



Neonatal Abstinence Syndrome Advisory Committee

Annual Report to the General Assembly

3/31/2018

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Executive Summary

In 2015, the Neonatal Abstinence Syndrome (NAS) Advisory Committee (Committee) was created pursuant to Section 2310-677 of the Civil Administrative Code of Illinois (Department of Public Health Powers and Duties Law) (20 ILCS 2310). The Committee is charged with advising and assisting the Illinois Department of Public Health (IDPH) to:

1. Develop an appropriate standard clinical definition of NAS;
2. Develop a uniform process of identifying NAS;
3. Develop protocols for training hospital personnel in implementing an appropriate and uniform process for identifying and treating NAS;
4. Identify and develop options for reporting NAS data to IDPH by using existing or new data reporting options; and
5. Make recommendations to IDPH on evidence-based guidelines and programs to improve the outcomes of pregnancies with respect to NAS.

The Committee consists of up to 10 members appointed by the Director of IDPH. Members receive no compensation for their services, and represent different racial, ethnic, and geographic backgrounds. Members and the roles they fill on the committee include:

1. David Soglin, MD, La Rabida Hospital – representing a statewide association of hospitals
2. Open, Representative of a statewide organization of pediatricians
3. Open, Representative of a statewide organization of obstetricians
4. Shelly Musser-Bateman, March of Dimes, Illinois – representing a statewide organization that advocates for the health of mothers and infants
5. Leslie Caldarelli, MD, Northwestern Medicine – representing a statewide organization of licensed physicians
6. Jodi Hoskins, RNC, MSN, Rockford Memorial Hospital – a nurse (LPN, RPN, or APN) with expertise in the treatment of newborns in NICU
7. Open, Representative of a local or regional public health agency
8. Ira Chasnoff, MD, Children's Research Triangle – a member with expertise in the treatment of drug dependency and addiction

The following persons or their designees serve as ex officio members of the Committee:

1. IDPH Director, Nirav Shah, MD, JD (Designee: Andrea Palmer)
2. Illinois Department of Human Services Secretary, James T. Dimas (Designee: Open)
3. Illinois Department of Healthcare and Family Services Director, Felicia Norwood (Designee: Arvind Goyal, MD)
4. Illinois Department of Children and Family Services Director, Beverly Walker (Designee: Paula Jaudes, MD)

There are also several non-voting members who regularly contribute their expertise to the Committee:

Ellen Mason, MD, Obstetrician

Ginger Darling, MD, Neonatologist

David Ouyang, MD, Maternal Fetal Medicine

Mary Pulchalski, DNP, APN

Omar LaBlanc, MSW

Elaine Shafer, RN

Christine Emmons, RN

Emily Miller, MD, Obstetrician

Since the March 2017 report was submitted, the Committee has held five meetings. To date, the Committee has made the following recommendations:

Charge 1: Develop an appropriate standard clinical definition of NAS

Neonatal Abstinence Syndrome refers to the collection of signs and symptoms that occur when a newborn prenatally exposed to prescribed, diverted, or illicit opiates experiences opioid withdrawal. This syndrome is primarily characterized by irritability, tremors, feeding problems, vomiting, diarrhea, sweating, and, in some cases, seizures.

Charge 2: Develop a uniform process of identifying NAS

Substance use screening using a validated verbal or written questionnaire for all pregnant women. At a minimum, this screening should occur at their first prenatal visit and when presenting for evaluation of labor or for delivery. Toxicology screening should always be considered if it would help guide clinical management.

All infants with history, signs, or symptoms due to prenatal opioid exposure should be referred for early intervention evaluation and subsequent services as indicated. It is recognized that all infants affected by prenatal substance exposure require early intervention evaluation.

All newborn infants with history of or evidence suggesting prenatal exposure to opiates, or with behavioral symptomatology consistent with NAS as defined by this Committee, should be evaluated with a published, reliable tool that indicates the presence and quantifies the severity of NAS. This evaluation should be initiated within two hours of delivery in the case of known opiate exposure, or any time behavioral symptomatology emerges, and repeated on an inpatient basis every three to four hours for at least five days before the infant is discharged. This can be done while the infant is rooming in with the mother during her hospital course of stay. It is recommended that (1) all physicians, APNs, and nursing personnel are thoroughly trained on the assignment of an abstinence score using the chosen NAS tool, and (2) interrater reliability be measured within each hospital at least on an annual basis. If validated NAS scoring tools become available, they should be implemented.

Charge 5: Make recommendations to IDPH on evidence-based guidelines and programs to improve the outcomes of pregnancies with respect to NAS.

Universal screening, brief intervention, referral, and treatment for substance use among pregnant women in the state of Illinois.

The Committee shall provide an annual report of its activities and recommendations to the IDPH Director, General Assembly, and Governor by March 31 of each year, beginning in 2016. The final report shall be submitted by March 31, 2019.

Introduction

Neonatal Abstinence Syndrome

Neonatal Abstinence Syndrome was first described in the 1970s, identified among neonates whose mothers most commonly used heroin or were on methadone maintenance. NAS refers to the collection of signs and symptoms that occur when a newborn prenatally exposed to opiates experiences opioid withdrawal. The syndrome is primarily characterized by irritability, tremors, feeding problems, vomiting, diarrhea, sweating and, in some cases, seizures.ⁱ

According to Dr. Ira Chasnoff, in his editorial for the Journal of Perinatology, the incidence of NAS has varied over the past several decades, usually correlated with the ebbs and flows of heroin use in the general populations. Chasnoff further notes that the current increase in NAS is associated with an a wide spectrum of pregnant women's use of opiates, including heroin addiction, polydrug use, prescribed and illegal prescription opioid use, and methadone or buprenorphine assisted treatment (MAT).ⁱ

National surveillance studies have demonstrated that the incidence of NAS increased from 1.2 per 1,000 hospital births in 2009 to 5.8 per 1,000 births in 2012 – a 70% increase in only three years.^{ii,iii} Since 2000, there has been a five-fold increase in NAS.ⁱⁱⁱ In 2012, the NAS rate for Midwest states (including Illinois) was 6.9 per 1,000 hospital births. Only the New England and East South Central regions had higher NAS rates than the Midwest region.ⁱⁱⁱ Compared to infants without NAS, infants with NAS were more likely to be male, to reside in low-income zip codes, and to be covered by Medicaid.^{iv} In 2012, Medicaid was the primary payer for hospital charges for 80% of all NAS infants.ⁱⁱⁱ

Opioid Use Disorder: Overall Population

In 2016, about 0.4% of the U.S. population aged 12 and older used heroin during the last year and 0.2% within the last month. These rates are similar to what was seen in 2014-2015, but higher than prior years. Heroin use remains highest among 18-25 year olds, with 0.7% of the population using heroin during the last year in 2016. Heroin use has increased the most among this age group.^{v,vi}

In 2016, approximately 4.3% of the U.S. population aged 12 and older misused prescription opioid pain relievers during the last year, and misuse was highest among adults 18-25 years old (7.1%). The most common types of prescription opioids that were misused were hydrocodone and oxycodone. The most commonly cited reasons for prescription opioid misuse were: to relieve physical pain (62.3%), to feel good or get high (12.9%), and to relax or relieve tension (10.8%). Among those who misused prescription opioids, the most common sources for obtaining the opioids were family or friends (53.0%) or a prescription from a single physician (35.4%).

It is estimated that approximately 20% of patients presenting to physician offices for pain symptoms or pain-related diagnoses receive an opioid prescription. In 2012, health care providers in the United States wrote 259 million prescriptions for opioid pain medication, and per capita opioid prescriptions increased 7.3% from 2007 to 2012.^{vii} One study used pharmacy data to highlight the widespread state-by-state variation in the prescribing of opioid medications. Illinois had one of the lowest per capita opioid prescribing rates in the United States, ranking 43rd out of the 50 states and District of Colombia, at 67.9 prescriptions per 100 persons (the national rate was 82.5 prescriptions per 100 persons). Additionally, Illinois had the second

lowest prescribing rate for long-acting/extended-release opioids and for high-dose opioid pain relievers.^{viii}

In March 2016, the Centers for Disease Control and Prevention (CDC) issued new guidelines related to prescribing of opioids for primary care providers who treat patients with chronic pain in outpatient settings. These guidelines provide recommendations based on the review of evidence for three topics: (1) determining when to initiate or continue opioids for chronic pain; (2) opioid selection, dosage, duration, follow-up, and discontinuation; and (3) assessing risk and harms of opioid use.^{ix}

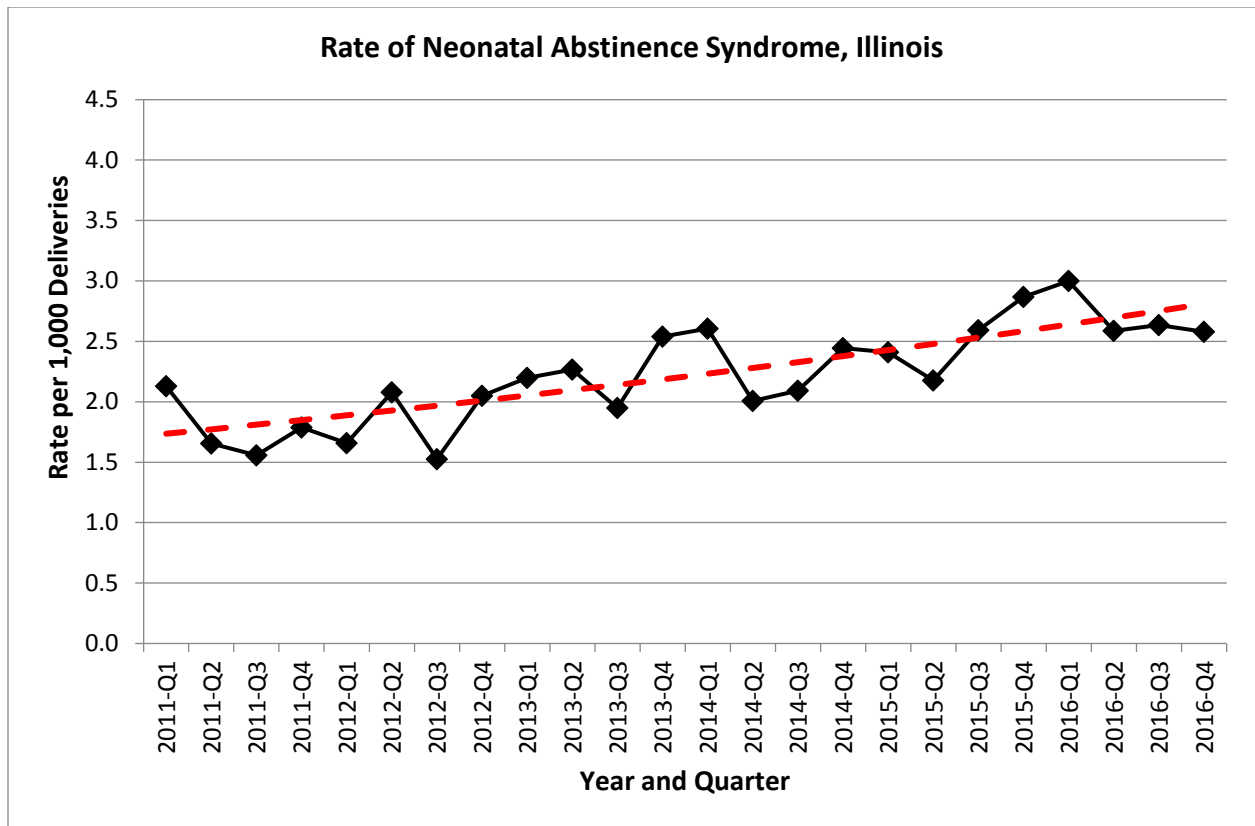
In Illinois in 2013, there were approximately 11,900 persons enrolled in opioid treatment programs receiving methadone and 1,200 persons receiving buprenorphine. The number of persons receiving methadone in treatment programs has remained fairly consistent since 2009, but the number of persons receiving buprenorphine more than doubled between 2009 and 2012.^x

Purpose of This Report

The purpose of this annual report is provide a statutorily mandated update to the IDPH Director, General Assembly, and Governor regarding the Committee's activities and recommendations. (See 20 ILCS 2310/2310-677)

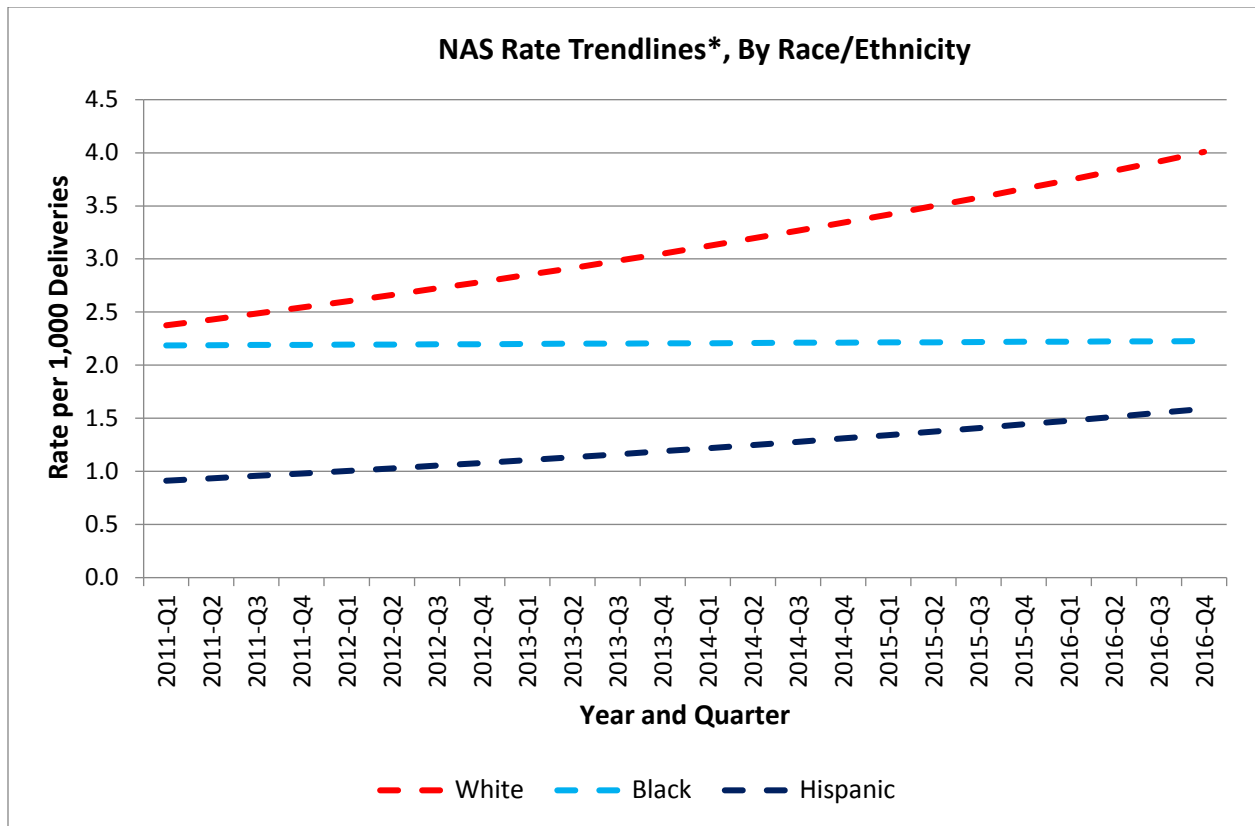
NAS in Illinois

Since 2011, the rate of NAS in Illinois has trended upward. In fact, from 2011 to 2016, there was a 53% increase in the NAS rate in Illinois, according to hospital discharge data for all Illinois hospitals. In 2011, the statewide NAS rate was 1.77, per 1,000 deliveries; in 2016 the NAS rate was 2.70 per 1000 deliveries.



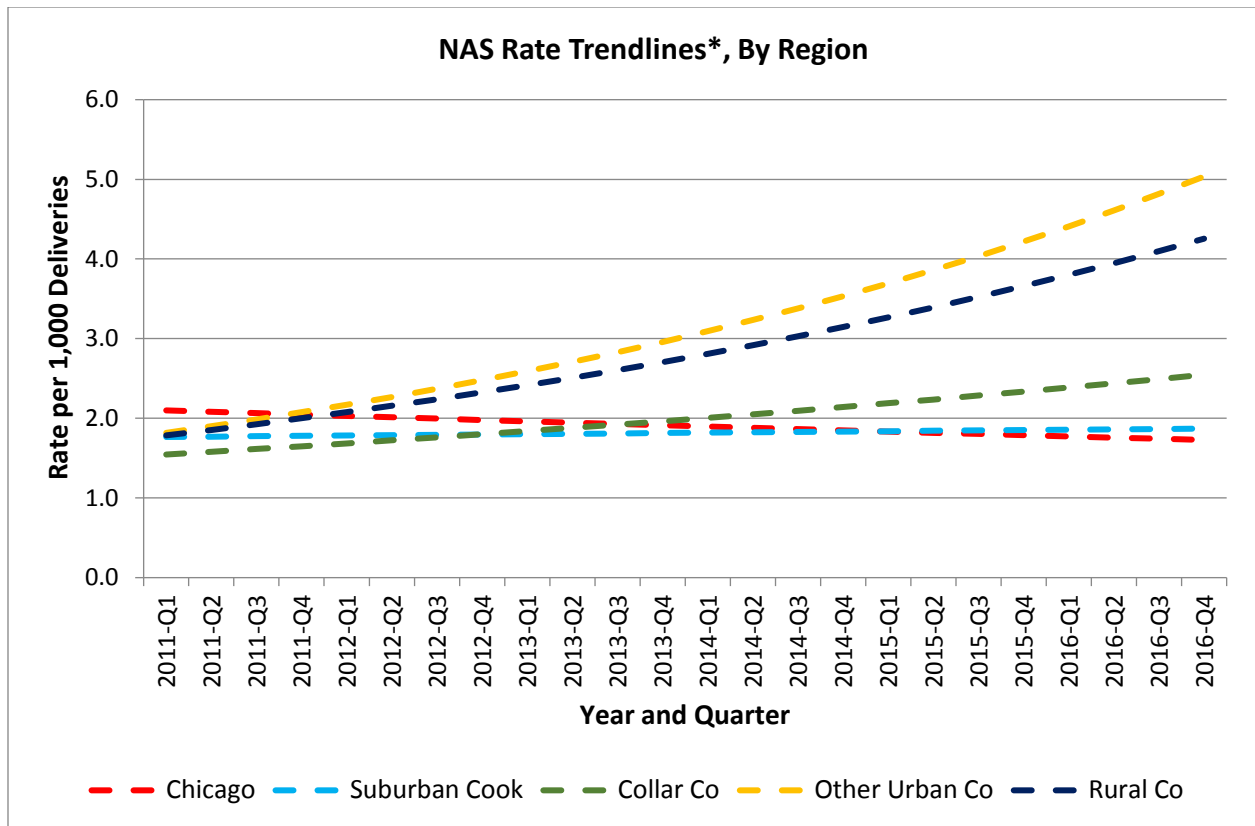
Average increase was 2.1% per quarter over the full time period. ($p < 0.001$)

Illinois hospital discharge data also indicates varied rates of NAS by race, geographical area, and insurance type. Non-Hispanic Whites had the highest rate of NAS (3.8 per 1,000 live births) in 2016 compared to non-Hispanic Blacks (2.3 per 1,000 live births), Hispanics (1.7 per 1,000 live births), and Other/Unknown races (1.5 per 1,000 live births). However, from 2011 to 2016, Hispanics saw the largest percent increase in NAS rates (138%) compared to non-Hispanic Whites (61%) and non-Hispanic Blacks (1%).



** trend lines are based on the predicted values from linear regression of quarterly NAS rates*

The NAS rate is highest in urban counties outside of the Chicago metropolitan area at 5.1 cases per 1,000 live births. The NAS rate is 1.8 per 1,000 in Chicago and Suburban Cook County, 2.0 per 1,000 live births in the Collar Counties (counties contiguous to Cook County), and 3.7 per 1,000 live births in rural counties. However, from 2011 to 2016, the change in NAS rate was highest in rural counties (+223%) compared to Chicago (-9%), Suburban Cook County (+2%), the Collar Counties (+27%), and Other Urban Counties (+127%).



* trend lines are based on the predicted values from linear regression of quarterly NAS rates

Franklin County, Winnebago County, Logan County, and Iroquois County have the highest NAS rates in the state (over 7.0 per 1,000 births). The table below lists Illinois counties, with at least 10 cases of NAS from 2012-2016, from the highest to lowest rates of NAS.

County	Births 2012-2016	# NAS cases 2012-2016	NAS Rate 2012-2016
Franklin County	2242	17	7.58
Winnebago County	17329	130	7.50
Logan County	1604	12	7.48
Iroquois County	1496	11	7.35
Ogle County	2463	15	6.09
Macon County	6533	30	4.59
Jackson County	3351	15	4.48

LaSalle County	5744	25	4.35
Grundy County	3000	12	4.00
Adams County	3850	15	3.90
Sangamon County	11119	42	3.78
Vermilion County	4580	17	3.71
Boone County	2752	10	3.63
Madison County	11350	41	3.61
Tazewell County	7786	28	3.60
Williamson County	3641	12	3.30
Will County	37828	109	2.88
Champaign County	11320	31	2.74
Peoria County	13094	33	2.52
Kankakee County	6260	15	2.40
McHenry County	16032	38	2.37
St. Clair County	12403	29	2.34
Rock Island County	7279	14	1.92
Lake County	39034	75	1.92
Cook County	326129	592	1.82
Kane County	32317	54	1.67
DuPage County	54588	86	1.58

Lastly, the NAS rate is higher among Illinoisans with public insurance (5.1 per 1,000 births) or other/self-pay insurance (4.9 per 1,000 births) than among those with private insurance (0.7 per 1,000 births).

Costs of NAS

Infants with NAS are more likely to have other adverse outcomes and complications at birth, including: low birth weight, respiratory problems, jaundice, feeding difficulties, seizures, and sepsis.^{iii,x} Infants with NAS have longer hospital stays and higher hospital charges than infants without NAS. A national study of 2012 data showed that NAS infants had a mean hospital stay of about 17 days, compared to two days for an uncomplicated term infant. The average hospital charges for an NAS infant were \$66,700 in 2012, compared to about \$3,500 for an uncomplicated term infant.ⁱⁱⁱ Overall, one in twenty-five infants are born experiencing withdrawal,

accounting for an estimated \$1.5 billion in hospital charges.^{xvii} Additionally, infants with NAS are 150% more likely than uncomplicated term infants to be readmitted to the hospital within 30 days after birth.^{xi}

The burden on neonatal intensive care units (NICUs), due to NAS, has increased over time. In one study of hospital NICUs throughout the United States, the percentage of total NICU days attributed to infants with NAS increased from 0.6% in 2004 to 4.0% in 2013 – a five-fold increase. They also demonstrated that length of stay for NAS infants significantly increased by about six days between 2004 and 2013.^{xii}

Implications of NAS

It is difficult to discern the long-term implications of NAS on development due to difficulties isolating the effects of opioids, other substances (e.g., tobacco, alcohol), and other environmental factors.^{xiii} There is some evidence that opioid-exposed infants experience reduced fetal growth, but this could be due to polysubstance use and other environmental factors.^{xiv} Additionally, there is no evidence that opiate exposure has a long-term effect on growth.^{xiii} There is some evidence that opiate exposure increases hyperactivity, short attention spans, and memory and perceptual problems in toddlers and older children.^{xiii}

According to the *New England Journal of Medicine*, there is strong evidence that breastfed infants with neonatal abstinence syndrome tend to have less severe symptoms, require less pharmacologic treatment, and have shorter stays in the hospital than formula-fed infants. There is also emerging evidence that infants who stay in the room with their mothers, known as rooming-in, have shorter hospital stays, duration of therapy, and are more likely to be discharged home with their mothers. Despite the benefits of breastfeeding and rooming-in, the *New England Journal of Medicine* indicates that there are barriers to implementation of these recommendations. With respect to breast feeding, health care providers, unaware of the benefits, do not encourage mothers receiving opioid-replacement treatment to breast feed; these mothers may have difficulty with infant feeding and often, their babies are separated from them and admitted to special-care nurseries. The *New England Journal of Medicine* goes on to state, “institutional limitations, such as lack of funding, lack of personnel, and poor design of hospital units and reluctance to introduce practices based on new evidence may prevent hospitals from providing rooming as a standard practice.”^{xv}

Availability of Substance Use Treatment During Pregnancy

Nationally, there is a dearth of services for women seeking substance use treatment during pregnancy. In 2012, only 2.2% of physicians nationally had received a waiver to prescribe buprenorphine. Of those physicians who did receive this waiver, 25% had not treated any patients since receiving the waiver.^{xvi}

Less than 50% of eligible pregnant women receive MAT during pregnancy nationally. Only 33.2% of eligible women receive MAT during pregnancy in states that permit child abuse charges for illicit drug use during pregnancy, as opposed to 51.33% of eligible women in states without these laws.^{xvii}

In Illinois there are 86 drug treatment resources offering services for women who are pregnant and insured by Medicaid across the state, and 64 of these resources offer MAT. The following counties have at least one MAT resource available to pregnant women: Bond, Boone, Champaign, Cook, Jackson, Jo Daviess, Kane, Kankakee, Lake, Macon, Macoupin, Madison,

McHenry, McLean, Peoria, Rock Island, Saline, Sangamon, St. Clair, Tazewell, Union, Will, Williamson, and Winnebago. Adams, Carroll, Coles, Effingham, Grundy, Iroquois, Jasper, Lee, Livingston, Ogle, Perry, Wabash, and Whiteside counties have substance abuse treatment services for pregnant women, but do not currently offer MAT.

There are a number of innovative models and collaborations to provide pregnant women with substance use treatment across Illinois. The Healthy Southern Illinois Delta Network, comprised of local health departments from Alexander, Franklin, Gallatin, Hardin, Jackson, Johnson, Massac, Perry, Pope, Pulaski, Randolph, Saline, Union, White, and Williamson counties are working together to provide substance use treatment to pregnant women. There are also two integrated prenatal and substance abuse treatment pilot programs serving women in the State. One is located at PCC Wellness, a federally qualified health center (FQHC) system serving Cook County, and another is located at the WISH Center in St. Louis, Missouri.

IDPH has solicited feedback from providers about the provision of substance use services to pregnant women. The feedback received indicates that, across providers, knowledge of, and comfort with, prescribing MAT to pregnant women is inconsistent.

Forging Solutions: Evidence-Based Recommendations to Reduce NAS in Illinois

The Committee has been charged with advising and assisting IDPH to:

1. Develop an appropriate standard clinical definition of NAS;
2. Develop a uniform process of identifying NAS;
3. Develop protocols for training hospital personnel in implementing an appropriate and uniform process for identifying and treating NAS;
4. Identify and develop options for reporting NAS data to IDPH by using existing or new data reporting options; and
5. Make recommendations to IDPH on evidence-based guidelines and programs to improve the outcomes of pregnancies with respect to NAS.

Since its inception, the Committee has grounded all recommendations around these five charges in evidence-based research aiming to reduce NAS in Illinois. The following research has been foundational in the Committee's recommendations.

When developing an appropriate standard clinical definition of NAS, the Committee relied on internal expertise, as well as the definition of NAS from the American Academy of Pediatrics (AAP), which is the leading professional pediatric association, and the March of Dimes (MOD). The AAP defined NAS as "a result of the sudden discontinuation of fetal exposure to substances that were used or abused by the mother during pregnancy."^{xviii} The MOD expands on this definition by highlighting that opiate use is the most common cause of NAS.^{xix} The Committee used this research as the foundation for its definition, but also chose to include the characteristics of NAS in the clinical definition, as the presence of these symptoms is paramount to making an accurate diagnosis.

The Committee consulted research that demonstrates infant outcomes improve when pediatricians and OBGYNs are aware of maternal substance use during pregnancy.^{xx, xxi} ACOG specifically recommends universal substance use screening for all pregnant women throughout pregnancy using validated verbal tools.^{xvii} This is important because drug screening during pregnancy helps identify substance use disorders, which enables early access to treatment. Early access to treatment potentially decreases the co-morbidities of preterm delivery and small for gestational age and low birth weight newborns. Early access to treatment also alerts the

newborn provider that the infant is at risk for NAS, which helps to prevent delayed treatment due to a missed NAS diagnosis. Additionally, the American College of Obstetrics and Gynecologists (ACOG) supports the use of toxicological screening if a woman gives her informed consent.^{xvii} This research informed all recommendations around the need for universal screening throughout pregnancy and at delivery for all women.

Research also indicates a need to approach treating NAS from a new framework.^{xxii} Historically, NAS has been diagnosed using the Finnegan Neonatal Abstinence Scoring System (FNASS). This tool has been largely unchallenged since its inception, despite never being validated, and is used by multiple hospital systems as the primary tool for diagnosing NAS. However, multiple scoring categories on the FNASS may be related to discomfort or fatigue, as opposed to being signs of withdrawal. Thus, there is burgeoning evidence that the FNASS should not be used in isolation as the primary diagnostic tool for NAS. New research also suggests that infants with NAS improve when treated with their mothers in low-stimulation environments and are held, rocked, and comforted, similar to infants without NAS. This new research refutes the notion that pharmacologic interventions are the most beneficial to infants with NAS. The Committee's recommendations around how to diagnose and treat NAS are grounded in this evidence.

Lastly, the Committee's recommendation around early intervention for children with prenatal opioid exposure is based on evidence that the early intervention program improves academic achievement, behavior, and overall development.^{xxiii}

Recommendations

To date, the Committee has made the following recommendations:

Charge 1: Develop an appropriate standard clinical definition of "NAS"

Neonatal Abstinence Syndrome refers to the collection of signs and symptoms that occur when a newborn prenatally exposed to prescribed, diverted, or illicit opiates experiences opioid withdrawal. This syndrome is primarily characterized by irritability, tremors, feeding problems, vomiting, diarrhea, sweating, and, in some cases, seizures.

Charge 2: Develop a uniform process of identifying NAS

Substance use screening using a validated verbal or written questionnaire for all pregnant women. At a minimum, this screening should occur at their first prenatal visit and when presenting for evaluation of labor or for delivery. Toxicology screening should always be considered if it would help guide clinical management.

All infants with history, signs, or symptoms due to prenatal opioid exposure should be referred for early intervention evaluation and subsequent services as indicated. It is recognized that all infants affected by prenatal substance exposure require early intervention evaluation.

All newborn infants with history of or evidence suggesting prenatal exposure to opiates, or with behavioral symptomatology consistent with NAS as defined by this Committee, should be evaluated with a published, reliable tool that indicates the presence and quantifies the severity of NAS. This evaluation should be initiated within two hours of delivery in the case of known opiate exposure, or any time behavioral symptomatology emerges, and repeated on an inpatient basis every three to four hours for at least five

days before the infant is discharged. This can be done while the infant is rooming in with the mother during her hospital course of stay. It is recommended that (1) all physicians, APNs, and nursing personnel are thoroughly trained on the assignment of an abstinence score using the chosen NAS tool, and (2) interrater reliability be measured within each hospital at least on an annual basis. If validated NAS scoring tools become available, they should be implemented.

Charge 5: Make recommendations to IDPH on evidence-based guidelines and programs to improve the outcomes of pregnancies with respect to NAS.

Universal screening, brief intervention, referral, and treatment for substance use among pregnant women in the state of Illinois.

Conclusion

Opioid use disorder is a growing public health crisis across the nation and in Illinois. The incidence of opioid use has significantly increased over the past seven years in the general population, for women of reproductive age, and for pregnant women. Thus, the rate of infants born with NAS has also grown since 2011 in Illinois.

The NAS Advisory Committee was created to address this epidemic and provide guidance and recommendations to IDPH on ways to reduce the incidence of NAS. The Committee has made recommendations in accordance with the Civil Administrative Code of Illinois, Department of Public Health Powers and Duties Law (20 ILCS 2310/2310-677). These recommendations, to date, address charge one, charge two, and charge five of the NAS Advisory Committee. All of the Committee's recommendations are grounded in evidence-based research.

The Committee will continue to make recommendations as required by statute. The Committee is finalizing a "decision tree" that shall be recommended for use by providers to identify and treat NAS effectively, in accordance with charge two of the Committee.

The Committee is working alongside the Illinois Perinatal Quality Collaborative (ILPQC) as they implement quality improvement projects for mothers and newborns affected by opioids across all of Illinois' birthing hospitals. This work will inform the Committee's recommendations around charge three, "developing protocols for training hospital personnel in implementing an appropriate and uniform process for identifying and treating NAS."

Additionally, the Committee will be reviewing findings from the state's NAS enhanced surveillance project, conducted by the Adverse Pregnancy Outcomes Reporting System (APORS) to inform recommendations around charge four, "identifying and developing options for reporting NAS data to IDPH by using existing or new data reporting options." This project is funded by the CDC and March of Dimes and leverages the birth defects surveillance system to identify NAS cases and collect detailed information on these infants. Medical charts for NAS cases that occurred during 2015 and 2016 are currently being abstracted by APORS staff. The information collected will allow for an in-depth analysis of the characteristics of NAS infants, a comparison to the health outcomes of infants without NAS, and an assessment of healthcare expenditures related to NAS.

The NAS Advisory Committee remains committed to recommending solutions that reduce the incidence of NAS in the state of Illinois.

Glossary of Terms

AAP: American Academy of Pediatrics

ACOG: American College of Obstetrics and Gynecologists

APN: Advanced Practice Nurse

APORS: Adverse Pregnancy Outcomes Reporting System

CDC: Centers for Disease Control and Prevention

Committee: Neonatal Abstinence Syndrome Advisory Committee

FNASS: Finnegan Neonatal Abstinence Scoring System

IDPH: Illinois Department of Public Health

ILPQC: Illinois Perinatal Quality Collaborative

MAT: Methadone or Buprenorphine assisted treatment

MOD: March of Dimes

NAS: Neonatal Abstinence Syndrome

NICU: Neonatal Intensive Care Unit

OBGYN: Obstetrician-Gynecologist

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