Substance Exposed Newborns and Part C: New Challenges and New Opportunities

IDIO Conference
August 2018
Neonatal Abstinence Syndrome (NAS)

A drug withdrawal syndrome that presents in newborns after birth when transfer of harmful substances from the mother to the fetus abruptly stops at the time of delivery. Most frequently due to opioid use in the mother, but may also be seen in infants exposed to benzodiazepines, and alcohol.
Fetal exposure usually occurs for one of three reasons:

- Mothers are dependent/addicted to opioids, either prescribed or illicit.
- Mothers require prescription opioids for another disease process.
- Mothers receive Medicaid Assisted Therapy (MAT) to facilitate safe withdrawal from addiction to prescription or illicit opioids.
Some states have more painkiller prescriptions per person than others.

Number of painkiller prescriptions per 100 people:
- 52-71
- 72-82.1
- 82.2-95
- 96-143

SOURCE: IMS, National Prescription Audit (NPA™), 2012.
Prescribing Rates per 100 Persons

United States

- Opioid pain relievers: 82.5
- Long-acting extended release opioid pain relievers: 10.3
- High-dose Opioid pain relievers: 4.2
- Benzodiazepines: 37.6
Drug Overdose Rates by State

US Resident Overdose Deaths by State, 2015

<table>
<thead>
<tr>
<th>State</th>
<th>Age-Adjusted Rate Per 100,000 Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>NH</td>
<td>34.3</td>
</tr>
<tr>
<td>VT</td>
<td>16.7</td>
</tr>
<tr>
<td>MA</td>
<td>25.7</td>
</tr>
<tr>
<td>RI</td>
<td>28.2</td>
</tr>
<tr>
<td>CT</td>
<td>22.1</td>
</tr>
<tr>
<td>NJ</td>
<td>16.3</td>
</tr>
<tr>
<td>DE</td>
<td>22.0</td>
</tr>
<tr>
<td>MD</td>
<td>20.9</td>
</tr>
<tr>
<td>DC</td>
<td>18.6</td>
</tr>
</tbody>
</table>

Data Source: CDC Wonder
Changes from 2015-2016

Drug Overdose Deaths per 100,000 Residents


Source: National Center for Health Statistics, CDC
Prevalence of Maternal Opioid Use

Rate per 1,000 births/year

- 2000: 1.1
- 2001: 1
- 2002: 1.2
- 2003: 1.2
- 2004: 1.4
- 2005: 1.6
- 2006: 2.1
- 2007: 2.1
- 2008: 2.4
- 2009: 2.9
- 2010: 3.9
- 2011: 3.9
- 2012: 4.9
- 2013: 5.7
- 2014: 6.5
Prevalence of NAS

Rate per 1,000 births/year

- 2000: 1.2
- 2003: 1.5
- 2006: 1.96
- 2009: 3.39
- 2012: 5.8
- 2013: 6
NAS Incidence Rates 2012-2013
DRAMATIC INCREASES IN MATERNAL OPIOID USE AND NEONATAL ABSTINENCE SYNDROME

The use of opioids during pregnancy can result in a drug withdrawal syndrome in newborns called neonatal abstinence syndrome (NAS), which causes lengthy and costly hospital stays. According to a new study, an estimated 21,732 babies were born with this syndrome in the United States in 2012, a 5-fold increase since 2000. Every 25 minutes, a baby is born suffering from opioid withdrawal.

Average length or cost of hospital stay:

<table>
<thead>
<tr>
<th></th>
<th>With NAS</th>
<th>Without NAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length</td>
<td>16.9</td>
<td>2.1</td>
</tr>
<tr>
<td>Cost</td>
<td>$66,700</td>
<td>$3,500</td>
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</table>

NAS and maternal opioid use on the rise:

<table>
<thead>
<tr>
<th>Long Term Effects</th>
<th>Nicotine</th>
<th>Alcohol</th>
<th>Marijuana</th>
<th>Opiates</th>
<th>Cocaine</th>
<th>Meth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Growth</td>
<td>No Consensus</td>
<td>Strong Effect</td>
<td>No Effect</td>
<td>No Effect</td>
<td>No Consensus</td>
<td>No Data</td>
</tr>
<tr>
<td>Behavior</td>
<td>Effect</td>
<td>Strong Effect</td>
<td>Effect</td>
<td>Effect</td>
<td>Effect</td>
<td>No Data</td>
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<tr>
<td>Cognition</td>
<td>Effect</td>
<td>Strong Effect</td>
<td>Effect</td>
<td>No Consensus</td>
<td>Effect</td>
<td>No Data</td>
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<tr>
<td>Language</td>
<td>Effect</td>
<td>Effect</td>
<td>No Effect</td>
<td>No Data</td>
<td>Effect</td>
<td>No Data</td>
</tr>
<tr>
<td>Achievement</td>
<td>Effect</td>
<td>Strong Effect</td>
<td>Effect</td>
<td>No Data</td>
<td>No Consensus</td>
<td>No Data</td>
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</table>
Thirteen States addressing NAS issue:

2015:
- Twenty states addressing NAS issue

2016:
- Eight states: Extensive efforts
- Twenty-three states: Some efforts
- Nine states: Beginning to address

2017:
- Twenty states addressing NAS issue
So what does this mean for Part C?
Implications for Service Delivery

- Increasing referral numbers
- Understanding the impact of drug exposure or NAS on infant development (Assessment and Intervention)
- Understanding the needs of mothers experiencing addiction
- Collaborating with other community partners to support family needs
- Potential need for specialized service coordination
Substance Exposed Newborns and Part C: New Challenges and New Opportunities
West Virginia Versus United States

2001-2016 Resident Drug Overdose Mortality Rates
West Virginia and United States

Data Source: WV Department of Health and Human Resources, Health Statistics Center, Vital Surveillance System and CDC Wonder
Rates are age-adjusted to the 2000 US Standard Million
Economic Impact


US Total Costs - $503,640,006,000
• In October, 2016 WV started documenting births impacted by substances

• WV now gathers each baby’s exposure to substances and diagnosis of NAS at birth
Tracking Data Through Birth Score

• West Virginia’s Birth Score Program started collecting Intrauterine Substance Exposure and NAS data October 1, 2016.

• What exactly is collected?
  • Intrauterine Substance Exposure
    o Includes any medication prescribed and not prescribed by a physician that has a psychoactive affect
  • How Intrauterine Substance Exposure is documented
    o Self-reported, documented in prenatal record, positive maternal drug test, unknown, other
  • Infant has clinical signs consistent with NAS diagnosis
Percent Infant Drug Exposure at Birth

Legend
Percent
8.35 - 12.00
12.01 - 14.00
14.01 - 17.00
17.01 - 20.00
20.01 - 26.00
Suppress

Percent prevalence of intrauterine substance exposure
Percent Babies Diagnosed with NAS at Birth
Collaboration with initial health care providers

WV has newborn centers which are specializing in treatment of infants with NAS

Referrals of these babies to Part C may come directly from the hospital, or through CPS
Increase in CPS Referrals to WVBTT

CPS Referrals to WV Birth to Three

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<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Total CPS Referrals</td>
<td>332</td>
<td>324</td>
<td>381</td>
<td>427</td>
<td>425</td>
<td>559</td>
<td>672</td>
</tr>
</tbody>
</table>
Eligibility for WV Birth to Three

Concerned about babies born with FAS who may not be identified

Babies are evaluated closely to determine if the child meets our eligibility criteria in any way

Maternal Substance Exposure is an At-Risk factor

NAS is not an automatic eligibility in WV Birth to Three
WV Birth to Three Enrollment

Number of Children

- 2012: 5233
- 2013: 5677
- 2014: 6029
- 2015: 6469
- 2016: 6471
- 2017: 6735
SSIP Professional Dev. Activities

- Monthly Webinars on Key Topics
- Understanding Impact of Substances on Child Development – Short and Long Term
- Understanding What Families Need
- Understanding Impact of ACES
Home Visiting

Maternal, Infant, and Early Childhood Home Visiting Program

The Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV) gives at-risk pregnant women and families necessary resources and skills to raise children who are physically, socially, and emotionally healthy and ready to learn.
# Home Visiting Benchmarks

<table>
<thead>
<tr>
<th>BENCHMARKS</th>
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<tbody>
<tr>
<td><strong>Left Column</strong></td>
</tr>
<tr>
<td>Improved maternal and newborn health</td>
</tr>
<tr>
<td>Improved school readiness and achievement</td>
</tr>
<tr>
<td>Improved family economic self-sufficiency</td>
</tr>
<tr>
<td><strong>Right Column</strong></td>
</tr>
<tr>
<td>Reduced child injuries, abuse, and neglect</td>
</tr>
<tr>
<td>Reduced crime or domestic violence</td>
</tr>
<tr>
<td>Improved coordination and referrals for community resources</td>
</tr>
</tbody>
</table>
Final Thoughts

1. Identify children as early as possible.
2. Understand mother and child.
3. Develop protective factors.
4. Deliver evidence-based programs.
5. Support families in recovery.
Indiana
Christina Commons
Part C Coordinator
Vision:

• All perinatal care providers and all hospitals have an important role to play in assuring all babies born in Indiana have the best start in life.

• All babies born in Indiana will be born when the time is right for both the mother and the baby.

• Through a collaborative effort, all women of childbearing age will receive risk appropriate health care before, during and after pregnancy.
Perinatal Substance Use Taskforce

• 5 workgroups developed as a result of 2017-2018 taskforce deliverables
  • Pharmacologic Treatment
  • Non-Pharmacologic Treatment
  • Medical Home—Women
  • Medical Home—Infant
  • Transfer Protocol
Medical Home—Infant Workgroup

• Charge—Develop a universal protocol for substance exposed infants to include:
  • Guidelines for follow-up for infant primary care providers
  • Guidelines for communication between infants and maternal primary care providers
• Strengthen the medical home for infants and mothers
Considerations

• Appropriate discharge planning must occur prior to the release of the infant and parent
• All children and families are different and will require different levels of support
• Professionals are most comfortable with screening protocol when they know next steps and are supported
• Consistency in discharge and communication with identified primary care physicians is critical for the success of the infant and mother or other caregivers
Tools Developed

• Discharge planning for infants with prenatal substance exposure
• Discharge checklist
• Primary care provider letter
• Screening recommendations for children who were prenatally substance exposed
## Discharge Planning & Follow-Up for Substance-Exposed Infants

<table>
<thead>
<tr>
<th>Universal</th>
<th>Targeted</th>
<th>High Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharge Planning</td>
<td>First Steps</td>
<td>Sub-Specialty Care</td>
</tr>
<tr>
<td>Notification to Department of</td>
<td>Department of Child Services</td>
<td>Perinatal Center</td>
</tr>
<tr>
<td>Child Services</td>
<td>Developmental Pediatric Referral</td>
<td>Developmental Follow-Up</td>
</tr>
<tr>
<td>Primary Care Provider</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral Health Resource</td>
<td></td>
<td></td>
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<tr>
<td>Home Visiting</td>
<td></td>
<td></td>
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<tr>
<td>Individual Care Plan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help Me Grow</td>
<td></td>
<td></td>
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<tr>
<td></td>
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</tbody>
</table>
Impact on Part C

• Referrals
• Fiscal resource needs
• Human resource needs
• Training needs and resources
• Service delivery methods
Massachusetts

Patti Fougere
Part C Coordinator
Substance Exposed
Newborns and
Part C: New Challenges and New Opportunities
MA EI System Overview

40,110 children served in FY’17

$200 Million Annual Budget
- Allocation from State Legislature
- Federal Office of Special ED
- Health Insurance companies

Services are provided by 60 Certified EI Programs throughout the state
CHILDREN WITH A CONFIRMED DIAGNOSIS OF NAS

A child with a diagnosis of NAS is automatically eligible for EI Services for up to one year.

Subsequent eligibility must be based on factors other than the diagnosis, i.e. risk or established delay.

The evaluation identifying this condition does NOT have to be the initial evaluation.
Children diagnosed with Neonatal Abstinence Syndrome (NAS)

The number of children referred to EI having an NAS diagnosis steadily increased between fiscal years 2010 and 2017. Significant increases occurred between 2011 and 2014. The number of new referrals has slowed down since then.

Exhibit 1: NAS Child Counts & Client Status (table)

<table>
<thead>
<tr>
<th>Date of Referral Fiscal Year</th>
<th>Total</th>
<th>% Change from Prev FY</th>
<th>Evaluated &amp; Eligible but no IFSP</th>
<th>IFSP Signed but no further services</th>
<th>IFSP Signed, received services</th>
<th>Avg Length of Stay (in mos)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>255</td>
<td>NA</td>
<td>26</td>
<td>6</td>
<td>223</td>
<td>7.4</td>
</tr>
<tr>
<td>2011</td>
<td>338</td>
<td>32.5%</td>
<td>35</td>
<td>11</td>
<td>292</td>
<td>10.6</td>
</tr>
<tr>
<td>2012</td>
<td>422</td>
<td>24.9%</td>
<td>28</td>
<td>10</td>
<td>384</td>
<td>10.8</td>
</tr>
<tr>
<td>2013</td>
<td>556</td>
<td>31.8%</td>
<td>74</td>
<td>9</td>
<td>473</td>
<td>11.2</td>
</tr>
<tr>
<td>2014</td>
<td>692</td>
<td>24.5%</td>
<td>59</td>
<td>20</td>
<td>613</td>
<td>11.0</td>
</tr>
<tr>
<td>2015</td>
<td>766</td>
<td>10.7%</td>
<td>60</td>
<td>17</td>
<td>689</td>
<td>12.0</td>
</tr>
<tr>
<td>2016</td>
<td>803</td>
<td>4.8%</td>
<td>61</td>
<td>21</td>
<td>698</td>
<td>13.1</td>
</tr>
<tr>
<td>2017</td>
<td>869</td>
<td>8.2%</td>
<td>63</td>
<td>20</td>
<td>772</td>
<td>12.9</td>
</tr>
</tbody>
</table>

4,701                        | 406   | 114                   | 4,144                            |

* The majority of NAS diagnosed children have received IFSP services
Engaging Families Impacted by NAS: Promising Practices from MA Part C Pilots

Trend data shows significant increase in the number of EI enrolled infants having an NAS diagnosis

Convened a small work group to focus on the system implications of the recent increase in NAS referrals – April 2015
Goal of the Workgroup

Raise awareness statewide of the impact on infants and young children

Ensure EI participation in statewide initiatives

EI is an entry point for all families throughout the state/established certified EI program in each community

Develop a position paper that highlights the role of EI; addresses the concern of the system and the long term impact on the child and family.

Continue to share community and regional resources and opportunities that address best practices in serving the NAS population.
NAS Pilot

- MDPH received small amount of funding to support a part-time Early Intervention professional to work in coordination with a level III neonatal intensive care or community birthing hospital staff to outreach to parents of children born with a diagnosis of NAS prior to discharge.

- The goal of the program is to make an early connection with parents without paperwork to help familiarize them with EI services and provide a “warm referral.”

- The EI program will establish and/or strengthen relationships with hospital staff to educate them on early invention, meet parents sometime after birth, and become part of the discharge planning team to support and engage the family in receiving early intervention services.

- Align with MA EI home visiting approach - PIWI
Outcome of the Pilot

- Improved relationships and increase in referrals from the hospitals in general
- Enthusiasm of many hospital staff
- Most successful with 1-2 regular EI staff
- Warm referral – no paperwork at initial meeting
- Permission to follow-up
- Inclusion of EI at other initiatives
Outcome of NAS Workgroup

Development of a “Model of Support” flyer for providers, referral sources and other community partners (see attached)

Family Education

Strategies

Training
- Emphasis of content on:
  - Relationship Based Services
  - Supporting the parent-child dyad
  - Building competence and confidence of parents in supporting their child’s development
Title V Substance Use priority - State Performance Measure:
• Percent of infants diagnosed with neonatal abstinence syndrome (NAS) in MA hospitals who are receiving Early Intervention service

2017 Policy Academy: Improving Outcomes for Pregnant and Postpartum Women with Opioid Use Disorders and their Infants, Families and Caregivers – Recommendations:
• Automatic 3 year eligibility NAS diagnosis
• Automatic 1 year eligibility SEN diagnosis

Neonatal Quality Improvement Collaborative of Massachusetts (NeoQIC) NAS summit.
Contact Information

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