MEMORANDUM

DATE: April 26, 2016

TO: All Members of the Delaware State Senate and House of Representatives

FROM: Ms. Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

RE: H.B. 268 (Substance Exposed Infants & Medically Fragile Children]

The State Council for Persons with Disabilities (SCPD) has reviewed H.B. 268 which seeks to codify certain sections of the federal law known as the Child Abuse Prevention and Treatment Act ("CAPTA"). While the proposed legislation may be well-intentioned, it has drastic unintended consequences. Background is included in the attached articles. In a nutshell, approximately 3% of babies born in Delaware qualify for a diagnosis of neonatal abstinence syndrome (NAS) in which the infant undergoes opiate withdrawal. That percentage has been growing in recent years. DFS substantiates abuse in approximately 10% (44/448) of cases of suspected neglect or abuse reported to it among babies born with drugs or alcohol in their system. See attached Mach 7, 2016 News Journal article. Medical professionals prefer to place pregnant women with addictions on methadone resulting in only short-term effects on babies treated for withdrawal upon birth. See attached “Addicted babies”, Delaware News Journal (November 20, 2015).

H.B. 268 (lines 63-64) would require health care providers to report substance exposed infants not more than 4 weeks of age (line 51) to the DSCY&F. Such reports would be entered into the child protection registry on the same basis as reports of abuse or neglect (lines 79-81). Although reports of abuse or neglect can be made anonymously, this is not permitted for reports of substance exposed infants (lines 82-84). A “plan of safe care” would be developed for cases accepted by DFS for investigation or family assessment (lines 16-19 and 110-111). Apart from substance exposed infants, the bill would also require development of a plan of care for cases accepted for investigation or family assessment involving any “medically fragile child” (lines 126-127) of any age (lines 42-44).
While the proposed legislation may be well-intentioned, it has drastic unintended consequences as currently written.

First, the legislation reinforces an autocratic model in which the State imposes requirements and offers little help to new mothers with substance abuse profiles. The bill (lines 45-50) contemplates unilateral development of the “plan of safe care” with zero input from the parent. This “top-down” plan is then shared with agencies but not the parent (lines 47-49). This kafkaesque approach is not a collaborative model which “engages” the new mother in a joint venture to benefit her infant.

Second, the articles describe successful outcomes for parents receiving wrap-around services while highlighting the paucity of resources available to many parents:

Holly Rybinski, of Newport, said she had to go to jail in order to get the drug treatment she needed. That was almost two years ago. She had stayed clean for five years, but while she was pregnant with his child, her partner overdosed and died. Consumed with grief, Rybinski turned to heroin and cocaine during the last five months of her pregnancy. After she gave birth to the son James on April 8, 2014, at Christiana Care’s Wilmington Hospital, she was ready to be clean. She said the Division of Family Services told her that they had to take custody of him since James tested positive for drugs, she wasn’t in a treatment program and Rybinski had a record. They told her she had 90 days to find employment, treatment and stable housing and then they could discuss putting him back in her care. That request was easier said than done. “I tried five different times to get into treatment,” Rybinski said. “It was one obstacle after the other.” As the number of pregnant and addicted mothers grows, the need for treatment is even more critical. Community members, families and those now in recovery, like Rybinski, have long lamented Delaware’s lack of residential treatment options. Many people have to wait days and even weeks to get a bed. Currently, there is one state-run treatment program for expectant or new mothers recovering from addiction in Delaware, but it is only for women who are incarcerated and it is in Newark. Brandywine Counseling ran a program for expecting moms wrestling with addiction, called Lighthouse, downstate in Ellendale, but is closed in September due to budget cuts and staffing shortages. (It was extremely successful. Nearly 100 percent of women were able to give birth to babies free of drugs.

“More treatment key for addicted moms”, Delaware News Journal (March 4, 2016)

Third, the bill envisions development of the same autocratic “plan of safe care” for any parent of a “medically fragile child” of any age if the parent is “unable” to “provide or ensure necessary care” (lines 42-44 and 126-127). The definition of “medically fragile child” is extremely broad, i.e., essentially covering any child at risk of a condition that requires services of a type or amount beyond that of an average child (lines 42-44). The implication is that parents of a child with a disability are at fault, culpable if they cannot guarantee (“ensure”) necessary care, and subject to the same “plan of safety care” as parents delivering addicted babies. This is reminiscent of the
1960s view of autism as caused by “frigid” mothers - stereotyping parents of children with disabilities as ‘at fault’ for their child’s medical condition.

Fourth, the central plan of care for medically fragile infants and toddlers is the collaborative family support plan developed under Title 16 Del.C. §§214 and 215. It is counterproductive to supplant the family support plan with a “plan of safe care” administered by a child neglect/prevention agency.

SCPD has the following recommendations:

1. The “medically fragile child” references (lines 42-44 and 126-127) should be deleted.

2. The “plan of care” provisions (lines 45-50) should be amended as follows:
   a. Ensure parental input and collaboration in development of the plan; and
   b. Ensure that the plan includes support services rather than simply directives or benchmarks for parents to achieve on their own. For example, consider the following amendment:

   The plan of care shall identify all material impediments to family preservation and the itemized, available resources specifically offered to the parent to overcome each impediment including, if relevant:
   a. mental health treatment;
   b. substance abuse treatment;
   c. safe housing; and
   d. any public assistance program operated or administered by a State agency.

3. The State should expand resources and programs available to expectant mothers with addictions and mothers of substance exposed infants.

Thank you for your consideration and please contact SCPD if you have any questions regarding our observations on the proposed legislation.

cc: The Honorable Matthew Denn
    Mr. Brendan O’Neill, Public Defender’s Office
    Ms. Teresa Avery, Autism Delaware
    Mr. Brian Hartman, Esq.
    Governor’s Advisory Council for Exceptional Citizens
    Developmental Disabilities Council

HB 268 substance exposed infant & medically fragile children 4-19-16
Katie Morgan is a heroin addict in recovery, a 28-year-old expecting a child in January.

She is part of a novel Delaware corrections program: Rather than serving time in prison for drug crimes and probation violations, Morgan is being held at a Newark group home—where she receives treatment for addiction, and can retain custody of her baby.

Methadone, the synthetic opioid Morgan takes to treat her heroin addiction, courses through her blood and the blood of the baby boy she’s carrying.

That means her newborn will likely spend his first weeks in the throes of opiate withdrawal—fighting neonatal abstinence syndrome, or NAS, a condition that makes babies sleep-deprived, irritable, prone to tremors and vomiting, and difficult to feed.

The first sensations felt by her child will be similar to what heroin addicts feel when they quit cold turkey—wracked with pain, clawed by cravings.

"I can imagine what he’s going to go through when he comes out. I’ve been through withdrawal before," Morgan said, sniffing. "I’m really upset with myself. I cry about it a lot because I did it to him. But he’s healthy, and the doctors say he’s going to be OK. So, it’s just a mistake I have to learn from."

Morgan’s predicament is becoming far more common in America. Heroin use more than doubled in the last decade, and more and more babies are starting their lives in withdrawal. In 2004, 39 babies were discharged from a Delaware hospital after being treated for NAS. Last year, 300 babies received that diagnosis—nearly 3 out of every 100 born here.
Delaware's heroin babies: Starting life in withdrawal

While heroin and methadone are much less likely to affect a child later in life than other drugs expectant mothers are urged to avoid during pregnancy -- such as alcohol, tobacco and cocaine -- the quick rise in NAS cases in Delaware is an unsettling trend.

Christiana Hospital, which has seen more than twice as many NAS babies since 2010, announced plans Thursday for a $260 million overhaul of its women and children's services at its Stanton campus. That expansion will create eight new floors and provide more room for its neonatal intensive care unit and a new nursery just for high-risk infants, such as those exposed to opioid drugs during pregnancy.

To medical staff accustomed to giving care in stressful conditions, infants with NAS can seem to be in agony. And caring for them is agonizing.

"What's different about babies who are born to moms on opiates is it does cause fairly immediate withdrawal symptoms," said Dr. David Paul, chief of pediatrics at Christiana Care. "Immediate means babies can show symptoms of withdrawal in the first hours after birth."
Delaware's heroin babies: Starting life in withdrawal

Adds Nancy Forsyth, a neonatal nurse at Beebe Hospital in Lewes: "They may cry inconsolably. If you listen to their cry, it's the cry of a baby that is in pain. It's really distressing to see a baby going through this."

Like other states around America, Delaware is struggling through the heroin pandemic. Overdose deaths have nearly tripled in the past decade -- from 63 in 2004 to 185 in 2014.

High school nurses are being trained to give emergency doses of opiate-blocking drugs to prevent fatal overdoses, and police officers and emergency medical technicians carry the drug Narcan to save the lives of those who have overdosed.

In New Castle County, heroin seizures climbed 400 percent between 2012 and 2013, and emergency rooms are being inundated with overdose victims.

The signs of stress are visible statewide.

"The addiction epidemic is straining our public system beyond its capacity, with many people turned away for services when they are ready for treatment," Gov. Jack Markell said in August.

Jim Martin, the leader of a Georgetown home for homeless men and a director of a Seaford addiction resource center, knows of parents in Seaford who routinely sweep heroin baggies off their sidewalks so their children don't find them.

Heroin "has just exploded in our communities. It's like a nuclear bomb went off and little heroin packets are going everywhere," Martin said. "The experience I'm having dealing with heroin is folks seem to have so much more relapse. The drug just pulls you back, even if you've had some clean time. It's just a terribly addictive drug."

Three years into treatment for heroin addiction, Courtney Murphy, 31, brought her baby girl, Sophia, into the world on Oct. 27. Murphy had taken methadone and the baby showed signs of NAS in the hours after her birth, but made it through the rough patch and was discharged without much fuss six days later.

"Her tremors did scare me a little bit. I'd never experienced that," Murphy said as she rocked Sophia, in her Nike booties and a pink-and-white outfit, to sleep in her New Castle apartment.

Murphy's sons, ages 2 and 6, watched cartoons in a bedroom while, nearby, her 11-year-old daughter fussed with her hair. The church where Murphy attends addiction group therapy each week is just a few minutes' walk down the street.

"It's an everyday struggle," she said of her recovery from addiction. She said it began at age 18 after a car crash when she was prescribed opiate painkillers. She's been clean three years now.

"It's made me become a better mom," Murphy said. "My daughter's 11 -- she'll be 12 soon -- and I was actively using when she was younger" -- taking street drugs in the child's presence. "Now, I've been able to..."
Delaware's heroin babies: Starting life in withdrawal
be there a lot. Not just physically. Mentally. Knowing
what's going on with my kids. I mean, it's a big
difference.

"I am doing the right thing. It's not being embarrassed
by my drug history. I'm proud of myself today, from
where I came from," she said.

31 year-old Courtney Murphy rocks her 2-week-old daughter Sophia
while talking to Daniel, her 6-year-old son. A younger son, 2-year-old
Duke, and Sophia were both born while Murphy was using methadone
to treat her addiction to heroin.

(Photograph: JENNIFER CORBETT/THE NEWS JOURNAL)

Drugs and delivery

CHAPTER 2

More than it ever has, heroin is reshaping lives throughout the United States. In 2005,
380,000 people said they had used heroin in the past year, according to the National
Institute on Drug Abuse. By 2012, 670,000 people were in that group.

As public policy measures deliberately made it harder for people to access and abuse
prescription drugs, they often turned to heroin (http://www.drugabuse.gov/about-
nida/legislative-activities/testimony-to-congress/2015/americas-addiction-to-opioids-
heroin-prescription-drug-abuse), "which is cheaper and in some communities easier to
obtain than prescription opioids," the NIDA says.

The rise in heroin use is happening even as use of most other illegal drugs is dropping,
according to the institute's research. Fewer people use cocaine and hallucinogens now
than they did 10 years ago. But heroin's popularity is soaring.

Delaware's heroin babies: Starting life in withdrawal

In interviews around the state, doctors and nurses who work in obstetrics departments say an increasing amount of their time is spent in the care of women who are actively using heroin and other opiate drugs or, more commonly, being treated for addiction with methadone. It is a clinical scenario that used to pop up on occasion, but is now a near-daily reality.

"This is constant. It's pretty much all the time. It's rare that I don't have a baby who's been exposed [to opiates] here," said Beebe's Forsyth. "We used to have a lot of moms coming in on oxycodone, street or otherwise, when they came in to deliver. Now, we're not seeing that. All we're seeing, pretty much, is the methadone. ... It's pretty much a constant. Ask anybody else at a birthing hospital and they'll say the same thing."

Nationwide, about 16 percent of pregnant teens and 7 percent of pregnant women ages 18 to 25 use illegal drugs when pregnant, according to a federal survey of recent data. Between 2000 and 2009, the number of mothers using opiates during pregnancy increased 500 percent, according to a 2012 report by the American Medical Association.

The obstetrics field has seen the effects of drug abuse on pregnant women before, when the drugs involved were different. Alcohol abuse during pregnancy can lead to fetal alcohol syndrome and can cause facial deformities and brain damage; cocaine use by the mother can cause premature birth.

But heroin, as well as methadone, can lead to neonatal complications all their own, said Paul, of Christiana. About 60 to 80 percent of babies born dependent on either heroin or methadone develop symptoms of NAS.

An infant with NAS can show symptoms like tremor, irritability, an unsettling high-pitched cry, seizures, poor feeding, sneezing a lot, vomiting, diarrhea and difficulty breathing. All of this is because after birth, "the infant then begins to withdraw from the narcotics previously received from the mother in utero," as a 2013 article in the International Journal of Childhood Education put it. If not treated, NAS can be fatal.

In 2010, Paul said, 100 infants were treated for NAS at Christiana. In 2014, 170 were diagnosed there, the hospital where more babies are delivered in Delaware than at any other hospital. Statewide, 300 babies delivered at Delaware hospitals were diagnosed with NAS in 2014, compared to 242 babies in 2013, according to data Paul presented to other physicians in April.

About 10,800 babies were born in Delaware in 2014, according to federal health data. That means 2.7 percent of babies born that year were treated for NAS. More than that were evaluated for it because their mothers were known to have methadone or opiates in their systems, but not diagnosed.

Dr. David Paul, chair of the pediatrics department at Christiana Care Health System, talks about the hospital's care for drug-dependent infants right after they're born.

(Photo: JENNIFER CORBETT/THE NEWS JOURNAL)
Delaware's heroin babies: Starting life in withdrawal

The increased incidence of NAS is an echo of overall heroin use in Delaware. Drug treatment programs funded by the Delaware Division of Substance Abuse and Mental Health admitted 1,263 patients in 2011 whose primary drug was heroin. In 2014, that number was up to 3,182 heroin-dependent people, and for the third year in a row, those programs treated more heroin addicts in Delaware than users of any other drug.

"I've had 22-year-olds sit in my triage chair and they're crying. They're devastated. They know their lives have changed. They've burned through all their support systems," said Kathy Keating, a forensic nurse examiner program coordinator at Nanticoke Memorial Hospital in Seaford, speaking to a community group in September about the heroin crisis. "But when people are honest with me about their drug history, I thank them. As long as you know what's in them it's much easier to treat them."

"I am hopeful that at some point it's going to peak," Paul said of the heroin epidemic. "If we learn lessons going back to crack cocaine in the 1980s, it seemed like that was never going to end, but it largely went away as a problem. So it's my hope as a clinician, and as a citizen of Delaware, that we're going to see this wane at some point."

Pills led to addictions

CHAPTER 3

For many, opiate drugs legally prescribed for pain following an injury become the gateway to heroin addiction. Brittiny Yost, 23, of Seaford was a 16-year-old playing school sports when injuries aggravated by softball and martial arts led to physical therapy. A doctor wrote her a script for Tramadol, an opiod pain medication; when Tramadol's usefulness faded, she said, she was prescribed Percocet, another narcotic.

"Percosets became my new addiction and the way I coped with a lot of the pain," Yost said in an interview at New Expectations, a Department of Corrections-supported home for pregnant women who have been sentenced for criminal offenses and are also undergoing methadone treatment. "And I found myself, every single time I got depressed, using more and more all the time. Heroin was introduced by my brother."

Delaware’s heroin babies: Starting life in withdrawal

Criminal offenses and probation violations, the first at age 17, led Yost to one of state’s substance abuse programs for offenders, and then supervised probation. But while on probation, she used drugs again and her probation officer found out, landing her back behind bars this year.

“I was three weeks pregnant when I went to jail. I didn’t even know I was pregnant,” Yost said. “Going through withdrawal, the risk of losing the baby and miscarriage and stuff, that definitely isn’t an option for me.”

Women in Delaware’s correctional system can get methadone treatment while in prison only if they are pregnant, and Yost did so. But she said she knew other women in the prison considered her and other pregnant, methadone-using women beneath them, contemptible.

“There’s a lot of other inmates who look down on you being in a pregnancy pod’ and getting methadone treatments, Yost said. ‘It was depressing, in a way, but at the same time I knew it was the best option.’

If she had not been caught using and learned of her pregnancy, Yost isn’t sure she would have sought treatment for her addiction.

“Probably not, to be honest,” she said quietly. The parole violation conviction, she said, “was sort of a blessing. The influences that were around me back then, they’re not now, being that I’m in treatment.”

To an outsider, it might seem surprising that medical professionals encourage expectant mothers addicted to opiates to use methadone instead of finding a way to completely flush opiates from their bodies by the time the baby is born.

But doctors and nurses interviewed for this story said outcomes are better for the baby if an expectant mother is following prescribed treatment for methadone, even though there is a decent chance the baby will develop NAS.

“The long-term outcomes seem to be a lot better for these babies than with fetal alcohol syndrome or your cocaine-addicted babies,” said Dr. Erin Fletcher, a Lewes pediatrician who is on staff at Beebe Healthcare. “There are some studies showing possibly some higher ADHD or learning disabilities in the long term. But for the most part, it’s not causing any major obvious birth defects. For the most part, once we get them through this treatment period, these babies tend to do very well.”

For most people, going cold turkey is simply ineffective as a way of battling heroin addiction; the cravings for the drug are just too powerful. Methadone helps block the nervous system receptors in the brain that create the craving for the drug.

“Mothers in methadone programs are doing the best they can under unbelievably difficult circumstances,” said Forsyth, the Beebe nurse practitioner. “That is a piece I always share with them. By seeking treatment and getting prenatal care, they have done the best thing they can for their unborn baby.”
Stigma an issue

CHAPTER 4

Underlying the concerns about NAS and newborn's health is a recognition that the infants' mothers, in most cases, are struggling, often in the middle of difficult recovery from addiction, and routinely stigmatized for being pregnant at the same time they're addicted to drugs.

"Having a child is difficult; babies are very demanding. When you add into that the stress of a parent who is, whether they are actively using or are in treatment, there's a tremendous burden of guilt," said Forsyth. "Dealing with those issues, as well as the guilt that they're feeling and a baby that is far more irritable and difficult to care for than most, is overwhelming."

Bridget Buckaloo, who directs women's health services at Beebe Healthcare, says medical staff should be careful not to stigmatize such women more than they already are.

"Nursing curricula, medical school curricula, dental school curricula: All these different aspects of health care really don't prepare us to deal with addiction. We don't have a good understanding of addiction as a disease," Buckaloo said. "We see it as a choice... A diabetic, we don't judge them for taking their insulin. People who have an addiction, who are substance dependent, they're at a point where they are taking the drug to feel OK. They're not taking the drug to get high. Most of these women have had some kind of trauma if you strip away the drug. The medication makes them feel better; it makes the pain of the trauma go away.

"As a health care profession, there's a lot of judgement and stigma we place on these mothers. It becomes a barrier to their recovery. It's sad, but it's true."

For pregnant women in the justice system, the New Expectations house can be a novel road to recovery. A joint project of the Department of Corrections and its contracted health care provider, Connections Community Support Programs, the Newark home blends in on a block sprinkled with college-student housing.
Delaware's heroin babies: Starting life in withdrawal

Women there are transported to prenatal care appointments; take part in group therapy and support counseling; and can see visitors once a week. If they complete their required probation term without breaking house rules, they can retain custody of their babies, which they couldn't do if they gave birth while incarcerated. The women can even stay at New Expectations for up to six months with their new babies, taking time to get on their feet.

Some of the women said they made the choice to seek treatment because of their pregnancies.

"When I found out I was pregnant, I was on the run for, like, 9 months," said Bonnie Quill, 32, of New Castle, in an interview at New Expectations. "I guess I was tired of running and I wanted to get it over with before the baby was born so I wouldn't have to be away from him."

As worried as the women in New Expectations are about methadone's possible effect on their babies, they are most concerned about the path their sober lives, out of the justice system, will take.

"They're trying to avoid incarceration, and they're trying to avoid having the baby taken away from them," said Catherine Devaney McKay, Connections' president and CEO. "Those are pretty serious first-order issues to address. The motivator is wanting to be out of jail when the baby is born, so you have a shot at keeping your baby."

Many women interviewed said they were determined not to return to the hometowns where they first became addicted, and where their circles of friends had, for years, included other addicts.
"Everybody that you seem to know is either doing pills or actually still on heroin," said Morgan, the Harrington woman due in January, recalling the times when she was at home in between probation violations. "They say change people, places, things. Even doing that, the new people that you meet seem to have a drug of choice, whether it be alcohol, marijuana or heroin. It seemed like somebody was always doing something."

The mothers have also given thought to how they will explain to their children, years down the road, what their lives were like when the children were born. Should they explain the whole scenario, drugs, addicts, handcuffs, courtrooms, tears and all?

"Without this program, I would be out there still," said Tamya Braxton, a New Expectations client who was cuddling her two-month-old son, Makai Brown, born while Braxton was recovering from an addiction to PCP. "I'll tell him this was a time in my life I had to get myself together."

Carlos Duran, a neonatologist at Christiana Care, is the director of Child Development Watch In New Castle County, a public health effort that keeps tabs on children at risk for developmental delays. To persuade more mothers of babies who were drug-dependent at birth to take part in the program, he said, doctors linked up with Brandywine Counseling to see the mothers and their infants once a month at the same Brandywine facility they go to for rehabilitation and addiction treatment.

"The wave of new patients, that was really one of the main driving forces. We'd been seeing these babies before in our regular program, but it was a much smaller number," Duran said. "Within the last two years or so is when we have really seen the most need."

Doctors and social workers keeping tabs on NAS babies, he said, tend not to think the babies' development is held back by their brief opiate withdrawal window alone. If those children show developmental delays, he said, it's more likely because of other factors: unstable home lives, and parents still distracted by their own addiction problems.

"They don't have medical problems. Their needs are different. And we have a fairly high no-show rate for these families. They may not understand what we're doing, or they may not have transportation," Duran said. "We are working through the process of how much
Delaware’s heroin babies: Starting life in withdrawal

more we can really screen or ask. We don’t want to be too intrusive, because this is a voluntary program. We don’t want to be seen as Big Brother. We’re still working on that: How much can we ask without driving them away?”

But, he said, even the parents struggling to raise their children want to do better.

“These moms, they love their babies and they want to do everything they can for them,” Duran said. “We help the mom to better manage the baby.”

For Murphy, the mother of two-week-old Sophia, her new normal is this: Her oldest daughter catches a bus to a charter school at 5:45 a.m. A 2-year-old son who was also born when she was taking methadone, Duke, walks to her father’s house, where he’ll be cared for. Murphy’s husband, a painter, goes to his 12-hour shift at a Dover worksite. Then, Murphy and Sophia make their way to the clinic where Murphy’s methadone treatments are administered.

“I take the baby with me to the clinic. It’s a job just to get there, back and forth every day,” she said. When she can, Murphy makes time for Narcotics Anonymous meetings and church meetings on addiction. She’s learned, in recovery, to plan a day ahead wherever she can – making lunches, laying out school clothes. It’s a choreography she never could have sustained when she was abusing heroin.

In high school, “I was a cheerleader. I hated, despised anyone who did drugs. I never thought this would be my outcome,” Murphy said as she got her children ready for a lunchtime walk to the corner deli. “But I’m making the best of the situation. So, that’s all that matters.”

Staff writer Jen Rini contributed to this story. Contact James Fisher at (302) 983-6772, on Twitter @JamesFisherTNJ or jfisher@delawareonline.com.
Newborn addictions rise, triggering new hospital rules

Following an increase in babies born with drug or alcohol dependencies in Delaware, statewide hospital discharge forms for "high-risk" cases will be amended to ensure that the baby will go home to the safest environment and mom will have the necessary support system in place.

A committee of medical professionals, community leaders and state officials charged with studying and recommending how to care for infants who are born substance-exposed or medically fragile voted to add six conditions that will automatically trigger high-risk medical discharge reports from the hospital to the Delaware Division of Family Services.

The move is one of the first steps the committee, an arm of the Child Protection Accountability Commission, has made to figure out how to best help babies born with the dependencies and their families thrive.

The conditions originally were crafted by the Delaware Healthy Mother and Infant Consortium, a group that reviews and recommends programs and guidelines concerning maternal and fetal care.

The conditions are:
- Significant noncompliance with care of the infant, such as not visiting or participating in care.
- Mom is using substances, but is not in a treatment program.
- Evidence that drug use impacts care giving ability.
- Addicted infants must stay in the hospital for more than 30 days.
- Multiple substance use.
- Infant needs medically complex care.

According to the form that is submitted to DFS, a high-risk medical discharge is called for if there is an "increased risk for physical, developmental, behavioral or emotional conditions that require health and related services of a type or amount beyond that required by a child generally, and the child's family is unable or unwilling to provide or ensure the necessary care."

If a pregnant woman heavily uses opiates, such as heroin, codeine, oxycodone and even methadone or buprenorphine — which are used in drug treatment, those substances filter through the placenta. The baby is then born drug-dependent and soon suffers withdrawal.

When an expecting mom drinks alcohol while the baby is developing in the womb, the baby can develop fetal alcohol syndrome disorders as well.

Jennifer Donahue, child abuse investigation coordinator of Delaware and co-chair of the committee, said it is important a plan of safe care is established for these children when they leave the hospital.

Hospitals are already required to report to Delaware Division of Family Services if a baby is diagnosed as being substance exposed or with a fetal alcohol spectrum disorder.

There were 448 reports made in 2015. Not all require follow-up, however. DFS investigated 229 cases of babies who tested positive for drugs and 66 who tested positive for alcohol.

But the follow-up for families can be inconsistent Donahue said.

State and community agencies are doing "damage control" now to try to connect families to services such as home visiting nurses and are tasked with investigating near-death, injury and death instances that involve drugs. For instance, such a child death could be the result of a mom on methadone rolling over onto a baby in bed, suffocating the infant.

Draft legislation is in the works to formalize a plan of safe care for babies that will engage social workers, nurses, hospitals and other groups to ensure that families will not fall through the cracks and the baby is not in danger. Mothers would need to sign off on the plan at the hospital and would be monitored to make sure they are following it appropriately.

"We are trying to make it clear and formal," Donahue said. "It's not a discharge plan; it's a follow-through plan."
Others, such as Dr. David Paul, chair of the Delaware Healthy Mother and Infant Consortium and head of pediatrics at Christiana Care Health System, feel that the legislation is not the cure-all.

"There's not going to be a silver bullet," Paul said.

Jen Rini can be reached at (302) 324-2385 or jrini@delawareonline.com. Follow @JenRini on Twitter.

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Editorial: To save the kids, treat the addicted parents

At first glance, the deaths of kids like Aiden Hurley and Autumn Milligan (story/news/localsearchplay.ag/2016/03/04/delaware-addicted-parents/60935474/) point to Delaware's failed effort to safeguard children born to drug-addicted parents.

But in the bigger picture, such deaths also intensify the spotlight on our state's need for more addiction treatment services.

A proposed measure called "Aiden's Law" would require addicted mothers to sign an agreement with the state that they will properly care for their addicted children — or risk losing custody.

While we support any effort to keep kids safe, it's critical to remember this: We can send all of the case workers in the world to check in on kids, but if their parents don't receive adequate treatment for their addictions, the child always will be in danger.

Just as children born with addictions need treatment, so do their parents.

As pointed out in the Sunday News Journal front-page story, more than 130,000 children born in the United States in the last decade entered the world hooked on drugs, according to a Reuters investigation.

Reuters identified 110 cases since 2010 in which babies and toddlers whose mothers used opioids during pregnancy later died preventable deaths.

In Delaware, four addicted babies died in the care of a parent or caregiver in 2015, and three others were severely abused.

To combat this tragic trend, it's critical that addicted mothers-to-be feel comfortable seeking and have easy access to the prenatal and addiction care they and their babies desperately need.

We know this can be done.

The News Journal highlighted such an effort (story/news/local/2016/11/20/heroin-babies-starting-lives-withdrawal/78208368/) in November. While it may not be practical or ideal to use several group home settings across the state, we believe further investment in and expansion of such a program will lead to far more positive outcomes.

And while it's a given that mothers and children are the first priority, addicted fathers need access to help, too. Addicts say that the already difficult task of getting clean is made all the tougher when they're around people who continue to use.

On top of that, access to effective services remains limited, though a different facilities are opening this year.

In 2016, there were 9,877 admissions into state-funded treatment facilities — the highest number in more than 10 years, according to data collected by the state health department. In 3,723 of those admissions, people identified heroin as their primary drug.

As we have written in this space before (story/opinion/editorials/2016/01/10/wrenching-film-shows-heroin's-deadly-impact/78599492/), opiate/opioid addiction is a scourge that does not discriminate.

There remains for some the belief that addicts can choose to get and stay clean — that opioid addiction itself is a choice.

Yet, while the decision to first use opiates rests with the user, the power of the subsequent addiction overwhelms all logic and reason.

Still, one would hope that the risk of losing custody of a child would be motivation enough for any addicted parent to accept help if offered.

That help may cost us more in the short term, but the long-term benefit of such an investment is seeing all of our children grow up to be healthy and productive members of society. As it stands now, too many kids die before they even know what the word "addiction" means.

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Hospitals adapt to handle more drug-addicted moms

Delaware hospitals adapt to handle more drug-addicted moms

Hospital systems in Delaware are trying to adapt to a world in which heroin use and methadone treatment are increasingly marked "yes" on maternity ward intake forms.

At Christiana Hospital in Newark, those adaptations have included remodeling a section of the maternity unit into the Continuing Care Nursery, a place where NAS infants and their parents, as well as other babies who need special care, can stay several weeks after delivery. A $500,000 contribution from the Junior Board of Christiana Care helped the nursery open.

"One of the major functions of that unit, and the reason we designed it, is to be able to provide a quieter environment," said Dr. David Paul, chair in Pediatrics at Christiana. Babies sensitive to light and sound than healthy infants; the constant beeping and foot-shuffling of a neonatal intensive care unit is hard to handle.

"Ultimately, they can go home faster if they stay out of the NICU," Paul said.

On Thursday, Christiana Care unveiled a $260 million capital construction proposal that would turn the existing women and child eight-story haven for expecting moms with more room for its neonatal intensive care unit and create single-family patient rooms.

If approved by a state board that guides hospital expansion efforts, the new building could be complete by 2023, hospital officials said.

To treat babies with NAS, doctors and nurses administer tiny doses of morphine (http://www.chi.org/nch/topics/pediatrics/e-pain-relief.html) to relieve the pain of withdrawal from opiates, and within three to six weeks, also draw down the dose of morphine. The drug also eases seizures, fever and weight loss.

"It's a substitution drug," said Fletcher, the Beebe pediatrician. "It occupies the same receptor sites and neurons in the brain so withdrawal symptoms, minimizes cravings." It may seem odd to give infants morphine, but it's a common treatment for NAS throughout the country. Still, doctors don't want newborns any more than they have to.

"There are emerging data that there's an association between length of medical treatment with morphine with adverse neurodevelopmental effects we can keep babies on morphine in the hospital, potentially the better the baby's outcomes are," Paul said.

There are plenty of ways to soothe the babies that don't involve drugs, too. Tracey Bell, a NICU nurse educator at Christiana, said parents that "just holding them, cuddling them, giving them a quiet environment, talking to them softly and feeding them in a quiet area" can help. "They don't like a lot of additional stimulation," Bell said.

Volunteers assigned to the CCU will also cuddle and rock infants when parents aren't there. "That soothing, rhythmic rocking helps to settle any baby," said Pamela Jimenez, a nurse practitioner and coordinator of the CCU.

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On average, Paul said, babies with NAS stay in the hospital for 15 to 18 days postpartum. In the NICU, there's no place for parents to sleep that many nights. But in the CCU, each room is private and has a pull-out sofa.

The medical community is coming up with ways to track the progress of these infants into their second and third years of childhood. At Christiana, Jimenez keeps tabs on the babies and their families by encouraging them to take part in Child Development Watch, a state-supported early intervention program. "It's making sure that most needs are being met, and making sure the baby is developing appropriately," Jimenez said.

Bridget Buckwalter, executive director of women's health services at Beebe Healthcare, said Beebe also follows state guidelines and facilitates referrals of all NAS babies for developmental screening.

Staff writer Jen Rini contributed to this story. Contact James Fisher at (302) 983-6772, on Twitter @JamesFisherTNJ or jfisher@delawareonline.com.

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More treatment key for addicted moms

Holly Rybinski said she had to go to jail in order to get the drug treatment she needed. That was almost two years ago. She had stayed clean for five years, but while she was pregnant his child, her partner overdosed and died. Consumed by grief, Rybinski turned to heroin and cocaine during the last five months of her pregnancy.

After she gave birth to her son James April 8, 2014, at Christiana Care's Wilmington be clean.

She told the Division of Family Services that they had to take custody of him. Rybinski was positive for drugs, she wasn't in a treatment program and Rybinski had a record. They told her she had 90 days to find employment and housing and then they could discuss putting him back in her care.

That request was easier said than done. There were issues with insurance coverage and doctors who would not approve her treatment for mental illness because she had given birth only weeks before, she said.

"I tried five different times to get into treatment," Rybinski said. "It was just one obstacle after the other."

As the number of pregnant and addicted mothers grows, the need for treatment is even more critical. Community members, treatment providers, and women in recovery, like Rybinski, have long lamented Delaware's lack of residential treatment options. Many people have to wait days or weeks for a bed. Many have to go out of state.

That was the case with Rybinski. She tried to get admitted to rehabs in Maryland and Pennsylvania before turning back to her friends and family for help.

The treatment options available do boast results.

Over the last three years, about 774 women were helped by a Brandywine Counseling program that helped connect women to treatment and case management. In that same period, 169 babies were born and 167 were born free of illicit drugs, data from the housing.

About 145 were delivered to full term and 133 were born within a healthy weight.

Currently, there is one state-run treatment program for expectant or new mothers recovering from addiction in Delaware, but it is only for women who are incarcerated and it is in Newark.

Run through the Delaware Department of Correction and Connections Community Support Programs, the DOC's healthcare provider, a Judge can sentence women to the program, called New Expectations, as a condition of probation instead of house arrest or prison. The women live in a group home, receive prenatal care and take parenting classes.

Brandywine Counseling ran a program for expectant moms wrestling with addiction, called Lighthouse, downtown in Ellendale, but it closed in September due to budget cuts and staffing shortages.

About 28 to 40 women participated in the program at any one time over the five years it was active, said Lynne Fahey, Brandywine chief executive officer.

Lighthouse wasn’t just a group home — it offered a residential level of care to help women manage cravings with around the clock staffing. Fahey estimated it cost about $700,000 a year to support, but data from Brandywine shows it was extremely successful. Nearly 100 percent of women were able to give birth to babies free of drugs, Fahey said.

In the year before it closed, about 98 percent of women enrolled in Lighthouse re-established relationships with their children or immediate family members. Nine cases investigated by DFS closed during the women’s treatment and all women were able to find jobs.

"If the children had been taken, we were able to help the mom re-unify and get the children out of foster care," Fahey said. "It is an expensive level of care to do it right."

One of the other problems is spotty insurance coverage, explained MaryBeth Cichocki, a member of the advocacy group AddAsk Addiction.

There is a set amount of time people can stay in residential treatment programs, typically up to 30 days, and then people are back out on the streets.

"Medicaid pays thousands and thousands and thousands of dollars for all these babies in the hospital," Cichocki said. "Yet if they would just get the mothers into a good rehab and keep them there until their brain starts to heal so the cravings aren't so powerful and the mom wants to use again."

Rybiski was one such mom that had difficulty getting treated.

Frustrated that she couldn't get help, she ramped up her drug use and started stealing from vehicles in New Castle County neighborhoods to feed her habit. Eventually she was arrested and sentenced to two treatment programs run through the DOC. DFS terminated her parental rights.

Rybiski was just released after being incarcerated for 18 months. While she was in jail, a foster family brought James to see her every month. Her two other kids, Scarlet, now 3, and Gage, 8, stayed with her mom, and thought she was in "time out."

Had she been connected to treatment services immediately or had a halfway house to stay after she was discharged from the hospital, Rybiski said her life might have taken a different turn.

"I might have 16 months clean and been home for the past year," she said.

Though it wasn’t a perfect scenario, she is grateful she was separated from James when he was born. She acknowledged that caring for a newborn and trying to manage her addiction could have been detrimental to his health.

"I don’t think they should have given him back to me right then," she said.

Now she's happy that she gets to see him every other weekend and he is going to be adopted by her partner's, his dad's, family. She’s enjoying life with her other children, Scarlet and Gage, finishing her college degree in multimedia design, and counseling people struggling with addiction. Hearing Scarlet say "I love you to pancakes," the three year old's favorite food, is music to her ears.

"I lost [addiction] become my life. I need to stay clean," she said. "I forgot what my purpose was."

Jen Rini can be reached at (302)234-2386 or jrin@delswareonline.com. Follow @JenRini on Twitter.

Delaware failing heroin babies

Delaware is failing babies born addicted to heroin and other drugs, the state Children's Department acknowledges.

Four addicted babies died in the care of a parent or caregiver in 2015, and three others were severely abused.

The September death of 8-month-old Alden Ryder Hundley, who police say suffered horrible abuse at the hands of his parents, demonstrates gaping holes in the state's protocol for following up care of hundreds of addicted children annually discharged from Delaware hospitals to their parents.

A state commission and 16 state lawmakers are pushing legislation, named "Aiden's Law," that would require mothers under investigation to sign an agreement with the state that they will properly care for their addicted children -- or risk losing custody. It also would establish a unified plan all state agencies and community groups must follow in regard to at-risk children, eliminating the patchwork approach now being used statewide.

"We are going to have dead babies" without meaningful changes, Jennifer Donohue, statewide child abuse investigation coordinator for the Office of the Child Advocate, told a committee studying care for substance-exposed infants in January.

On Feb. 19 of last year, Alden was born at Beebe Healthcare, one of several Delaware hospitals that tests all newborns for addictions. His first 27 days were spent in withdrawal, or neonatal abstinence syndrome, a condition (story/news/local/2015/11/20/heroin-babies-starting-life-withdrawal752933580) that makes babies sleep-deprived, irritable, prone to tremors and vomiting, and difficult to feed.

After enduring that ordeal, the Division of Family Services permitted Alden to be discharged into the custody of his parents, Doyle J. Hundley Jr., 37, and Casey R. Layton, 28, of Harbeson -- both of whom have a long history of drug addiction, court records show.

The caseworker assigned to Alden should have performed a thorough investigation on the parents and their whereabouts to provide a safe environment for the child, said Carla Benson-Green, cabinet secretary of the agency that oversees DFS. That didn't happen. And Hundley and Layton, like many addicts who frequently move from place to place seeking shelter from friends and family, were lost by DFS.

Sixty-four days after the baby was discharged from the hospital, the caseworker found and visited the family but raised no red flags, Benson-Green said.

Two days later the parents called 911, explaining to first responders that the boy was having seizures. Doctors found freshly broken bones and bones beginning to heal from earlier breaks. He also suffered retinal hemorrhaging in both eyes, and he had an E. coli infection in his brain.

Aiden never left the hospital. He died Sept. 22 after being on life support four months.

The parents were charged with murder, contending the baby's injuries stemmed from abuse.

Hundley claims injuries to his son occurred when he tripped on a duffle bag while holding the baby.

The caseworker who failed baby Alden will be held accountable, Benson-Green said. But rather than instituting sweeping reforms, she said she has made changes to get DFS employees to do a better job.

"If the process was followed, it would not have been neglect by the agency," said Benson-Green. "You've got to see the child. You've got to see the family. ... You have to assess the home. All of that did not happen in this case."

Bringing agencies together

The Department of Services for Children, Youth and Their Families has come under fire for other high-profile cases, such as the August 2014 death of Autumn Millican (story/news/local/2014/11/07/mom-charged-girls-death-investigated-four-times/186715920).

The 4-year-old girl was beaten to death by her mother in a seedy New Castle-area motel after being investigated four times for neglect by DFS.

Delaware failing heroin babies

A NEWS Journal investigation detailed how DFS looked into four neglect complaints about her mother, Tanasia Milligan, including one brought by her sisters, who wanted the division to investigate the care of Autumn and her older brother, Ethan. That investigation was active at the time of the girl’s death.

DELAWAREONLINE

To save the kids, treat the addicted parents

(http://www.delawareonline.com/story/opinion/editorials/2016/03/04/save-kids-treat-addicted-parents/81335512/)

Although the sisters told child protection officials that the kids’ bodies had marks on them, authorities never examined Autumn or her brother Ethan for bruises.

Rather than forcing Milligan to better care for her children, state officials ruled that the complaint was unsubstantiated. DFS made the same ruling in three previous investigations, even though Milligan was living with a man alleged to be a pimp at a motel on U.S. 13, where Milligan sold her body and abused drugs.

Tiffany Greenfield, Milligan’s older sister, said the state fumbled several chances to save a vulnerable child from her troubled mother. She would welcome a new law with teeth that holds parents accountable, but points out that her sister agreed to a DFS demand that she take better care of her children or potentially lose them. At the end of the day, Greenfield said, the state didn’t enforce the agreement and the lack of followup resulted in Autumn’s death.

“They made Tanasia sign an action plan,” Greenfield said. “They told her she had to do this, and if she didn’t, she was told this would happen. She (Milligan) did nothing that they had listed and nothing happened, except the death of my niece.”

While these incidents are ultimately the parent’s fault, Greenfield said, the state must step into the breach when children are at risk.

“I just hope they can get it together before another child loses their life,” she said.

DFS admitted to flaws into the investigation of Milligan and acknowledged it was riddled with errors, confusion and systemic problems. In February 2015, the month Aiden was born, the state announced the results of an internal review and proposed several reforms aimed at averting a similar tragedy.

Four children have died since.

Jennifer R. Ranjil, then-secretary of the Children’s Department, said that in retrospect, it was clear they didn’t do enough to protect Milligan’s children. Last October, Ranjil was appointed a judge on Delaware’s Family Court by Gov. Jack Markell.

Benson-Green, who has worked in the department since its inception in 1982, took over in November. Even when caseworkers follow protocols, she said, there can be bad outcomes.

Sometimes the initial contact with a mother and baby occurs months after a referral is received. Other times, DFS gets wrong names or bad addresses or is hampered by a lack of communication between state agencies, including police and the Department of Justice.

“As of now there is no Delaware law that outlines what each agency has to do when there is a substance exposed infant,” said Conahue, the Investigator.

Federal law requires that a plan of safe care be established and that states have policy and procedures in place. While DFS has a protocol, other state agencies follow their own rules in regards to children at risk — meaning some newborns with drug dependencies won’t be under the watchful eye of the state.

“We’ve seen because of that disparity, because of the different cases, there are breakdowns and some agencies do not know what their role is,” Conahue said.

There were 448 cases of suspected neglect or abuse reported to DFS among babies born with drugs or alcohol in their system, and the agency reported it found enough evidence to investigate 296 of them. Those 296 cases involved 364 children. In 44 cases, abuse was substantiated, 11 more are still pending.

A DFS spokeswoman said that they do not keep more accurate statistics of the types or severity of neglect or abuse.

"This is our problem," said Tanis Culley, child advocate for the state of Delaware, one of the leaders of the legislative effort. "This is Delaware's problem and we all need to hold hands together to help solve it and support these mothers while making sure these babies are safe."

Nationwide, more than 130,000 children born during the past decade entered the world hooked on drugs, according to a Reuters investigation. Reuters identified 110 cases since 2010 in which babies and toddlers — whose mothers used opioids during pregnancy — died unnecessarily.

Being born drug-dependent didn't kill these children. Each recovered enough to be discharged from hospitals, but they were sent home to families ill-equipped to care (story/news/health/2016/01/17/newborn-addictions-rise-triggering-new-hospital-rules78861832V) for them, the report found.

More than 40 of those children suffocated. Thirteen died after swallowing toxic doses of methadone, heroin, oxycodone or other opioids. In one case, a baby in Oklahoma died after her mother, high on methamphetamine and opioids, put the 10-day-old girl in a washing machine with a load of dirty laundry.

Linda Carpenter, a program director with the National Center on Substance Abuse and Child Welfare, is helping states avoid issues related to substance-exposed deaths among infants. Carpenter said she worked with Delaware officials on amending state code to align with federal law that requires a plan of safe care for moms and substance-exposed babies.

The legislation, co-sponsored by Reps Melanie George Smith, D-Bear, Ruth Briggs King, R-Georgetown, Senate President Pro Tem Patricia Blevins, D-Elsmere, Sen. Cathy Cloutier, R-Heatherbrooke, and 12 others would define what a plan of safe care means for babies and moms. It would require social workers, nurses, hospitals and other groups to make reports and share information to ensure that families can't move without notifying authorities, and that babies are not in danger.
"One of the concerns in Delaware is we send moms and babies home sometimes and then there's nobody monitoring or not monitoring on a regular basis and then something happens. And that shouldn't surprise anybody," Carpenter said. "The plan of safe care and timing is critical. That should be written and everyone is on board before the baby even leaves the hospital."

At a community meeting last fall, Briggs King heard cases where a substance-exposed child was sent home with a parent struggling with addiction and died, or nearly died. She wanted answers, but found they were hard to find — even for a lawmaker.

"It just seems to be a big question mark there," Briggs King said. "We need to protect these children."

To draw attention to the lack of follow-up, she drafted a bill that would have allowed police or a physician to take temporary custody immediately if a child is born drug-dependent or suffering from fetal alcohol syndrome.

Briggs acknowledged that it could deter women from receiving the substance abuse treatment they need, so she dropped the legislation and instead is backing the other effort.

Helping moms get into a successful recovery program is one of the best ways to start her and baby on a good path, says Dr. Elizabeth Drew, medical director of Summit Behavioral Health in Pennsylvania.

But moms-to-be who are in recovery are often afraid to disclose their situation.

"We need to make women who are pregnant feel like they can come forward with an addiction without already feeling like they are going to lose custody of their child," Drew said.

"We've got to catch up"

Of the three deaths besides Aiden's last year, two involved instances in which a mother using methadone, a drug taken to kick a heroin habit, fell asleep and smothered her baby. The other baby died of Sudden Infant Death Syndrome.

Benson-Green said in these cases, her caseworkers did everything properly.
There have been many cases across the country where moms have had adverse reactions to methadone after giving birth, unintentionally harming their babies, Carpenter said. Studies have shown that methadone can increase the likelihood of SIDS.

After a mother gives birth her body changes, Carpenter explained, noting that the mom may not respond to methadone as she did before giving birth. If she is not being closely monitored and the dose is too high, she may feel sleepy or dizzy, which can affect how she cares for the baby.

There have been a number of cases in which moms on methadone have fallen asleep, inadvertently rolling onto the child and smothering it.

Benson-Green said caseworkers take it hard when a child dies because the state likes to believe it has everything in place to keep children safe. After Aiden’s death, DFS has changed its protocol. Now a supervisor must sign a hospital discharge letter acknowledging the caseworker’s findings and clearing the newborn to be released to parents or caregivers.

There is also more training to help caseworkers recognize child abuse and its triggers, and a substance abuse counselor accompanies caseworkers to the hospital when parents test positive for drugs. An informal assessment is made about whether the parent needs additional services.

In spite of steps that have resulted in the deaths of infants, Benson-Green said citizens should not give up on the state to care for children at risk.

“The vote of confidence should still be there from the public,” Benson-Green said. “There should be no reason for them to waiver from it. It’s a challenging job when you are always dealing with constant changes in family dynamics and family behavior and the fact that the culture within the community is changing.”

“We’ve got to catch up and work with those things that are now set before us.”

Sitting on the shelf of a messy home in Harbeson is a white ceramic tile, with “Aiden Ryder” printed in black. A heart stands in for the the dot over the “i” in Aiden, and tiny blue footprints decorate either side of Aiden’s date of birth and death — 02-15-15 to 09-22-15 (/story/news/crime/2015/12/11/mother-tamer-cherryd-killed-8-month-old-son/7143184/).

A tea cup with a broken handle and the word “Mother” holds the tile upright. Those objects and the proposed law in the boy’s name appear to be the only physical memories left of him.

Contact Esteban Parra at (302) 324-2299, eparra@delawareonline.com or Twitter @eparra3. Jen Rini can be reached at (302) 324-2386 or jrini@delawareonline.com. Follow @JenRini on Twitter.

Child Protection Accountability Commission findings

A review of findings reported last month to the Child Protection Accountability Commission, the committee writing the new legislation, cited instances of breakdowns:

• One child was not able to be seen by a local child abuse expert because of a dispute between the hospital and insurance company.
• A report was not made to the state Division of Family Services’ when a victim’s sibling was born substance-exposed in 2013.
• The same division did not verify a mother’s participation with a substance abuse provider.
• There was a delay in planning for the safety of a dead baby’s siblings residing in a home where the death occurred because the mother did not sign a safety agreement. The division also entered into a safety agreement via telephone with an out-of-state relative for the other children six days after incident.

Don’t miss a thing