

# Neonatal Opioid Withdrawal Syndrome Coalition Lancaster, PA

Community Assessment 2022

#### THE LANCASTER COUNTY NOWS COALITION

The Lancaster County Neonatal Opioid Withdrawal Syndrome (NOWS) Coalition is a multidisciplinary team convened improve the outcomes for mothers and babies affected by NOWS in Lancaster County, Pennsylvania.

The coalition includes representatives from the following entities:

- A Woman's Concern
- Align Life Ministries
- ARS Ephrata
- ARS Lancaster
- Bethany Christian Services Safe Families for Children
- Bethany Christian Services ReNew
- CAP- Domestic Violence Services
- CAP First Ten
- CAP Parents as Teachers
- CAP WIC
- Compass Mark
- DSAA
- Gatehouse
- Gaudenzia/Vantage
- Joining Forces for Children
- Lancaster County Children and Youth
- Lancaster County Drug and Alcohol Commission
- Lancaster County Early Intervention
- LGH Addiction Medicine
- LGH Healthy Beginnings
- LGH Nurse Family Partnership
- Lancaster Osteopathic Health Foundation
- Milagro House
- Millersville University/Opioid Workforce Expansion Program
- Pinnacle Health Lititz NICU
- RASE Project
- SACA
- Union Community Care
- United Way
- Wellspan Foundations Pregnancy Support Systems (FPSS)
- Wellspan, Healthy Beginnings Ephrata
- Women & Babies Hospital

#### **BACKGROUND**

Neonatal Abstinence Syndrome (**NAS**) is a group of conditions that can occur when newborns withdraw from certain substances, including opioids that they were exposed to before birth. Withdrawal caused specifically by opioids during the first 28 days of life is called neonatal opioid withdrawal syndrome (**NOWS**).

NOWS can be linked to neurodevelopmental and behavioral concerns. Longer lasting effects may also manifest in the areas of behavior, cognitive skills, and physical dexterity. Both NOWS and NAS can be determined by using scoring systems and screening tools administered by birthing hospital staff. The Finnegan scoring system assesses several of the most common signs of neonatal withdrawal symptoms based on symptom significance and severity. Many hospitals, including the birthing hospitals in Lancaster County, have transitioned to administering the Eat Sleep Console (ESC) model.

**Eat, Sleep, Console** focuses on three key areas to help separate withdrawal symptoms from normal newborn behavior:

- Eat: Is the baby feeding normally? (Ten minutes at the breast or 10 mL from a bottle)
- Sleep: Is the baby able to sleep for one hour between feedings?
- Console: Can the baby be consoled or comforted within 10 minutes of crying?

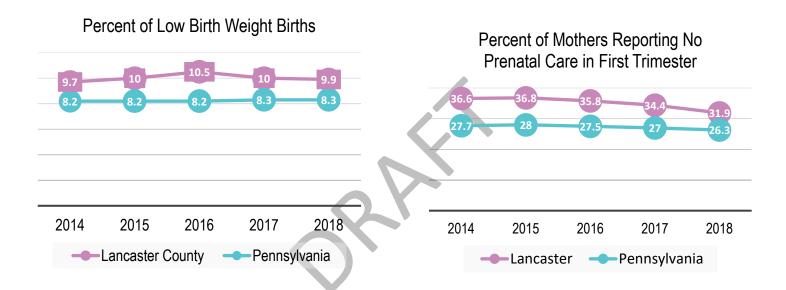
The ESC approach emphasizes the idea of "parent as treatment". This treatment approach incorporates rooming-in, skin-to-skin contact, swaddling techniques, and breastfeeding support. The use of ESC has led to fewer babies needing care in the neonatal intensive care unit (NICU), a decrease in the length of hospital stays, and decreased use of medications to manage the baby's withdrawal symptoms.

#### PENNSYLVANIA TRENDS

#### MATERNAL AND CHILD HEALTH INDICATORS

The Maternal and Child Health Indicators below are reported by the Pennsylvania Department of Health's Informatics Division. Information is available from selected birth certificates at the state and local levels. Current and historical maternal and child health indicator reports are available on the department's website.

(https://www.health.pa.gov/topics/HealthStatistics/Pages/health-statistics.aspx)



Additional maternal and child health indicators are reported through the Pregnancy Risk Assessment Monitoring System (PRAMS). The PRAMS survey is sent to new mothers asking questions about the care they received, and their experiences, and behaviors around the time of their most recent pregnancy. PA PRAMS is a joint research project between the Pennsylvania Department of Health, the Bureau of Family Health, and the Centers for Disease Control and Prevention (CDC). Names are selected randomly, on a monthly basis, from the state birth certificate registry. About 1,800 individuals are chosen each year to participate in the study. (CDC, 2021)

PRAMS data for Pennsylvania from 2017 indicate that:

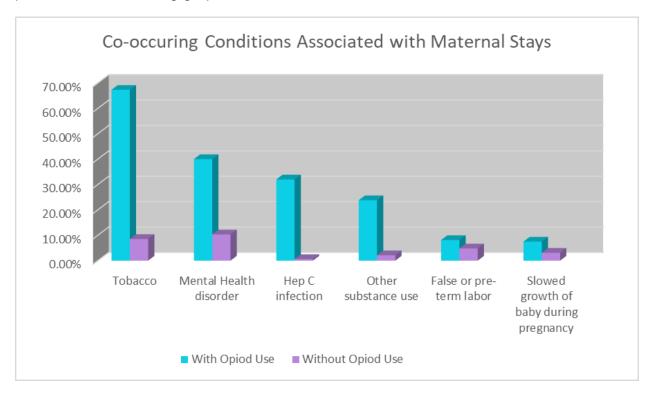
- 3.2 percent of individuals reported heavy drinking (8 or more drinks in one week) during the 3 months before their pregnancy
- 10.5 percent of individuals reported any cigarette use during the last 3 months of pregnancy

- 6.4 percent of individuals reported any e-cigarette use during the last 3 months of pregnancy
- 14.0 of individuals surveyed identified self-reported depression during their pregnancy.

Using self-reported data from the PRAMS, about 7% of women reported using prescription opioid pain relievers during pregnancy (CDC, 2021). Of those, 1 in 5 reported the misuse of prescription opioids. Opioid misuse during pregnancy presents additional risks to the unborn child. Conversely, complete detoxification from opioids presents an increased risk of fetal distress and loss of pregnancy.

#### MATERNAL AND NEONATAL HOSPITALIZATION

Neonatal abstinence syndrome was present in nearly 1 in 50 neonatal hospital stays in Pennsylvania in 2015. In 2018, an estimated 3,350 Pennsylvania newborns were exposed to substances prior to their birth, but only 55% were diagnosed with NAS (PA Health Care Cost Containment Council, 2018). Maternal hospital stays with opioid use were more likely to have the following co-occurring conditions and indecent rates, as plotted on the following graph<sup>1</sup>.



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<sup>&</sup>lt;sup>1</sup> Pennsylvania Health Care Cost Containment Council (PHC4) (2018).

#### **LANCASTER COUNTY OVERVIEW**

Lancaster County is located in South Central Pennsylvania along the Susquehanna River. It is an area of just 984 square miles, houses a population of about 540,999 residents. (2019 American Community Survey) Lancaster County is home to a diverse population with agricultural roots, a large Amish community (about 39,000 members as of June 2019), 60 municipalities, a third-class city, and a strong sense of history.

With easy access by car, bus, or train to five major urban cities (Philadelphia, Washington DC, New York City, and Baltimore), Lancaster County allows for opportunities to experience a mix of rural serenity or the hustle and bustle of the big city. Lancaster County's nine higher-education institutions coupled with just shy of twenty retirement communities help to create a beautiful melting pot of individuals and experiences.

With approximately 204,700 households in Lancaster County, only 26% (53,222 households) include children. Of the households with children, 7,589 households reported a new birth within the past twelve months. Lancaster County households reporting new births have steadily increased by about 21.9% since 2015. The majority of babies are born to mothers ages 20-34. (2019 American Community Survey)

#### CHILD WELFARE

The number of reports that Children and Youth received has steadily increased since 2012. The increase is due, in part, to parental substance use. This has resulted in an increase in the number of Children and Youth investigations, but also a significant increase in the number of young children being referred to Early Intervention for an evaluation. Both agencies report higher caseloads, staff turnover, and an increase in spending. Despite these very real challenges, they continue to explore innovative and collaborative ways to serve children and families. This includes exploring ways to identify children at risk as early as possible – including the implementation of **Plans of Safe Care.** 

A **PLAN OF SAFE CARE** is designed to improve the health, safety, development, and well-being of a mother, infant, and the infant's family/caregiver by identifying, guiding, and directing appropriate services and supports.

Any infant or pregnant individual will be offered the option to work with a multidisciplinary team to develop their own *PLAN OF SAFE CARE*. In Lancaster County, the offer to develop a plan will be offered to any pregnant individual regardless of the substance(s) they may have used at any point during their pregnancy.

Special funding was made available to child welfare agencies to support the implementation of Plans of Sare Care. Lancaster County Children and Youth Agency contracted with Joining Forces for Children to do a community awareness educational campaign about Plans of Safe Care. The campaign includes print materials, an animated explainer video, and web-based targeted advertising. See <a href="majorage-appendix##">appendix ##</a> for sample campaign materials.

The Lancaster County Child Welfare Agency has explored other ways to ensure the health and wellbeing of families. This includes partnering with the Drug and Alcohol Commission to host a **Recovery Specialist** from The RASE Project. This dedicated recovery specialist functions in an intake capacity to help get families stabilized during a crisis. The Recovery Specialist connects caregivers to treatment and/or recovery support to help them regain their health in order to safely parent their child(ren). Since September 2018, the recovery specialist has received 287 referrals to work with caregivers whose children are 0-2 years old. The Recovery Specialist's clients range in age from 18 to 38 and have an average of 2 children living in their household.

#### **EARLY INTERVENTION**

Infants and toddlers who are prenatally exposed have the best outcomes when they and their caregivers engage in Early Intervention (EI) services. The **PLANS OF SAFE CARE** for Lancaster County allows the Early Intervention team to meet with caregivers prior to delivery, explain the EI evaluation process, what kinds of services and supports they can provide, and answer questions from families. Moving this process further upstream for families helps them prepare for the arrival of the baby.

From June 7, 2017, to April 21, 2021, there were 257 infants identified with a referral reason for prenatal drug exposure. 82% of those families remained engaged with Early Intervention services.

## **NEONATAL ABSTINENCE SYNDROME (NAS)**

In 2018, there were 2,140 reported cases in Pennsylvania of NAS infants who were prenatally exposed to opioids and were also symptomatic. Prenatal exposure due to prescription opioid use, medication-assisted treatment (MAT), or illegal use are all counted in the reported cases. In Lancaster County, there were 67 NAS infants in 2018. (PA Department of Health, 2019). These infants represent about 1% of the total births in Lancaster County in 2018.

Between January 2020 and August 2021, there were a total of 60 births that had prenatal substance exposure at Women's and Babies Hospital. Once discharged, 86% of the babies that were included in the report had gone home with their parents. For

those infants not discharged to their parents, five were placed in the custody of Children and Youth and three were discharged with other caregivers.

All of sixty births were reported to Childline, though only 56 participated in a Plan of Safe Care. It is also important to note that 86% of the identified infants were referred to Lancaster County Early Intervention (EI). Referrals were also made to home visiting services and medical homes or primary care facilities, in addition to EI in some cases.

#### ACCESS TO CARE FOR SUBSTANCE USE DISORDERS

#### **MEDICATIONS FOR ADDICTION TREATMENT (MAT)**

The national standard of care set by the American College of Obstetricians and Gynecologists (ACOG) and the American Society of Addiction Medicine (ASAM) is to initiate or maintain pregnant patients on opioid agonist medications such as methadone or Subutex. Medication maintenance programs have the benefits of sustaining opioid concentrations in the mother and fetus in amounts that minimize opioid cravings, suppress abstinence symptomatology, block opioid-induced euphoria, and prevent fetal stress. Other benefits include increased compliance with prenatal care and maternal physical and mental health, as well as anticipation of potential withdrawal signs in the newborn infant.

In Lancaster County, pregnant patients have the opportunity to initiate medication for opioid use disorder in an outpatient setting including the county opioid treatment program (also referred to as "methadone clinic"). Each hospital system and the county Federally Qualified Health Center (FQHC) can provide medication for opioid use disorder (MOUD) along with care coordination for their patients. Additional wrap-around services are available through community-based providers.

Similarly, pregnant patients who are incarcerated can access prenatal care including MOUD and case management through a strong network of providers.

#### INPATIENT CARE

Some of the issues reported by pregnant patients with substance use disorders are inadequate child care and a lack of transportation. Many inpatient facilities require that patients be stable on MAT prior to being admitted. Patients must provide dosing records, a current ultrasound, prenatal records, and a letter from their prescribing doctor stating that they will be accepted back into treatment after their in-patient stay or the baby is born. If the patient is not currently receiving prenatal care, they will need medical clearance from a doctor.

Circumstances that will impact a pregnant person's ability to participate in inpatient treatment:

- Greater than 28 weeks gestation
- currently prescribed a high dose of Methadone
- significant mental health needs

#### **OUTPATIENT CARE**

Pregnant patients requiring access to outpatient care have access to programming through the hospital systems. Though the programs differ slightly, they all include a team approach where the patient has access to a nurse and social worker to holistically meet the needs of the patient, prepare them for their baby's arrival, and provide ongoing care coordination during the baby's first year of life. Programs are funded through grants and are available for free to patients who meet income eligibility requirements.

Throughout Lancaster County, access to ongoing treatment of substance use disorders is happening in a family practice setting through a block scheduling appointment. During these appointments, patients meet with the provider to medically manage their illness as appropriate and meet with their care coordinator during the same visit to address other areas of need.

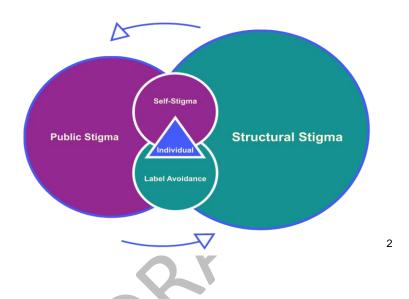
Other ancillary services, including peer support, are available through community-based providers. Coalitions, like the NOWS Coalitions, keep hospital-based and ancillary service providers connected to foster communications and a robust referral network. The coalition can also serve as a mechanism for sharing updated guidance and best practices that meet the needs of substance-affected infants and their families.

#### STIGMA

It is well documented that negative attitudes and beliefs about people who use drugs (stigma) interfere with their readiness to ask for and accept help. These negative attitudes and beliefs held by friends, family, and some professionals lead to negative experiences seeking care (Shatterproof, 2021). Lancaster Joining Forces recently conducted a community-wide survey to understand the impact of stigma on individuals with substance use disorders and/or mental illness. The results of the survey will be available in Spring 2022.

Stigma creates an environment in which addiction thrives. Stigma also creates barriers to treatment by devaluing the person with a SUD and increasing social isolation.

People with SUDs feel the burden of stereotypes and fear, causing *self-stigma* and a lack of trust in themselves. Fear of judgment also leads to *label avoidance*, a process in which individuals avoid being identified as people who would need treatment and forgo needed services (Corrigan, 2014). When met with negative publicly held views towards substance use, the individual suffers discrimination and isolation. Structurally, institutions and regions add to discrimination by making it harder for people who have a history of substance use to receive treatment for their disease.



The sharing of positive stories of recovery and opportunities for people to meet and interact with people in recovery are two strategies that have evidence to support their effectiveness. In Lancaster County, activities and resources such as those listed below, demonstrate some of the work being done to reduce negative attitudes and beliefs about people who use drugs.

- Recovery Day Lancaster, a celebration of recovery and opportunity for the community at large to "see what recovery looks like", now in its 9th year
- Lancaster Newspaper's BALANCE Magazine series, We Recover, presented by Penn Medicine Lancaster General Health, Lancaster Joining Forces, and the Lancaster County Recovery Alliance with support from Culliton Foundation and Retreat Behavioral Health
- Lancaster County Recovery Alliance's Media Education Project
- Lancaster County Recovery Alliance's Building Recovery Capital Project
- Speaking engagements from The RASE Project's In My Own Words Speakers Bureau

<sup>&</sup>lt;sup>2</sup> P. Corrigan (2014)

#### **FAMILY SERVICES**

Addiction is an illness that affects families, and as such, requires a family approach to treatment and recovery. Increasing access to family services ensures that all family members receive education and skill-building to recover from the family illness of addiction.

Parents and caregivers in various stages of recovery need support. Programs that include parenting skills and education, attachment-building activities, self-management, emotional regulation, and effective communication all contribute to the healing of individuals and families.

In Lancaster County, it is estimated that there are 32,000 individuals under the age of 18 living with someone suffering from a substance use disorder. Children are often the first to be impacted and the last to get help when addiction is in the family. Children impacted by addiction often experience an environment of secrecy, loss, conflict, violence or abuse, emotional chaos, role reversal, and fear. Infants and toddlers may miss out on early opportunities for bonding and attachment due to substance use.

To protect children and improve the overall wellbeing of the family, families need supports and services that keep the family intact while promoting healthy attachment and bonding, strengthening parenting skills, and building recovery capital.

## SUBSTANCE USE PREVENTION

Substance Use Prevention is about preventing the use and misuse of substances. Prevention programs and practices that are effective in changing behaviors and improving public health are called evidence-based practices. Through prevention science, we know that individuals have different levels of risk for developing a substance use disorder (Substance Abuse and Mental Health Services Administration [SAMHSA], 2017). To address the varying levels of risk, prevention activities are offered in three different ways. They are:

**Universal prevention** reaches the general population (e.g. *all adults or all children*);

**Selected prevention** targets groups who have an above-average risk of developing a SUD (e.g. *children of people who use substances*);

**Indicated prevention** is for those whose actions put them at high risk for substance use (e.g. *risky behaviors or proximity to someone who is using substances*).

Substance use prevention saves more than \$740 billion annually in spending related to crime, decreased work productivity, and health care expenses, according to SAMHSA's Center for Substance Abuse Prevention (2008). An investment in prevention programming brings in an average return of \$18 for every \$1 spent.

Substance use prevention for pregnant and parenting people is viewed as a key way to mitigate the health consequences experienced by substance-affected infants. Providers should discuss NAS/NOWS with women who have a history of substance use or are prescribed medications to treat behavioral health conditions (MOUDs, antidepressants, benzodiazepines, etc.).

#### HARM REDUCTION

Harm reduction includes a spectrum of strategies such as: safer use, managed use, abstinence, and meeting people who use drugs "where they're at." Harm Reduction focuses on treating people who use drugs with dignity and respect. In its principles, harm reduction acknowledges that people make health decisions based on their unique needs and circumstances. Effective harm reduction strategies for pregnant and parenting include:

- Affirming Dignity People who feel respected and trusted are more likely to be honest with their providers and seek the help available to them.
- Co-location of Services For participants experiencing the barriers of childcare, transportation, and others, having a single access point for supportive services provides greater opportunities for individuals and families to actively engage in services.
- Medications for Opioid Use Disorder (MOUDs) –
- Motivational Interviewing (MI) Motivational interviewing is a participant-centered way of interacting that promotes change and builds readiness to participate in treatment.
- Naloxone responding to overdose in a pregnant person is exactly the same, and can be safely reversed if treated in time with naloxone and emergency medical attention
- Peer Support A Recovery Specialist, with lived experience, is a role model, mentor, advocate, and motivator.
- Screening and Referrals One evidence-based approach is Screening, Brief Intervention, and Referral to Treatment (SBIRT) method.

#### STRATEGIES TO ADDRESS IDENTIFIED BARRIERS

#### I. Prevent substance use during pregnancy

- 1.1 Raise awareness about the impacts of prenatal substance use across the community, but especially for individuals of reproductive age (all genders)
- 1.2 Promote messages of no substance use among families who are planning pregnancies via targeted advertising and healthcare providers
- 1.3 Promote the use of universal screening and use of Screening, Brief Intervention and Referral to Treatment (SBIRT)

#### II. MITIGATE THE IMPACTS OF SUBSTANCE USE DURING PREGNANCY

- 2.1 Increase Access to MAT programs
  - 1) childcare
  - 2) transportation
- 2.2 Provide access to naloxone kits and education about overdose prevention and responding to overdose incidents
- 2.3 Promote harm reduction strategies, as allowable by law
- 2.4 Encourage providers to be trained in motivational interviewing
- 2.5 Encourage the use of plans of safe care

#### III. INCREASE ACCESS TO EVIDENCE-BASED FAMILY SERVICES

- 3.1 Access to education for parents and families in recovery
  - 1) child development
    - 2) parenting skills (discipline, communication, boundaries)
    - 3) repairing/rebuilding relationships
    - 4) attachment and bonding
- 3.2 Support for partners/caregivers (including kinship and resource families)
  - 1) understanding addiction, treatment, and recovery
  - 2) understanding the specific needs of babies with NOWS/NAS
  - 3) knowledge of local services and how to access them
- 3.3 Support for children impacted by substance use
- 3.4 Family-based, trauma-informed treatment options
  - 1) functional family therapy
  - 2) attachment-based family therapy

#### IV. INCREASE COMMUNICATION AMONG PROVIDERS ACROSS SECTORS

- 4.1 Host bi-monthly NOWS Coalition meetings
- 4.2 Facilitate working groups as needs are identified

# V. REDUCE NEGATIVE ATTITUDES AND BELIEFS ABOUT PEOPLE WHO USE SUBSTANCES

- 5.1 share stories of recovery in collaboration with the Lancaster County Recovery Alliance and Lancaster Joining Forces
- 5.2 provide education for NOWS partners and the broader community about substance use and recovery
- 5.3 promote the use of evidence-based terminology (ex: person-first language)



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