# Every Infant Counts: Better Data for a Better Response to Neonatal Abstinence Syndrome in Pennsylvania

Family & Community Health

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### A Mother's Story

"This baby saved my life," a mother told me, gazing lovingly but anxiously at her 5-day-old daughter, who was sweating, whimpering and fighting with jittery limbs as her nurse tried to swaddle her. "I don't think I'd be here if it weren't for her." Her daughter was withdrawing from the opioids that were slowly leaving her system after birth. The mother had been using heroin for years, but when she found out she was pregnant, she got her life together, started taking methadone and began regular prenatal care.

The baby, like a third of the other patients in my 30-bed inpatient unit in Boston, was experiencing what's called neonatal abstinence syndrome, or NAS - a postnatal withdrawal syndrome usually caused by opioid exposure during pregnancy. The number of NAS cases is skyrocketing across the country, and some states like Tennessee have seen a 10-fold increase since 1999. Kentucky similarly reports a 11-fold increase in NAS cases between 2001 and 2011. This condition is a consequence of the nationwide opioid crisis that has been attracting so much recent attention from policymakers.

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### Unanswered Questions

NAS is a large and growing problem across the country, including here in Pennsylvania. For example, what populations and which parts of the state are most affected, what are the health and economic costs of NAS, how do infants fare after they leave the hospital, how can we best allocate resources for prevention, and more.

Motivated by my bedside conversations with countless families affected by NAS, I am studying the health care utilization and injury patterns in the first two years of life of infants with NAS as well as the mental health characteristics of their mothers at the Children's Hospital of Philadelphia (CHOP). Together with colleagues Scott Lorch and Molly Passarella of CHOP's Center for Perinatal and Pediatric Health Disparities and Meredith Matone of CHOP's PolicyLab, we are using birth certificates linked to Medicaid claims data to identify a group of young mothers and infants in Philadelphia. Our preliminary results show that mothers of infants with NAS have a high prevalence of several mental health conditions that have lasting negative impacts on both the mother and child. We've also found that in the first two years of life, infants with NAS had more inpatient admissions and fewer well-child visits than those without NAS. Thankfully, children with NAS were not more likely to have fractures or toxic ingestions.

**A Need for Data**

Our research has also confirmed that we need more robust data on families affected by NAS than what administrative data (discharge information created by hospitals for billing purposes) can provide. For example, administrative codes (called ICD-9 codes) can show that an infant has NAS, but there is no record in the mother's claims to identify her as taking opioids during pregnancy (whether prescribed or illicit).

Given the limitations of administrative claims data, we interpret our findings with caution and identify areas of opportunity for future research. For instance, we are further investigating why over 26% of our comparison group – more than 4,000 women – who did not have an infant with the NAS code were prescribed an opioid pain reliever during pregnancy, yet we have a surprisingly small number of infants with the ICD-9 code for NAS in our sample. We also take into consideration the potential for false negatives, which is when infants who were not identified as having NAS during the birth hospitalization may be having withdrawal symptoms at home, which puts them at risk for readmission, poor maternal-child attachment or maltreatment.

These inconsistencies in our linked mother and infant Medicaid claims limit our ability to fully understand the complex interplay of factors within the mother-infant pair that could be targets of interventions to prevent and better manage NAS.

**Better Surveillance for a Better Response to NAS**

In order to adequately address NAS, we must know how many babies it's affecting. That's where making NAS a reportable condition comes in.

Last month, the Pennsylvania Department of Health announced that NAS is now a reportable condition, much like tuberculosis or measles. All babies born dependent on opioids must be reported to the state along with key data about the mother.

Tennessee implemented this kind of statewide surveillance system in 2013, and health officials have already found it useful for detecting real-time trends and opportunities for intervention, opportunities for intervention, as well as determining how mothers were obtaining opioids. The data show that a sizable proportion of mothers were prescribed opioids by a physician, which contradicts widespread assumptions that most were obtained illegally. Florida, where the number of new cases increased nearly ten-fold since 1995, also made NAS a reportable condition in June 2014. The details of Pennsylvania's system are still in the works, but it holds great promise to be a valuable tool for researchers and public health practitioners. Data collection and reporting, however, must be done in a way that does not further stigmatize these families, ensures confidentiality and maintains their trust in the health care and public health systems.

Good surveillance is the foundation for public health interventions. In Pennsylvania, let’s address NAS not with judgment, stigma or stereotyping. Rather, let’s use a high-quality surveillance system to design creative, compassionate and family-centered solutions to this complex public health challenge. Accurate data is imperative to better understand the impact of NAS on infants, families and communities. Every infant counts.