

### Maine CDC Snuggle ME Guidelines Developed to Standardize Care for Families of Drug-Affected Babies

Maine CDC, led by Director Sheila Pinette, DO, has released *Snuggle ME*, a practitioner's comprehensive guide to caring for drug-affected babies and their families from the prenatal period through the first year of life. *Maine CDC Snuggle ME* is the product of a workgroup of volunteer stakeholders who came together to try to standardize care and ease frustrations.

In the last eight years, Maine has seen a nearly five-fold increase in the number of drug-affected newborns in its hospitals. In [2005](#), the Maine Department of Health and Human Services (MDHHS) received 165 reports of drug-affected newborns; in 2012, that number grew to 779.

The number of newborns affected by perinatal substance use is subject to underreporting, since some hospitals notify MDHHS only if a baby needs medication to treat withdrawal symptoms. The spike in reports is as much an actual increase in drug-affected births—tied to a rise in the nonmedical use and abuse of prescription opioid analgesics—as an increase in reporting, thanks to a 2004 [law](#) requiring<sup>1</sup> birth attendants to notify child welfare authorities if a child may be affected by substance or alcohol abuse or is experiencing withdrawal symptoms.

Drug-affected infants experience mild to severe withdrawal symptoms due to prenatal exposure to narcotics; their central nervous systems are overstimulated, causing stiff or jittery muscles, tremors, and, in severe cases, seizures. These newborns don't snuggle into their caregivers the way healthy infants do, but rather are overly responsive to touch. They may also cry uncontrollably, be unable to sleep, not eat well, and vomit or have diarrhea. Neonatal abstinence syndrome (NAS) is an emerging condition; without specific care guidelines and with few evidence-based treatments, newborns received dramatically different levels and kinds of care across the state. Hospitals developed ad hoc care plans because they were unsure about treatment protocols or where to refer families for specialized or extended treatment. Pediatric caregivers were frustrated by the disjointed system, as were families<sup>2</sup>, who were often surprised by what occurs after birth and left out of their child's care plan. Finally, parents and families were not being treated as partners in their children's care, though they play a pivotal role in maintaining their own health and that of their children once they leave the hospital.

Co-leaders Amy Belisle, MD, and Kelley Bowden, MS, RN, brought together a group of stakeholders to develop [The Snuggle ME Project: Embracing Drug-Affected Babies and Their Families in the First Year of Life to Improve Medical Care and Outcomes in Maine](#). Belisle, a former pediatric hospitalist, worked on this project outside her "day job" as a board member of the Maine Chapter of the Academy of Pediatrics (AAP). Bowden worked on Snuggle ME in her role as a perinatal outreach nurse educator for Maine CDC (ME CDC), a role that has her facilitating quarterly meetings with Maine's perinatal nurse managers and conducting training and educational activities with professionals on a variety of perinatal issues. Both

#### ME CDC Snuggle ME includes:

- Screening for substance use in pregnancy.
- Provider checklist for care.
- Chapters on antepartum care by trimester, intrapartum care, postpartum care, and newborn care.
- Family educational materials, including a trifold and longer family packet.
- Resource lists for providers.

women work under broad mandates to improve perinatal health outcomes—a charge general enough to allow them to lead the development of ME CDC Snuggle ME—and are supported by a variety of state, federal, nonprofit foundation, and other grants.

### Steps Taken:

- Belisle and Bowden began comparing notes on the wide variation in the treatment of drug-affected babies (DAB) in the summer of 2010, after a spring AAP chapter meeting where many pediatricians broadly identified concern about the care of drug-affected babies. Bowden had been hearing similar frustrations at the perinatal nurse manager gatherings. Initially, the two discussed the issue from the pediatric hospitalist's viewpoint and explored more specific information than the major national organizations had available.
- At the time, comprehensive care guidelines did not exist. The pair started bringing up the issue of drug-affected babies at a variety of already-functioning collaboratives around the state, including the perinatal nurse manager meeting and a state task force on DAB organized by the director of the Office of Child and Family Services, Ginny Marriner. They also received guidance and support from Stephen Meister, MD, former medical director of maternal and child health at ME CDC.
- A consensus emerged that every hospital treated drug-affected babies and families differently. No one had a comprehensive picture of existing resources or treatment options available for infants in withdrawal. If confusion existed within the medical community, families dealing with these issues were doubly confused and frustrated.
- Out of these conversations, a workgroup of hospital staff throughout the state began having phone meetings with Belisle and Bowden. By October 2010, two things became obvious: Guidelines were needed to address the prenatal period, and the workgroup had to be interdisciplinary to standardize care for addicted mothers and babies.
- The workgroup's leaders reached out to Maine's experts in treating DAB and their families and asked them to donate their time and expertise to help create resources to fill the gaps. The workgroup eventually grew to include medical experts in obstetrics, maternal and fetal medicine, neonatology, pediatrics, and substance abuse, as well as nurses, social workers, representatives from three NICUs and seven community hospitals, state agency staff, the ME CDC state Title V Maternal and Child Health director, health department staff, the Maine Child Abuse Action Network, the Maine chapters of AAP and the American College of Obstetricians and Gynecologists (ACOG), and ME CDC. Child welfare professionals also informed the process since the issue has clear implications for social services.
- The ME CDC provided a small grant to pay for quarterly meetings for the first two years and lent staff expertise early on in the process.
- In three years, the 30 member quarterly workgroup developed ME CDC Snuggle ME for the medical side of drug-affected babies. To begin, the group conducted a thorough literature review. Several smaller groups met bimonthly for approximately six months to develop different sections. The group used guidelines originally developed in Vermont and Washington and talked with experts from those states about how they developed the resources. They also relied on general information developed by national organizations, such as AAP and ACOG.
- Workgroup members began training professional groups to use the tool in March 2013. Training continues through a series of webinars, hospital site visits, and presentations with instructions

for using the guidelines. While Bowden's training work is supported by her position with ME CDC, all other workgroup members continue to donate their time with the rollout of activities.

- ME CDC Snuggle ME was released in its final format in May 2013. The ME CDC was instrumental in Snuggle ME's final phase by donating staff time to format and post the document.
- Between September 2013 and July 2014, Belisle and Bowden are hosting a monthly series of ["Snuggle ME" webinars](#) with presentations by both national and state experts to help facilitate the implementation of the Snuggle ME guidelines. The webinars are focusing on how to identify the substance exposed pregnancy/newborn and optimize care and coordination for women and children affected by substance use in pregnancy. They are meant to be a community conversation with a wide variety of stakeholders.
- With assistance from the ME CDC, the workgroup is actively seeking grant dollars to support the implementation and evaluation of ME CDC Snuggle ME. The workgroup's ultimate goal is to see the system change in ways that support holistic treatment for these families, who easily fall through the cracks and go without education or wraparound services that would help them and their children thrive.

### Results:

- The final ME CDC Snuggle ME product was much bigger than its leaders originally anticipated. Belisle and Bowden set out to create a newborn care guideline, but developed much more. The workgroup realized early on that they had to involve professionals across the maternal and child health spectrum to create an effective, comprehensive document.
- The early feedback from groups who received training is that they are glad to have ME CDC Snuggle ME and think it will change their practices and inform the way they treat DAB and their families. However, the most frequent comment is that the tool is overwhelming and providers feel that implementing all the guidelines will be a huge undertaking. The Snuggle ME trainers are working this feedback into their message, saying, "Take this in sections. It doesn't all have to be implemented at once."
- The group had hoped to collect data about ME CDC Snuggle ME's implementation and track outcomes among participants who adopt the guidelines, but has no funding to do so.

### Lessons Learned:

- It wasn't always easy to get people to agree on how the tool should handle specific situations. Workgroup participants often had strong feelings toward a particular model or practice. Rather than force solutions, the group took the time to listen, share personal experiences, and review what evidence and other recommendations were available. Though this was a time-consuming process, the group was in agreement by the end, resulting in a stronger document. At times, the quest for compromise led to the development of supplemental resources for the guidelines; for instance, some providers' unease with discussing a patient's drug use led to the creation of a sample script to walk doctors through these conversations.
- ME CDC Snuggle ME's leaders advise people looking to emulate this process to think ahead to the evaluation process and build in ways to encourage funder support. In ME CDC Snuggle ME's case, funders thought hospitals should be doing this kind of work already—though they weren't—and since experts were already volunteering their time, there was no clear need for start-up support. Additionally, the volunteers had limited time to chase funding for the project during development. Still, the workgroup leaders wonder if they should have been searching

and applying for grants to track data and evaluation as the tool was developed, rather than after it was complete.

- A clear policy consideration emerged from ME CDC Snuggle ME: Medical education has yet to catch up with the emerging DAB problem. Medical and nursing school curricula do not focus on treatment models, and only a few offer any baseline education about addiction.
- Workforce development is another policy consideration. While ME CDC Snuggle ME offers practitioners resources and links to treatment options for patients who screen positively for drug use, Maine faces a shortage of providers who treat substance abuse, including those who treat Medicaid beneficiaries. Those who do offer such treatment are reluctant to accept pregnant patients because the cases can be complex. Rural areas, where rates of substance abuse are especially high, face an even more acute provider shortage. The ME CDC Snuggle ME workgroup is looking for resources to facilitate collaboration between maternity care and substance abuse treatment practitioners. This work would ideally include a policy component, to explore creative ways to finance the prevention, education, and wraparound services these high-need patients require.
- The workgroup also feels that further study is needed about integrating trauma-informed care – care with a basic understanding about how trauma affects individuals seeking services – and education into the care plans for these families.
- The workgroup wanted to include families in the development of the tool but found it very difficult to choose the right setting for meaningful engagement. Several agencies on the social services side got direct feedback from families, so the workgroup felt that these professionals could inform the family education materials well enough.
- Group leaders feel that ME CDC Snuggle ME is just a start. Now that they have the hospital guidelines, they would like to focus on the big picture: What is the best system of care for these families? How do we make them partners in the care of these babies?

**For more information:**

Sheila Pinette, DO  
Director, ME CDC  
Department of Health and Human Services  
Email: [sheila.pinette@maine.gov](mailto:sheila.pinette@maine.gov)

Kelley Bowden, MS, RN  
Perinatal Outreach Nurse Educator, ME CDC  
Maine Medical Center  
Email: [bowdek@mmc.org](mailto:bowdek@mmc.org)  
Website: <http://www.bbch.org/Programs/perinatal-outreach/Pages/Overview.aspx>

Toni Wall  
Director, ME CDC Children with Special Health Needs Program  
Department of Health and Human Services  
Email: [toni.g.wall@maine.gov](mailto:toni.g.wall@maine.gov)

Ellen Schleicher Pliska, MHS, CPH  
Family and Child Health Director



## Maine CDC Releases New Guidelines to Help Practitioners Care for Drug-Affected Babies

Association of State and Territorial Health Officials  
[epliska@astho.org](mailto:epliska@astho.org)

---

<sup>1</sup> The law requires professionals present at the birth to notify child welfare authorities if the child may be affected by substance or alcohol abuse or is experiencing withdrawal symptoms. The agency must investigate the report; determine if the infant is being abused or neglected; develop a safe care plan for the infant with the assistance of the mother or the child's medical or mental health provider; and provide family with referrals for substance abuse treatment and social service agencies. According to state sources, it is very rare for these investigations to result in a child being removed from the home. Most often, child protective services staff act as case managers and make sure that the infant is thriving (e.g., gaining weight, family coping with the stress of caring for a DAB). Often they send in public health nurses to act as a resource for the family. Child protective services staff worked with the Snuggle ME team to reduce the stigma for these families.

<sup>2</sup> Familial frustration could be eased by better communication between parents and healthcare providers, especially during the prenatal period. For instance, parents may not have been told or may not realize that prenatal exposure to drugs—even maintenance drugs, used to treat a mother's addiction—means their babies will face a withdrawal period. Without planning and education during the prenatal period, parents may not realize that their infants need to stay in the hospital for observation for five to seven days after birth. The average length of stay for infants who start drug treatment for withdrawal is 14-21 days, depending on the hospital. Withdrawal symptoms take 24 to 48 hours to develop, which is also a challenge for parents, who may think that their infants are healthy. Furthermore, with no existing quick screening test to definitively diagnose NAS, doctors rely on an observational scoring tool, which is subjective. This can be hard for parents who may think their infants are being "over scored." Once NAS babies overcome withdrawal, they may have lasting developmental issues. A host of services are available, but follow-up care is not standardized across the state or across agencies, meaning that families are not always aware of or able to take advantage of early developmental screenings or the knowledge of public health nurses.