



Neonatal Abstinence Syndrome Advisory Committee

Annual Report to the General Assembly

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Legislative Mandate

In 2015 the Department of Public Health Powers and Duties Law (section 2310-677) created the Neonatal Abstinence Syndrome (NAS) Advisory Committee. The committee, chaired by the Director of the Illinois Department of Public Health (IDPH), or his designee, is 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 the Department by using existing or new data reporting options; and
5. Make recommendations to the Department on evidence-based guidelines and programs to improve the outcomes of pregnancies with respect to NAS.

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

Background

Neonatal Abstinence Syndrome (NAS) 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.¹

According to Dr. Ira Chasnoff, in a 2015 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 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)¹

Opioid Use and Abuse

Overall Population

In 2014, about 0.3% only of the population 12 and older used heroin nationally; this represents a significant increase over prior years. Heroin use remains the highest among 18-25 year olds, with 0.8% of the population having reported using heroin in 2014. Heroin use increased the most among this age group between 2002 and 2014.²

Approximately 1.6% of the United States population 12 and older used prescription pain relievers for non-medical reasons in 2014. However, non-medical use of prescription pain relievers decreased over time, down from 1.9%-2.1% seen during 2002-2010. Non-medical use of prescription pain relievers is

most common among 18-25 year olds (2.8% in 2014), but this age group also experienced the largest recent decreases in non-medical prescription pain reliever use.³

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 2012.² Another 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 Columbia, 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.³

In March 2016, the Centers for Disease Control and Prevention (CDC) issued new guidelines related to the prescribing of opioids for primary care providers who treat patients with chronic pain in outpatient settings. These guidelines provide evidence-based recommendations 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.²

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 2012.⁴

Women of Reproductive Age

A study of 2008-2012 health insurance claims among women of reproductive age (15-44 years old) showed that approximately 27.7% of privately-insured women and 39.4% of Medicaid-enrolled women

filled a prescription for an opioid from an outpatient pharmacy each year. For both insurance groups, the most commonly prescribed opioids were: hydrocodone, codeine, and oxycodone. Of women who filled an opioid prescription, the average number of per capita opioid prescriptions filled per year was 2.6 prescriptions for privately insured women and 4.3 prescriptions for Medicaid-enrolled women. Older women (30-44) were more likely to have filled an opioid prescription during the last year for both insurance groups. Among Medicaid-enrolled women, Non-Hispanic white women were the most likely to fill an opioid prescription (46.4%, vs. 35.2% among Non-Hispanic black women and 33.6% among Hispanic women). Race/ethnicity information was not available for the privately-insured women.⁵

Pregnant Women

A study of Tennessee Medicaid-enrolled pregnant women found that 28% filled at least one prescription for an opioid pain reliever during pregnancy. Among women prescribed opioids, the vast majority (96%) received short-acting medications (e.g., oxycodone hydrochloride). Within the last 30 days of pregnancy, approximately 8% of pregnant women filled opioid prescriptions, 94% of whom were prescribed short-acting medications.⁶

Neonatal Abstinence Syndrome (NAS)

Descriptive Epidemiology

National surveillance studies have demonstrated that the incidence of neonatal abstinence syndrome (NAS) increased from 1.2 per 1,000 hospital births in 2000 to 5.8 per 1,000 births in 2012 – a 70% increase in only 4 years.^{7,9} 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.⁸ Compared to infants without NAS, infants with NAS were more likely to be male, to reside in low-income zip codes, and be covered by Medicaid.⁸ In 2012, Medicaid was the primary payer for hospital charges for 80% of all NAS infants.⁹

Impact 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.^{8,9} Infants with NAS have longer hospital stays and incur 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.⁸ Additionally, infants with NAS are 150% more likely than uncomplicated term infants to be readmitted to the hospital within 30 days after birth.⁹

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 2013.¹⁰

Relation of NAS to Opioid Use

The Tennessee Medicaid-enrolled pregnant women study found the risk of NAS increased when a woman was prescribed any opioids during pregnancy. Among women with no prescribed opioids, 0.5% of their infants developed NAS (presumably due to illicit use of opioids). If a woman was prescribed

short-acting, long-acting, or maintenance opioids during pregnancy, the percent of infants with NAS respectively increased to 1.4%, 14.7%, and 29.3%. In addition, this study found that NAS risk was increased even more when opioid use was combined with tobacco or selective serotonin reuptake inhibitors (SSRI) during pregnancy.⁷

Another study in Tennessee collected and examined detailed case information for infants diagnosed with NAS. In 2013, 42% of NAS cases involved maternal use of prescription opioids during pregnancy, 22% involved both exposure to a medication prescribed by a health care provider and an illicit/diverted drug, and 33% involved exposure to illicit/diverted substances only. In addition to the clinical signs of NAS, over 98% of cases had at least one of the following: positive maternal screen, positive neonatal drug screen, or history of maternal substance use.¹¹

The summaries in the previous sections mostly rely on studies using national data; very little Illinois-specific information is available from these published reports and studies.

NAS Advisory Committee

Activities

The Neonatal Abstinence Advisory Committee (Appendix I) has been established in accordance with the Act. The committee first met on February 10, 2016 as an orientation. Following are highlights from the meeting:

1. The NAS Advisory Council By-Laws were adopted (Appendix II).

2. The group will meet quarterly for four hours from 1:00 to 5:00. Meetings will be accessible by tele-conference, video, and perhaps adobe connect, if possible.
3. The first task before the group is to establish a common language, including the definition of NAS and current clinical standards
4. Some resources the group would like available for future meetings include:
 - a. Inventory of data available in Illinois (e.g., infants affected, NICU data, interface between Electronic Health Record (EHR) and Prescription Monitoring Program (PMP))
 - b. Overview of state laws and child protective services' policies regarding children born exposed to opioids
 - c. A specialist in Addiction Medicine added to the Committee
 - d. A patient's perspective, either from direct testimony to the Committee or through a clinical caseworker

Recommendations

The Neonatal Abstinence Committee has not established any recommendations to date.

Potential Future Data Analysis in Illinois

To understand the trends and opportunities for prevention in Illinois better, the state can and should conduct analyses using existing data sources.

Hospital Discharge Data

Hospital discharge data is an administrative / billing record available for all hospitalizations in Illinois facilities, including the newborn hospital stay. This dataset includes many fields where diagnosis codes relevant to the hospital stay can be recorded. NAS is identifiable via the presence of the ICD-9

(International Classification of Diseases, version 9) diagnosis code 779.4 in any diagnosis spot on the newborn's discharge record. A time trend analysis of discharge data could examine how NAS rates have changed over time. The benefit to the use of hospital discharge data for NAS surveillance is that it is a relatively simple dataset to analyze and use in case identification.

However, discharge data may underestimate the true NAS incidence rates. A study in Florida showed that linking supplemental data sources such as NICU admission logs and inpatient pharmacy data to hospital discharge data increased NAS case identification by 30%.¹² Supplementing discharge data with data from other sources would likely increase the number of identified NAS cases in Illinois.

Adverse Pregnancy Outcome Reporting System (APORS)

APORS is the IDPH surveillance system for a variety of adverse outcome in infants, including: birth defects, very low birth weight, positive drug screens, and drug withdrawal symptoms. The main purpose of APORS is to identify high-risk infants and to refer these children and their families to the Illinois Department of Human Services' High-Risk Infant Follow-up Program, which provides case management services until the infant is two years old.

There are two categories of high-risk infants reported to APORS that are relevant to NAS. The first is the identification of infants with any positive drug toxicity tests. These tests can also be classified by type of drug. A limitation to the data on these cases is that APORS cannot be used to produce prevalence estimates of prenatal drug exposure because the total number of infants tested for drug exposure is not known. A 2001 APORS report described how the data on drug exposure in pregnancy from this surveillance system are likely to be very incomplete and potentially biased.¹³ There is wide variation

across hospitals in how many and which infants are tested, with some hospitals testing every infant and some hospitals testing only infants perceived to be at higher risk of drug exposure. In hospitals without universal testing, there is likely to be an underestimate of prenatal drug exposure because some exposed infants might not be tested. Additionally, there may be testing bias related to which mothers/infants are screened for drug use, which could distort the observed demographic and geographic patterns in drug exposure. The reportable data on positive drug tests in newborns is useful for referring high-risk infants to follow-up case management services, but it is not likely to be useful for population-based surveillance of prenatal drug exposure.

The second relevant category of high-risk infants reported to APORS is infants with drug withdrawal symptoms, or an NAS diagnosis. Any infants with clinical signs of drug toxicity or exposure are reported by hospitals to APORS for follow-up services. Because drug withdrawal is based on symptoms of the infant during the delivery hospitalization, it should be more complete and unbiased than the drug test data.

Ideally, linking APORS data to hospital discharge data may provide the most accurate count of NAS cases in Illinois. Both data systems have collected data for several decades and could be jointly used to analyze trends in NAS, as well as relevant disparities by demographics or geographic area.

Medicaid Claims Data

Several studies have used Medicaid claims data to examine prescriptions for opioids among women of reproductive age and pregnant women. Pharmacy claims data from the Illinois Department of Healthcare and Family Services could be used for several purposes. The first would be for surveillance of

prescribing patterns and trends over time. Secondly, Medicaid claims data could be used to develop a quality metric that monitors appropriate vs. inappropriate prescribing patterns for women, and particularly for pregnant women. There are not currently any such quality measures endorsed by national quality or Medicaid organizations, but review of the very new CDC guidelines on opioid prescribing² may enable their development. Finally, Medicaid data could be linked to hospital discharge data and/or APORS records to examine the prescription history of women whose infants developed NAS. This may help to provide more information about the prenatal exposure history for NAS infants and to describe the risk associated with various prescribing patterns.

In any of these scenarios, the data would only be relevant to women enrolled in Medicaid, which covers about half of the births in Illinois. However, given that a national study found that over 80% of NAS cases occurred to infants of Medicaid-enrolled women,⁹ this limitation may not be particularly concerning.

Data Summary

While current data on NAS and opioid use are not readily available in published reports or scientific literature, Illinois does have options for using existing data sources to identify NAS cases and to examine opioid prescribing among women. There are not population-based data sources available to estimate the prevalence of heroin or illicit prescription opioid use among Illinois women.

There is also an opportunity to examine the current data collection systems and to determine whether additional information on NAS cases should be collected or current surveillance systems augmented.

For example, APORS could be supported to conduct chart reviews to verify NAS diagnosis and to collect

additional information on drug exposure during pregnancy. The linkage of multiple data sets would also likely increase the case ascertainment of NAS and provide more accurate estimates of NAS incidence among Illinois infants.

Conclusion

The increase in neonatal abstinence syndrome, resulting from the increased use/abuse of opioids by pregnant women, make the work of the NAS Advisory Committee critical to assuring healthy outcomes for Illinois' most vulnerable population. The Committee will continue the process of reviewing state specific available data and expects to be making recommendations in the future on ways to improve the outcomes in regards to NAS.

¹ Chasnoff, I, Gardner, S. (2015). Neonatal abstinence syndrome: a policy perspective – *Journal of Perinatology* (2015) 35: 539-541

² Center for Behavioral Health Statistics and Quality. (2015). *Behavioral Health Trends in the United States: Results from the 2014 National Survey on Drug Use and Health*. (HHS Publication No. SMA 15-4927, NSDUH Series H-50). Retrieved from <http://www.samhsa.gov/data/>

³ Paulozzi LJ, Mack KA, Hockenberry JM. (2014). Vital signs: Variation among states in prescribing of opioid pain relievers and benzodiazepines – United States, 2012. *Morbidity and Mortality Weekly Report*, 63(26): 563-568.

⁴ Substance Abuse and Mental Health Services Administration. (2015). *Behavioral Health Barometer: Illinois, 2014*. (HHS Publication No. SMA-15-4895IL). Retrieved from <http://store.samhsa.gov/product/Behavioral-Health-Barometer-2014/SMA15-4895>

⁵ Ailes EC, Dawson AL, Lind JL, et al. (2015). Opioid prescription claims among women of reproductive age – United States, 2008-2012. *Morbidity and Mortality Weekly Report*, 64(2): 37-41.

⁶ Patrick SW, Dudley J, Martin PR, et al. (2015). Prescription opioid epidemic and infant outcomes. *Pediatrics*, 135(5): 842-850.

⁷ Patrick SW, Schumacher RE, Benneyworth BD, Krans EE, McAllister JM, Davis MM. (2012). Neonatal abstinence syndrome and associated health care expenditures. *Journal of the American Medical Association*, 307(18): 1934-1940.

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- ⁸ Patrick SW, Davis MM, Lehman CU, Cooper WO. (2015). Increasing incidence and geographic distribution of neonatal abstinence syndrome: United States, 2009-2012. *Journal of Perinatology*, 35(8): 650-655.
- ⁹ Patrick SW, Burke JF, Biel TJ, Auger KA, Goyal NK, Cooper WO. (2015). Risk of hospital readmission among infant with neonatal abstinence syndrome. *Hospital Pediatrics*, 5(10): 513-519.
- ¹⁰ Tolia VN, Patrick SW, Bennett MM, et al. (2015). Increasing incidence of neonatal abstinence syndrome in U.S. neonatal ICUs. *New England Journal of Medicine*, 372(22): 2118-2126.
- ¹¹ Warren, MD, Miller AM, Traylor J, Bauer A, Patrick SW. (2015). Implementation of a statewide surveillance system for neonatal abstinence syndrome – Tennessee, 2013. *Morbidity and Mortality Weekly Report*, 64(5): 125-128.
- ¹² Lind JN, Peterson EE, Lederer PA, et al. (2015). Infant and maternal characteristics in neonatal abstinence syndrome – Selected hospitals in Florida, 2010-2011. *Morbidity and Mortality Weekly Report*, 64(8): 213-216.
- ¹³ Fornoff J, Egler T, Shen T. (2001). Surveillance of Illinois infants prenatally exposed to controlled substances, 1991-1999. *IDPH Epidemiological Report Series*, 1(4). Retrieved from: www.idph.state.il.us/about/epi/pdf/Epi01-4.pdf