State Data Approaches to Neonatal Abstinence Syndrome

September 16th, 2021
10:00 am-11:00 am EST

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- Thank you!
Today’s Speakers

Karen Scott
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Findings from the study can be found:
https://www.ForeFdn.org
About FORE

Founded in 2018, the Foundation for Opioid Response Efforts (FORE) is a 501(c)(3) private, national, grantmaking foundation focused on one urgent public health emergency – the opioid crisis.

Vision
To inspire and accelerate action to end the opioid crisis

Mission
To convene and support partners advancing patient-centered, evidence-based solutions addressing the opioid crisis

Focus
With patients at the center, our focus includes:

- Professional education
- Payer & Provider strategies
- Policy initiatives
- Public awareness
National Work Across Three Complimentary Activities

- Grantmaking
- Convenings
- Resources & Thought Leadership
National Work Across Three Complimentary Activities

**FORE Convening**
Access to Treatment (5/15/2019)
Family and Community Based Prevention (12/4/2020)

**FORE Grantmaking**
UNC Horizons, University of North Dakota, Renewal House

**FORE Resources & Thought Leadership**
COVID PPW webinar, Dyad Webinar, Issue Brief, Hendree Grantee Spotlight

**Webinar: Supporting the Care of Mother-Child Dyad in Substance Use Disorder Treatment**
March 16, 2021
Join Hendree E. Jones, PhD; Evette Hortan, PhD; Elisabeth Johnson, FNP, PhD; and Essence Hairston, MSW, LCSW, LCAS of UNC

**Foundation for Opioid Response Efforts**
Closing Gaps in the Continuum of Treatment Support Services for Pregnant and Parent Women with Opioid Use Disorder Treatment
March 16, 2021
The care of mothers who have an opioid-related diagnosis when delivering their baby increased 131% between 2010 and 2017, etc...

**Grantee Spotlight**
Helping Women Become and Thrive through Recovery, Opioid with Hendree Jones, Ph.D.
May 15, 2020
Interactive panel, PhD. Bonner

**THE UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL**

**UNIVERSITY OF NORTH DAKOTA**

**RENEWAL HOUSE**
Lay of the Land: How States Collect, Report, and Share NAS Data

Eliza Mette
Policy Associate, NASHP

September 16, 2021
Increasing Incidence of NAS & Burden on States

- Between 2010 and 2017, the rate of NAS diagnoses across states increased by 82%.
- Rates of NAS are also disproportionately high in babies born to people who are uninsured or covered by Medicaid.
- Babies diagnosed with NAS born to Medicaid-covered parents spend more time in the hospital and cost more than babies with NAS born to privately insured parents.
- Overall, Medicaid covered 83% of the costs for NAS births and services, underscoring the significant cost of NAS treatment for states.
State Reporting Obligations Under Federal Law

- Under CAPTA/CARA, states must:
  - (1) Have a system in place to identify and report to child protective services infants who present with substance withdrawal symptoms that indicate NAS, and
  - (2) A process for developing a Plan of Safe Care that addresses the health needs of both the infant and the parent or caregiver.

- CAPTA/CARA did not standardize definitions or data collection processes within states. It falls to states to define NAS, including how providers should diagnose the syndrome and when and how they are required to report infants.
State NAS Data Reporting Strategies

- Mandated reporters include individual healthcare providers and/or health care facilities, such as hospitals and birthing centers.
- Reporting methods range from comprehensive forms completed by providers to passive hospital registries with compiled infant diagnosis codes.
- Timing of reporting can occur within a few days of diagnosis or as part of regular chart review.
State NAS Data Reporting Strategies

NAS data are generally reported to:

- (1) the agency for child protection services in order to create a plan of safe care (POSC) pursuant to CAPTA/CARA, and
- (2) the department of public health for public health surveillance purposes and to address maternal opioid use disorder (OUD) and drug-associated maternal mortality.

Medicaid claims data, including procedure and diagnosis codes, frequently play a key role in state efforts to track NAS as well.
NAS, Parental OUD, and Improving Health Outcomes

- A report of NAS to CPS is generally not a de facto finding of child abuse or neglect.
- Best practice is to treat pregnant people with OUD with medication for opioid use disorder (MOUD)
  - Pregnant people with OUD may be hesitant to engage with the health care system due to fear of repercussions from the criminal legal system and CPS
- Despite siloed data systems, states are making efforts to link, share, and leverage data in order to address NAS and OUD and improve maternal and child health outcomes.
- For more information, see NASHP’s report, [State Approaches to Leveraging NAS Data to Inform Policymaking](#)
Pennsylvania’s Approach

Caryn Decker is a maternal and child health Epidemiology Research Associate in the Pennsylvania Department of Health’s Bureau of Epidemiology, Division of Community Epidemiology. In this role, Caryn provides epidemiological support to the Department’s Bureau of Family Health (BFH). Her work includes analysis and interpretation of data to characterize trends in population health status, contribution to interim and ongoing needs assessment activities, and provision of analytic support to public health programs and surveillance systems housed in the BFH including Neonatal Abstinence Syndrome surveillance, Child Death Review, and Pennsylvania’s Pregnancy Risk Assessment Monitoring System. Caryn received her bachelor’s degree at Dickinson College before pursuing her Master of Public Health (MPH) at the Boston University School of Public Health. She has been with the Department of Health since 2018 and during that time also worked as a public health program administrator. Prior to joining the Department, Caryn worked in research focused on environmental and occupational health.

Chelsea Hammond is a Nursing Services Consultant for the Pennsylvania Department of Health’s Bureau of Family Health, Division of Newborn Screening and Genetics. In this role, Chelsea assists with NAS data collection and analysis to provide ongoing monitoring of NAS program data. Chelsea works directly with birthing facilities to provide technical assistance for reporting of NAS cases, and receives, reviews and summarizes reports and other forms of information regarding NAS to ensure program standards are met. In addition, Chelsea collaborates with other agency and group contacts for data share purposes or other activities to improve outcomes for families and infants impacted by NAS. Chelsea is a Registered Nurse and received her nursing degree in 2009. Chelsea joined the Department of Health in 2020, and prior to that, has worked in various fields of nursing to include: Neurology, Behavioral Health, Medical/Surgical, Maternity and Nursing Management.
Pennsylvania Department of Health
Neonatal Abstinence Syndrome (NAS) Surveillance Program

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September 16, 2021
NAS Surveillance Authority

- 90-day opioid disaster declaration, renewed 15 times
  - Web-based reporting system operational within a month
  - State surveillance definition not defined in statute
  - Effective 2020 - case definition and reporting system evolved

- NAS reporting continues under Department of Health authority
Pennsylvania’s NAS Case Definition

• Criteria for NAS Reporting

All **confirmed** and **probable** NAS and neonatal opioid withdrawal syndrome (NOWS) cases in babies up to 28 days after birth that are showing symptoms of withdrawal due to prenatal exposure to opioids, benzodiazepines, or barbiturates via prescription, medical therapy, or illegal use.

**Confirmed NAS Case**
Positive infant drug screen (within four weeks prior to birth) for opioids, benzodiazepines, or barbiturates, **AND**
- a newborn diagnosis of NAS/NOWS (including, but not limited to ICD-10 codes P96.1, P04.49, P04.14, P04.17); **OR**
- a chief complaint that mentions NAS/NOWS; **OR**
- three or more clinically compatible symptoms of NAS/NOWS.

**Probable NAS Case**
Maternal self-report, positive maternal labs, or history of maternal drug use within four weeks prior to birth, **AND**
- a newborn diagnosis of NAS/NOWS (including, but not limited to, ICD-10 codes P96.1, P04.49, P04.14, P04.17); **OR**
- a chief complaint that mentions NAS/NOWS; **OR**
- three or more clinically compatible symptoms of NAS/NOWS.
NAS Reporting to DOH

- Reporting via iCMS (Internet Case Management System)
  - Web-based software application
  - Developed and supported by Neometrics/Natus
  - Utilized by the Pennsylvania Dept. of Health’s Division of Newborn Screening and Genetics (DNSG)
  - Single, comprehensive data system
NAS Reporting to DOH

- Report all **confirmed** and **probable** cases per CSTE’s definition for NAS
- Submit within four days of discharge or 28 days of life, whichever is sooner
- Do not report:
  - Non-resident NAS cases
  - Suspected cases
Neonate Assessment Scoring (complete all that apply, at least one)

- * Finnegan highest Score
- * Modified Finnegan highest score
- * None
- * Other
- * If Other, please specify the scoring method and the score
iCMS: NAS Reporting Form

Infant Status

Medications or Therapy Used to Treat Infant (check all that apply)
- Clonidine
- Methadone
- Other drug
- Chlorpromazine
- Morphine
- Nonpharmacologic therapy
- Diazepam
- Phenobarbital
- No treatment

Infant Signs/Symptoms of Withdrawal (check all that apply)
- Body shakes (tremors)
- Poor feeding (including poor or excessive suck)
- Loose stools
- Seizures (convulsions)
- Tachypnea
- Vomiting
- Hyperactive Moro reflex
- Fever
- Nasal congestion
- Myoclonus (including hiccups)
- Blotchy skin
- Sneezing
- Hypertonia
- Poor sleep
- Skin abrasions or excoriations
- High-pitched cry
- Lots of yawning

* If other, please specify

[Image: pennsylvania DEPARTMENT OF HEALTH]
<table>
<thead>
<tr>
<th><strong>Laboratory Testing Performed</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>* Was laboratory testing of neonate for substance exposure performed?</td>
</tr>
<tr>
<td>* If yes, what was the source of the lab sample?</td>
</tr>
<tr>
<td>* If other, please specify</td>
</tr>
<tr>
<td>* If positive results, which drug(s) did the infant test positive for?</td>
</tr>
</tbody>
</table>
### Infant’s Discharge Plan

- **Was a notification made to Childline?**
  - [ ] Yes
  - [x] No

- **Was a plan of safe care initiated?**
  - [ ] Yes
  - [x] No

- **If yes, Contact Name for plan of safe care:**
  - [ ]

- **If yes, Contact Phone Number for plan of safe care:**
  - ( ) -
  - Extension

- **Who was the baby referred to post-discharge?**
  - (check all that apply)
    - [ ] Early Intervention
    - [ ] Pediatrician experienced in working with NAS
    - [ ] Developmental assessment clinic
    - [ ] Other
    - [ ] Home visiting services
    - [ ] High-risk infant follow-up clinic
    - [ ] Medical home

- **If other, please specify**
  - [ ]

- **Infant discharge date**
  - [ ]

- **Who was the infant discharged to?**
  - [ ]

- **If other, please specify.**
  - [ ]

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**Pennsylvania Department of Health**
Mother's Discharge Plan

Did the mother's discharge plan include referrals to any of the following? (check all that apply)

- [ ] Continued MAT treatment
- [ ] Parenting support
- [ ] Other behavioral health services
- [ ] Care for substance use
- [ ] Community support programs
- [ ] Other
- [ ] Home visitation services

* If Other, please specify
iCMS: NAS Reporting Form

Antenatal Maternal Drug Use in the 4 Weeks Prior to Delivery

Evidence of any maternal drug use in any medical record (mother or infant)?

Was the mother receiving MAT during pregnancy?

- Alcohol/ethanol
- Amphetamines
- Antidepressants
- Antipsychotics
- Barbiturates
- Benzodiazepines
- Buprenorphine (Subutex or Suboxone)
- Bupropion (e.g. Wellbutrin)
- Cocaine
- Codeine
- Fentanyl
- Gabapentin
- Hallucinogens/inhalants
- Heroin
- Hydromorphone
- Hydrocodone
- Hydromorphone
- Kratom
- Marijuana/hash
- Methadone
- Meperidine
- Methamphetamine
- Morphine
- Naltrexone
- Opiates
- Oxycodone
- Phenycyclidine
- Propoxyphene
- Tobacco/e-cigarettes
- Tramadol
- Other

* If Other, please specify

Relating only to antenatal opioid use, indicate mother’s treatment received during delivery and/or postpartum

- Methadone
- No treatment
- Other
- Buprenorphine (Subutex or Suboxone)
- Unknown

* If Other, please specify
Data Transmission, Storage, and Access

Infant that meets the NAS reporting criteria is identified

Hospital NAS coordinator logs in to iCMS and enters case data

Hospital transmits data via SFTP to the PA iCMS server

Data are accessible to Department of Health staff
Goals of NAS Surveillance

- Estimate incidence of NAS
- Track trends, compare data by region to plan prevention and treatment
- Evaluate effectiveness
- Monitor long term health and developmental effects of in utero exposure to opioids
- Link birthing people with chronic opioid use to treatment
- Allocate resources to provide services to affected families
- Connect families with services aimed at promoting optimal child development and family well being
Additional Goals

• Collect outpatient referral information to guide development of a long-term follow-up program

• Conduct a needs assessment of counties lacking resources to adequately provide care for newborns and their families

• Ensure every newborn receives a referral to Early Intervention and other outpatient services

• Report total number of cases to the Opioid Command Center for the Governor for the duration of the Opioid Disaster Declaration
Thank You

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Kentucky’s Approach

Dr. Henrietta S. Bada is the Mary Florence Jones Professor of Pediatrics and Vice Chair of Academic Affairs, Department of Pediatrics, College of Medicine, University of Kentucky. She also serves as the Director of the Division of Maternal and Child Health of the Kentucky Department for Public Health in the Cabinet for Health and Family Services. She graduated from the University of Santo Tomas in Manila, Philippines. She completed her residency in Pediatrics and fellowship in Neonatology at the University of Louisville. She has a Masters of Public Health from the University of South Florida. Prior to her position at UK, she served as faculty at Southern Illinois University and University of Tennessee. Her areas of research include newborn brain disorders, physiological measurements, perinatal addiction, and developmental follow-up. She has numerous publications on these topics and is the PI of a NIDA grant to carry out a randomized trial on the treatment of neonatal abstinence syndrome.

Tracey Jewell has over 22 years of public health experience practicing Epidemiology. She is currently the Senior Maternal and Child Health (MCH) Epidemiologist with the Kentucky Department for Public Health and serves as Manager of the Program Support branch, which houses all Epidemiologists within the MCH Division. She has mentored several graduate students in public health and has guest lectured in several graduate level MCH and Epi courses. She also manages the Pregnancy Risk Assessment Monitoring System program for Kentucky, the Neonatal Abstinence Syndrome Registry for Kentucky as well as managing several federal grants for the Division of MCH. Tracey also has extensive experience in applying epidemiological principals/methods and data analysis to monitor trends, evaluate programs, establish surveillance systems, and enhance public health programs.
Neonatal Abstinence Syndrome Registry

Henrietta Bada & Tracey Jewell

September 2021

NASHP
- Opioid epidemic/crisis
- Deaths from overdose
- Increase in NAS cases
- Increase in hospital costs
2013: Kentucky General Assembly Enacted

- KRS 211.676: All cases of neonatal abstinence syndrome (NAS) diagnosed among Kentucky resident births shall be reported to the Kentucky Department for Public Health by the facility where NAS is diagnosed. The report shall be made at the time of NAS diagnosis pursuant to guidance issued by the department.

- KRS 211.678 calls for an annual report of de-identified, aggregate statistical data from this reporting.
NAS Trend Kentucky Resident Newborns

Almost 26-fold increase in rate from 0.8/1000 to 20.9/1000

NAS is defined by any mention of the ICD-9-CM codes 779.5 and V3x, or of the ICD-10-CM codes P96.1 and Z38. The U.S. transition to ICD-10-CM occurred on October 1, 2015. The transition to ICD-10-CM should be considered as a possible contributor to any changes in trend observed between 2014 and 2016. Years on the time axis represent the admission date (not the discharge date). *2015 -17 data from NAS State reporting

Produced by Kentucky Injury Prevention Research Center. August 2016

Data source: Kentucky Inpatient Hospitalization Claims Files, Years 2001-2015; Cabinet for Health and Family Services, Office of Health Policy Data for 2010-2017 are provisional and subject to change.
NAS and SUID Rates

**NAS**

NAS Rate per 1,000 live births, by ADD

- 5.95 - 7.35
- 8.19 - 22.24
- 27.26 - 36.82
- 48.89 - 64.98

Statewide Average: 22.35

**SUID**

Rate per 1,000 live births

- <1.25
- 1.25 - 1.50
- 1.51 - 1.75
- >1.75

January 3, 2018
Data Source: Kentucky Child Fatality Review database; Kentucky Certificate of Live Birth, 2011-2016
Shapettes from Kentucky Geography Network
Prepared by Emily Ferrell, MPH CPH
515 cases total for these years
NAS Surveillance Registry

- NAS reportable Disease Form
- Hospital where NAS diagnosed
- ICD 9 Codes: 779.5, 760.70, 760.71, 760.72, 760.73, 760.75, 760.79 subsequently cross walked with ICD 10
- Report infants with symptoms consistent with NAS, treated or not
- Fax completed form DPH/MCH using secure line (changed to web-based data entry) at later date
- Assurance that NAS report is not a report to DCBS/CPS
NAS Surveillance Registry Continued

- Data collected includes:
  - Demographics
    - Mother-including SSN and Medical Record number
    - Infant-including Medical Record number
    - Birthing facility, reporting facility, transfer facility, re-admission
  - Substances
    - Maternal history
    - Maternal test positive
    - Infant test positive
  - Signs/symptoms of NAS
    - Gastrointestinal
    - Neurological
    - Autonomic
  - Maternal MAT therapy
  - Breastfeeding status
  - CPS referral
  - Treatment of infant
    - Pharmacological-type of medication
  - Discharge Disposition
Annual Report

- Available **HERE**
- Sections:
  - Executive Summary
  - Background
  - Data and Results
  - Recommendations for Prevention
2019 Neonatal Abstinence Syndrome (NAS) Data
Reported by Hospital

KHS 211.474 established NAS as a reportable disease and mandatory statewide reporting to the Public Health. NAS Reporting Registry began on July 15, 2014. This registry collects information from Kentucky hospitals on Kentucky resident children who experience signs and symptoms consistent with NAS, and who have a confirmed or suspected history of perinatal substance exposure.

The purpose of the fact sheet is to supplement the Annual Report on 2019 Public Health Neonatal Abstinence Syndrome (NAS) Reporting Registry and to inform planning efforts at your facility. Your participation in this registry and in NAS prevention initiatives is appreciated!

Summary
1600 unduplicated Kentucky resident cases reported statewide
3.63% of births statewide were reported with NAS
62 Kentucky resident cases reported by this facility
This represents 1.69% of births at your facility

Most Common Substances Used, by History and/or Positive Test (a)

<table>
<thead>
<tr>
<th>Substance</th>
<th>History</th>
<th>Positive Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morphine</td>
<td>15 (94%)</td>
<td></td>
</tr>
<tr>
<td>Clonidine</td>
<td>2 (13%)</td>
<td></td>
</tr>
<tr>
<td>Phenytoin</td>
<td>1 (1%)</td>
<td></td>
</tr>
</tbody>
</table>

24% of cases reported from your facility received pharmacotherapy for NAS, compared to 42% statewide. Morphine was prescribed to 94% of infants receiving pharmacotherapy. Statewide, morphine is the most common treatment (82%), followed by clonidine (28%).

Length of stay ranged from 2 to 84 days and averaged 11.3 days, compared with 12.0 days statewide. Cases receiving pharmacotherapy had an average length of stay that was 16 days longer than untreated cases. At your facility, 59% of cases were discharged home and 1% were transferred to another facility.

At your facility, 76% of mothers had a valid prescription for replacement therapy drugs, compared to 45% statewide. This measure is used as a proxy for enrollment in medication-assisted treatment (MAT). Of the 50% of cases reported to DCBS by your facility, 5% had mothers in MAT. This compares to 25% of cases reported to DCBS statewide, of which 42% had mothers in MAT. At your facility, nearly all mothers reported to DCBS were accepted for investigation.

Reports made to DCBS and KDH are not interchangeable. Information about DCBS is current as of the date the case is reported to KDH and may not be accurate for reports made after KDH reporting.
Future Initiatives

- Linkage of NAS registry data:
  - Vital statistics
    - Comparison of NAS infants to general birth population
    - Outcomes included in annual report
  - Medicaid
    - Comparison of NAS Medicaid infants to non-NAS Medicaid infants
    - Assessed ER utilization of NAS Medicaid infants
    - Assessed completion of routine child health exams

- KASPER—Prescription drug monitoring program
  - Signed data use agreement and IRB in place
  - Exchange of data for linking mothers of NAS infants to KASPER
  - MAT vs. other drugs
  - Assess/compare outcomes of infants of mothers on MAT and those who were not
  - Publish any relevant findings
Thank you!
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Discussion

- Your states have both engaged in interagency collaboration in order to address NAS. How did this collaboration begin, what specific policy levers are used to facilitate it, and what platforms are used to maintain it?
- What have you learned about the interrelationship among NAS, maternal OUD, and maternal mortality, and how have you leveraged that knowledge into policy change?
- What has been the most significant innovation in your NAS data collection and how has it led to better policy and improved outcomes?
- If you had a magic wand and could implement policy change immediately, what you would change to tackle this problem and how would you accomplish it?
To ask a question, please use the ‘Q&A’ feature.
Thank You!

Thank you for joining this webinar!

Please complete the evaluation form following this presentation.