NAS was overall developmental delays which is clear when a child is behind their peers in developmental milestones. Participants 3, 8, and 9 are all speaking from the perspective of someone working with a child or evaluating their needs. Participant 5, an administrative role, said overall children typically transition from Part C to Part B in CDS with a developmental delay diagnosis, allowing them to continue to receive services.

¹⁰⁵ Participant 10.

Four participants, 1, 4, 9, 11, mentioned the need for children to have support for social-emotional delays. Participant 4 said that in her experience, learning delays most likely will come later in a child's life, such as when they reach school age. In the three to five age range, children typically demonstrate more social-emotional delays. Social-emotional delays can also manifest as difficulty with emotional regulation, which was mentioned by participants 4 and 9. Participant 11 mentioned social-emotional delays in children she works with at an older age, which we can assume began when they were younger. Participant 1, the only participant to mention social-emotional support that doesn't work with children, emphasized the need for social-emotional support, implying that children are experiencing difficulty in this area.

Dysregulation and impulsivity were mentioned often by participants during their interviews. Six participants total, 3, 4, 8, 9, 10, and 12, described impulsivity by explaining that children have difficulty with impulse control, with their attention span, and with emotional or behavioral regulation. Participant 4, a public pre-k teacher, even said the difficulty with regulation and impulse control that she sees seem to mimic attention deficit/hyperactivity disorder (ADHD). Three participants used the terminology "impulse control," four participants specifically referred to attention span, and four participants mentioned regulation or disorganization. All six participants that discussed dysregulation and impulse control cover a variety of occupations - two school psychologists, a pre-k teacher, a speech pathologist, an occupational therapist, and a former CDS employee that screened children. All of these participants currently work or previously worked with children with prenatal drug exposure.

The last main educational challenge that was mentioned by six participants is behavioral concerns. Participants 1, 2, 3, 5, 12, and 13 specifically referenced children struggling in terms of their behavior. It's important to recognize that behavioral concerns can arise as a result of any of the previously listed educational challenges. For example, Participant 13 explained that a language delay can result in children communicating with their behavior since they do not have the verbal skills to communicate their needs. Impulse control and dysregulation in children can lead to problematic behavior because they do not have the attention span to regulate themselves as a typically developing child would. This applies to social-emotional delays as well, as social-emotional delays can impact how children interact with the peers and adults in their lives.

Causes of Educational Challenges

Because several factors play into a child's development, it is nearly impossible to determine what exactly is caused by the prenatal drug exposure. Further, the drug exposure affects every child differently, adding another layer of difficulty when trying to determine what specifically results from the drug exposure. The additional factors that impact a child's development that were discussed during the interviews in this study are birth history in terms of family history and genetics, the child's attachment with caregivers, and the child's environment.

Though only mentioned by Participants 3 and 8, it is worth mentioning that genetics play a role in a child's development of educational challenges or disabilities. Participant 3 specifically mentions genetics and how that varies for every child.

Participant 8 mentioned family history in the context of a family history of learning disabilities. If a child's family has a history of learning disabilities, that could contribute to that child's own educational challenges. In this case, it would be nearly impossible to decipher between what is genetic and what is due to prenatal drug exposure.

Six participants mentioned children struggling with attachment. As Participant 13 explained in her interview, attachment issues are demonstrated in a variety of ways. For some children, they appear "emotionally closed" and "their approach to managing trauma is more of the fight or freeze response."¹⁰⁶ On the other end of the spectrum, she explains that some children are too open as seen when they climb in anyone's lap and do not seem to have the boundaries a typically developing child would. Every participant mentioned attachment in the context of a child's attachment to their caregivers. Participants 2, 5, 9, and 13 specifically referred to a child's attachment to the biological parents and how that relationship is more difficult when a parent is still affected by substance use disorder. Participants 9 and 12 also mentioned how attachment is impacted when a child is either in foster care, transitioning between homes, or has been adopted.

Environment, as already discussed, plays a critical role in a child's development. Environmental factors were mentioned by every participant, excluding Participant 7 who only discussed her knowledge of infants with NAS in the NICU. Because a child's environment was mentioned by twelve different participants, it was discussed in a variety of ways. The primary way a child's environment seems to be impacted is if the parent is still struggling substance use disorder. Participants 1, 2, 4, 9, 10, 11, 12, and 13 specifically explained that when a child's caregiver is experiencing drug misuse, they are

¹⁰⁶ Participant 13.

not able to provide for the young child as needed. Participant 13 explained that “it’s really hard to be nurturing and attending to a child if you’re feeling a lot of withdrawal and distress internally.”¹⁰⁷ Though not outwardly mentioned, Participant 3 alluded to parental drug use by addressing how “stressors at home” can impact a child’s development.¹⁰⁸ This means a total of nine participants acknowledged how ongoing parental drug use heavily influences a child’s development. Some participants explained this further by recognizing additional factors that tend to go along with parental drug use. Participants 1 and 10 mentioned how these families are often associated with lower economic status or poverty. Participant 2 explained how drug misuse can lead to domestic violence in the home, abuse, and neglect. Participant 3 addressed how parental health, stress, and trauma all impact a child’s environment as well. Participant 12 discussed how maternal depression can play a role in a mother’s substance use disorder, which in turn influences a child’s environment.

Lastly, seven participants, 4, 5, 6, 8, 9, 10, and 12, discussed how children may have been removed from the home and placed in foster care or adopted due to parental drug use creating an unsafe home environment. Participant 6 mentioned how children can transition through multiple foster placements at a young age, implying how that much change can have adverse effects. Further, participants 8 and 12 specifically mentioned foster care and how a child may not be with their biological parents due to drug use. Participants 9 and 10 addressed how some children have been adopted by the time they are old enough to receive services. Participant 5 said that anecdotally, many children are now placed with their biological grandparents, so there is some burden on the

¹⁰⁷ Participant 13.

¹⁰⁸ Participant 3.

grandparents to become caregivers due to their grandchild's parent's drug use. Whether a child is with their biological parents, a foster home, or adopted, children need a stable environment with an available caregiver that can attend to their needs.

Barriers to Service and Treatment

There are several barriers present to both children and adults that make it difficult to receive the services or treatment that they need. Beginning with children, the biggest barriers are identification, referrals, and a shortage of providers which can result in waitlists. Adults have their own set of challenges that make access to treatment difficult which include the stigma associated with drug use, access to treatment in terms of location and affordability, and the lack of support to engage in treatment. A barrier that impacts both adults and children greatly is funding concerns. This manifests as a lack of funding, underfunding, and defunding of necessary programs.

Barriers to Children Receiving Services

First, in order to help children born with NAS, those children need to be identified. Participants 2, 5, 6, 9, and 12 specifically mention how children need to be recognized earlier and we need to do a better job of reaching more people. As Participant 9 shared, she thinks "these children do tend to slip through the cracks."¹⁰⁹ Participants 5 and 6, a director and coordinator for CDS, discussed how two years ago Maine came in

¹⁰⁹ Participant 9.

last for identification. Maine moved up to second to last year, however this was due to another state falling behind. Maine has not made any progress in terms of identification. Another factor playing into the difficulty of identification was that previously there was no “black and white diagnostic criteria.”¹¹⁰ This makes identification even more difficult, especially when a “drug affected baby” could mean one thing in Aroostook County and another in Cumberland County. Progress has been made here according to Participant 5, who says now that line is drawn at medical intervention, which is then considered NAS.

The second piece to identification is referral: “We’re clearly not getting referrals for the infants nor find them eligible.”¹¹¹ Referral is the actual process of contacting CDS and having the child evaluated to see if they need services. For Part C, children born with NAS are auto-eligible, but those services can only be accessed if a referral is made. For Part B, referrals typically come from caregivers or from the child’s educational setting. A challenge with referral is that after the referral is made, parents are responsible for following through and communicating with CDS. If contact with the parent is lost, that child’s file is closed after a certain amount of time. Then if another referral is made for the same child, the file is reopened, but the process starts over again. Participant 6 said this is a cycle they see often. Early identification is crucial because the earlier a child is identified and referred, the sooner the child can get the services needed.

The next barrier to a child receiving services is a shortage of providers. Participant 2 said that 14% of CDS positions are vacant statewide which is due to a shortage of providers, such as speech therapists, occupational therapists, and physical therapists. The shortage of providers results in long wait lists for services, which means

¹¹⁰ Participant 5.

¹¹¹ Participant 5.

that even when a child is identified, that child could still go a long period of time without services. In addition to Participant 2, Participants 3, 4, 8, and 12 also mentioned lack of providers as a barrier to services. Participant 8 explained that she thinks the services are working in terms of helping children who were born with NAS, but services can only work if they are able to be accessed. Through early identification, completed referrals, and accessible services, children tend to make progress and overcome their delays, but the barriers discussed make this infinitely more difficult.

Barriers to Adults Receiving Treatment

There is a stigma surrounding drug use, which is something six participants - Participants 2, 4, 6, 7, 9, and 11 - discussed in their interviews. Participant 2 specifically used the term “stigma” while Participant 4 referred to the pressure and expectations from society to overcome substance use disorder. Participant 6 mentioned desensitization to substance use as some people do not understand the reality of addiction and the struggles those people face. Participant 9 said that “there’s such a stigma attached to substance use” and she thinks that “carries on to children who carry that diagnosis (of NAS).”¹¹² Participant 11 said that she hopes “we are changing the face of addiction,” explaining how important it is to “be aware of the fact that we can’t just assume that it’s a particular mold of a person.”¹¹³ Participant 7 said that the families of children born with NAS fear

¹¹² Participant 9.

¹¹³ Participant 11.

they will be stereotyped for their drug use, so it is important “to judge every individual on their own merit versus the diagnosis.”¹¹⁴

Accessibility is another barrier to adults getting treatment for substance use disorder. While most of the participants had insight into services for children, a few of the participants had insight into the treatment programs that are available to adults and how to access them. With her experience as a previous employee at Homeless HealthPartners, Participant 9 felt that treatment facilities are fairly accessible, but listed insurance and limited knowledge of resources as barriers. She explained the different types of treatment programs there are such as intensive outpatient programs, sober houses, and more therapy-driven programs, however she stated that “medically assisted treatment is really the one and only proven” treatment method.¹¹⁵ She also acknowledged how accessibility would be more difficult in rural areas than in the Portland area. Participant 11, a health educator, explained how treatment programs tend to have limited space and tend to be more short-term. This could be discouraging for someone who tries to enter a treatment program, but is told there is not enough room, which pushes them back to their usual environment. Participant 13 said in many ways, she feels “we do better at the children’s level than we do at providing open access to services for adults (and) providing medication assisted treatment options.”¹¹⁶ She notes that particularly “in rural and underserved areas,” finding treatment options can be a challenge.¹¹⁷

¹¹⁴ Participant 7.

¹¹⁵ Participant 9.

¹¹⁶ Participant 13.

¹¹⁷ Participant 13.

Funding as a Barrier

Both child services and adult treatment options have funding concerns. Participant 1 said Head Start is underfunded, and Participant 2 said both Head Start and CDS are underfunded. In fact, Head Start is underfunded by \$800,000 for its programs around the state. Participant 13 discussed the treatment program she used to work for and explained how the program was defunded entirely. The Infant Mental Health Residential Treatment Programs were one of three organizations in Maine that worked with entire families, but because it was an expensive model of treatment, the state decided to cut its funding. In addition to these specific examples from Participants 1, 2, and 13, Participants 3, 4, 5, 9, and 12 all mentioned how they felt increased funding was necessary to provide children born with NAS and adults with substance use disorders with the help they need.

Results

Every participant mentioned the need for family support in their interview. Though brought up in different ways, each participant discussed the importance of supporting the family in order to support the child's educational needs. Participants 2, 3, 4, and 5 specifically said that families need more support while Participant 1 said that parents need better coping skills. As mentioned before, Participant 6 discussed how parents often do not follow through with referrals, causing the child's file to close just to be open again with the next referral, leading to a cycle that could be helped by more family support. Participant 7 explained how she feels that from her experience "a third of

people intentionally get pregnant so that they can get on the replacement program to get off street drugs” and how opioid use is an epidemic, implying how family support is necessary to stop this cycle. Participant 8 emphasized the importance of supporting the family in order for the child to have a successful education. Participant 9 stated how important support for the pregnant mother is, prior to the birth of a child that may potentially have NAS. Participant 10 said that children with NAS tend to require continuous support, which means the family needs support in order to constantly support the child. Participant 11 explained how it is easy for family members and those close to us to fall down the slippery slope of substance abuse. This is a different perspective, but nonetheless it demonstrates the need for family support. Participant 12 shared that some families are too overwhelmed to even access the services they are receiving. For example, sometimes the children are either not at school or not ready when transportation services pick them up to go to school, so without family support, some families are not able to utilize the help and services they are receiving. Lastly, Participant 13 emphasized using a family model for treatment because the entire family needs support in order for the child to be successful.

In addition to family support and family treatment models, five participants advocated for more education on the topic of substance use disorder and children born with NAS. Participants 4 and 12 mentioned the need for further education and Participant 9 elaborated to say that there should be more education for biological parents of children with NAS and foster and adoptive parents. Participant 10, a recent graduate from the University of Maine at Orono for both her undergraduate and graduate degrees, shared that learning about substance-exposed infants was a special population discussed in one

of her core classes, indicating how Maine is making strides in increasing education on the topic. Participant 11, a health educator, explained that “the education format needs to be modified because it’s obvious we are missing the mark somewhere” since children with prenatal drug exposure is a major problem at both the state and national level.¹¹⁸ She emphasizes the importance of making sure people know about the services and treatment available to them, which comes through education.

While some participants mentioned the lack of research and others specifically mentioned the need for further research, it is clear that more research on the outcomes of children born with NAS is needed. Although isolating the effects of prenatal drug exposure is nearly impossible, long-term research would be helpful to gauge how well we are serving these children and if they are able to be successful in the long run. Participant 5 said we need a “comprehensive data system” to collect information on long-term effects and outcomes.¹¹⁹ Participant 6 recognized we are “on the cusp of collecting longitudinal data,” so progress in terms of long-term research is hopefully being made.

Five participants discussed the importance of early intervention. Early intervention is a direct result of better identification because the earlier a child is identified as needing extra support, the process to intervention can begin. In addition to early intervention, three participants mentioned the lack of collaboration between all the parties involved when a child is born with NAS. Participant 2 believes “there could be better collaboration between the medical experts and early childhood experts.”¹²⁰ Further, Participant 5 said he thinks “a lot of doctors are feeling that the medical services are

¹¹⁸ Participant 11.

¹¹⁹ Participant 5.

¹²⁰ Participant 2.

enough without understanding the value added of what (CDS) services are.”¹²¹

Participant 12 recognized that while all the services are well meaning, each program has its own mission and regulations, and there is not a lot of communication between them.

Participants 2 and 5 discussed how a “warm handoff” is important here. A “warm handoff” is understanding all the services and agencies available to families and helping families get in contact with them, not by sending over the contact information, but by sitting down and helping them call the services they need. Because of the lack of collaboration and coordination between services, transitioning between them is challenging for families, so directly assisting them in the task rather than sending them home with the information is a better way to guarantee contact with other agencies. Better collaboration and coordination would help to ensure each child is getting all the support and services that he or she needs.

Many participants recognized the cycle of substance use disorder and the importance of breaking that cycle. Participant 1 advocates for long term contraceptives. Though they are costly up front “they end up being cheaper because you can use them for many years and it doesn’t have to change.”¹²² As mentioned earlier, Participant 7 described how women are getting pregnant on purpose in order to be moved up on the waitlist for better treatment programs. Increasing availability and accessibility to treatment programs would eliminate the incentive to get pregnant and could overall reduce the amount of children born with NAS. When asked what needs to happen going forward to address the needs of children born with NAS, several participants said we

¹²¹ Participant 5.

¹²² Participant 1.

must address the opioid crisis we are in and increase prevention measures in order to protect children from being born with NAS.

Conclusion

Though there is a range of educational challenges resulting from NAS, it is important we try to understand what those challenges can be and how to address those challenges. As discussed, there are several barriers to children receiving services and adults receiving treatment. However, with better identification and referrals and more providers, we could see more children getting the support they need. As for adults, reduced stigma, more support from loved ones, and more accessible treatment would all help more adults with substance use disorder begin the treatment process. Improved funding, education, awareness, and research are all key factors when addressing the issue of children born with NAS. Lastly, better preventative measures should be introduced to help reduce the number of children born with NAS.

CHAPTER 5: CONCLUSION

The results of this study show that children born with NAS are more likely to face a wide range of educational challenges. Not only do the educational challenges of NAS vary, but the causes of those challenges vary as well. The bigger picture here is that the opioid crisis in Maine has far reaching implications which is affecting the entire state in a variety of ways, including children born with NAS. The current governor, Governor Janet Mills, has made the opioid crisis one of her administration's top priorities. Maine's Opioid Response Strategic Action Plan is a substantial start to addressing the opioid crisis.

The next step is implementation. Building on the results of this study, the first steps to implementation are increased awareness and education. Education is important not only for individuals and communities to help with prevention, but it is also crucial for educators to understand the challenges of a child with NAS in order to best help the child succeed. Awareness is helpful to reduce stigma by teaching the community that addiction can affect anyone, there is no specific mold of a person with substance use disorder, and it is harder to get treatment than it may seem. Decreased stigma and stereotyping can help encourage more adults suffering with substance use disorder to engage in treatment. Next, increased accessibility for both children needing services and adults seeking treatment is necessary. Increased funding must happen first to decrease the shortage of providers for children and to make treatment options more available and more affordable to adults. Once the resources are there to better serve children and adults, accessible services and treatment must continue expand to reach all areas of the state. There is no

simple answer, but the strides taken by Governor Mills administration is encouraging and hopeful in regard to addressing the opioid crisis. These efforts must continue in order to implement the changes necessary to ending the opioid crisis while simultaneously recognizing the children born with NAS who are here as a result of it.

This study acknowledges many of the challenges a child that is born with NAS can face. However, it is important to stay hopeful and recognize the progress children can make when given the resources they need. Participant 9 recognized that “damage has been done” but “there’s still hope.”¹²³ Participant 3 emphasized how he feels “it’s really important for us to have the belief that all children are capable when they’re given good educational support and their families are supported.”¹²⁴ According to Participant 4, it can be very difficult to work with these children and how “people that are doing that really love the job.”¹²⁵ Participant 11 addressed how “we need to make sure that our focus is the success of the child, not only their health, but also their academic success,” emphasizing how important it is for teachers to remember their purpose.¹²⁶ Participant 12 explained that “the brain is remarkably plastic and resilient” which means there is hope for children who get support at an early age.¹²⁷ It is important to acknowledge that many of the participants included hopeful remarks regarding children’s outcomes, proving that with the right support, children can overcome their obstacles. In the encouraging words of Participant 13, “Kids are amazingly resilient.”¹²⁸

¹²³ Participant 9.

¹²⁴ Participant 3.

¹²⁵ Participant 4.

¹²⁶ Participant 11.

¹²⁷ Participant 12.

¹²⁸ Participant 13.

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APPENDIX

A. Interview Questions

1. Could you please state your position and the area of the state in which you work?
2. Could you please state your age and gender?
3. What is your educational background? What degree(s) do you hold?
4. Where are you currently employed?
5. In your current position, do you see/treat children who were born drug affected? If so, how many? What age group do you work with?
6. What symptoms or delays do these children typically exhibit?
7. Are children able to overcome their delays? Do they need additional educational support to do so?
8. As far as you know, what policies are in place to help these children and their families? This can be from birth, to Child Development Services (CDS), to when these children enter kindergarten.
9. Where does the financial burden fall when providing services to these children? State government, municipal government, school systems, families, etc?
10. What is your assessment of the current policies on this issue - are they working? Why or why not?
11. In addition to policies that are currently in place, what do you think needs to be done to help the educational needs of drug affected children in Maine?
12. Is there anything else you would like to say regarding children born with NAS?
13. Is there anyone else you think I should reach out to?
14. Do you have any questions for me?

B. Interview Script

First, I would like to say thank you for taking the time to participate in my research. I'm interested in the opioid crisis here in Maine, and particularly how it has impacted children that are born drug affected, otherwise known as neonatal abstinence syndrome (NAS). Currently, about 7% of children in Maine are born drug affected. Our current state government is attempting to tackle the problem by taking measures to stop overdoses. This is a great start to the issue here in Maine; however, I'm interested in looking into the implications for the children who are already here and are significantly more likely to face educational challenges due to being born addicted to drugs.

Second, I would like to review the confidentiality of this interview. You are participating in a research project where your interview will be recorded and will be data for research. Your participation is voluntary and may be withdrawn at any point during the interview. Your name will not be released to anyone. Your name will not be published in my thesis or shared with anyone. I will use an assigned code that was randomly generated to identify your answers or any quotes used from your interview. The questions I will ask pertain to your experience working with drug affected children in Maine. You may skip any question or come back to a question at any point in time. All the data collected in this interview will be destroyed by December 2020.

Do you have any questions before we begin?

C. Email to Ask Individuals to Participate

Dear _____ ,

My name is Julia Casey and I am a senior student at the University of Maine. I am in the Political Science Department and I am in the Honors College. I am currently doing research for my Honors Thesis and I am looking for participants. I got your email from [indicate public website].

My research is regarding the educational needs of children who were born drug affected in Maine. If you have the time, I would like to meet with you for an interview. I will be conducting interviews through December and January. The interviews should last no longer than an hour. All interviews will be recorded and later transcribed to be used for my research. We could meet when and where it is most convenient for you. We could also do a phone interview if that works better for your schedule.

Please let me know if you would be interested in participating in this study and when you would be available to schedule a time for the interview. To schedule an interview, you can call me or email me. My number is 207-449-0148 and my email address is julia.casey@maine.edu.

Attached to this email is the consent form with more information about the study. Please let me know if you have any questions. You can also reach out to the advisor for this project, Dr. Mark Brewer, at mark.brewer@maine.edu.

D. Consent Form

You are invited to participate in a study being conducted by Julia Casey, an undergraduate student at the University of Maine in the Political Science Department. The faculty sponsor for this study is Dr. Mark Brewer from the Political Science Department. The purpose of the research is to investigate the educational needs of children who were born drug affected here in Maine.

What will you be asked to do?

In choosing to participate, you will be asked a series of questions regarding your work with children that were born with NAS and the policies currently in place to support the needs of these children. These questions could take up 45-60 minutes of your time. The entirety of this interview will be recorded.

Questions include but are not limited to:

- What is your educational background and where are you currently employed?
- Do you see/treat children who were born drug affected? What symptoms/delays do you see?
- What current policies are in place to help these children and their families?

Risks

Your only risks with participating in this research are time and inconvenience.

Benefits

There are no direct benefits for your participation. However, this research is an opportunity to use your professional knowledge to reflect on a prominent issue in Maine. Long term indirect benefits of participation could include a better understanding of drug-affected children in Maine and how to make a difference going forward.

Confidentiality

Your name will not appear on any documents or the thesis made from the results of this research. You will be identified only by your occupation and the area of the state in which you work (e.g. social worker in Southern Maine) in order to protect your identity, such as your legal name. Any data collected during the interview will be kept in a password protected laptop or a locked desk drawer. Data refers to the recording of the interview, the transcription of the interview, any hand written notes taken during the interview. The interview will be recorded on my phone and then transferred to my laptop within one week of the interview date. The recording will be deleted from my phone by April 2020. Once the recording is transferred to my laptop, it will be deleted from my phone. Each interview will be transcribed using the recording. All data will be deleted and destroyed by June 2020.

Voluntary

Participation is voluntary. If you choose to take part in this study, you may stop at any time during the interview. You can skip answers you do not want to answer or go back to questions you felt you did not answer clearly enough.

Contact Information

If you have questions about this study, you can contact me, Julia Casey, by phone at (207) 449-0148 or by email at julia.casey@maine.edu. You may also contact the advisor of this project, Dr. Mark Brewer, at mark.brewer@maine.edu. If you have questions about your rights as a research participant, please contact the Office of Research Compliance, University of Maine, (207) 581-2657, or email umric@maine.edu.

AUTHOR'S BIOGRAPHY

Julia Casey was born in Augusta, Maine on April 2, 1998. She grew up in Brunswick, Maine and graduated from Brunswick High School in 2016. Julia started at the University of Maine in the spring of 2017 where she majored in political science with minors in business administration and legal studies. She was also a member of the Honors College. Julia received the Steinmetz Book Award after her first semester in the Honors College. Julia was a student facilitator for Honors 170, a current events course in the Honors College. She was a Nickerson Scholarship Recipient her senior year. She has studied abroad twice. First, she went to Singapore after receiving the US-Singapore Summer Exchange Scholarship. Second, she completed a travel course on Human Sexuality in Europe. Julia had an internship on Senator Angus King's reelection campaign and two internships at the Attorney General's Office in Bangor under Child Protection. Julia was a member of the University of Maine Cheerleading Team for three years. She will attend the University of Maine School of Law in the fall of 2020.