Peer Reviewed

Family Centered Care (FCC) Taskforce: How to build a Family Advisory Council in your local NICU

Chavis A Patterson, PhD

This is the second of a series of Webinars from the Family Centered Taskforce. In this first interview, Mary Coughlin, MS, NNP, RNC-E described responding to " The Biological Urgency of Families in NICU Based on our Understanding of Trauma."

"Thank you so much for the invitation and for participating in this organization with its amazing activity of non-birthing support to NICU parents."

Chavis Patterson:

Thank you so much for the invitation and for participating in this organization with its amazing activity of non-birthing support to NICU parents. Just to give a little overview of the institution for those who are not familiar with CHOP, it is located in Philadelphia. Here is a picture of the outside and inside of CHOP. It is a level four NICU with 98 beds. We transfer in babies up to three months of age, and we work with approximately 1300 babies per year. We provide surgery and ECMO to the babies. We have approximately 400 nurses and approximately 44 neonatologists, and then a host of other support. This includes respiratory therapy, dietitian, OT/PT, speech, lactation, social work, psychology, child life and chaplain, and a host of others. That just gives you an outline of the institution at CHOP.

" I wanted to expand on what we think of for non-birthing parents and to be a little broader in my discussion today. This is when we talk about families that have two moms, families that have two dads, families that have a mom and a dad where there might have been a surrogate, there might have been an adoption or a gestational carrier."

I wanted to use this graphic as an example of what families might look like. You can read all the different arrows, and it can be a combination of one, two, or three. I wanted to expand on what we think of for non-birthing parents and to be a little broader in my discussion today. This is when we talk about families that have two moms, families that have two dads, families that have a mom and a dad where there might have been a surrogate, there might have been an adoption or a gestational carrier. I will talk about a broader range of what a family might look like. So I want to talk about the non-birthing parent. Sometimes the non-birthing parent is mom, sometimes it's dad, sometimes they are biologically related, and sometimes they are not. To give an idea of my discussion as a psychologist, when I think about supporting parents, and certainly non-birthing parents, I think about, Why people get pregnant? Usually, if I'm in person, I would pause and ask the audience. Virtually, it's a little tougher.

"You have a range of more positive and then sometimes negative reasons. This might be, again, pressure from families. It might be a way to stay connected with an individual. It might be a result of incest or rape. There's a wide range of reasons why people become pregnant, and as a psychologist, as a psychosocial person, I always think about that when I walk into the room."

It might be family pressure. There might be a financial reason to get pregnant. You have a range of more positive and then sometimes negative reasons. This might be, again, pressure from families. It might be a way to stay connected with an individual. It might be a result of incest or rape. There's a wide range of reasons why people become pregnant, and as a psychologist, as a psychosocial person, I always think about that when I walk into the room. This helps me get an understanding of what this pregnancy means to the family. Sometimes the pregnancy has been many years of trying to get pregnant. There's a lot of pressure on having this pregnancy. I think about how in my experience, this is what families imagine having a baby might be like, or the birthing process might be like. And if you look, everybody is very happy, and there's smiles, and there are no tubes or wires. Unfortunately, in my world, this is the reality of the family's experience. You have ECMO, bili lights, tubes, and wires. So again, understand that walking into the NICU is a very traumatic experience for families if we look at some of the rates of depression, post-traumatic stress disorder, and perinatal mood and anxiety disorders. You can see differences across NICU parents and non-NICU parents.

When I talk to parents, I get a wide variety of emotions that they express, from happy to sad to a sense of loss. There's anger and feeling overwhelmed. There's shame! There's hopelessness, sadness, and isolation. I'm thinking about these wide varieties of emotions that come into play and the different roles.

We have fathers and their roles. Some of the myths and truths that come out that society has put upon them. They think about fathers as providers, the emotional rock, the need to not be emotional. They need to be detached, so they can help the family. These are some of the pressures that some non-birth parents might feel. Their role, in terms of the birth of a child, and with men, society may big boys aren’t supposed to cry. They’re asking about, “How’s your wife doing? How’s the mom doing? How’s the family holding up?” and not talking about how they are, what their experience was like as a result of this pregnancy and birth.

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The quote that I like to share is, “As a dad, I feel like we were often overlooked in the family picture. I was terrified when we had our son seven weeks early.” Jeff Stimson stated, ‘It’s not a matter of a good hand, but playing a bad hand well.”

So thinking about different types of families, we wonder if some or many of the emotions are shared by the non-birth parent. We wonder if some are unique and if some are shared. With all families, no matter the makeup, there are many layers that come into play. There’s the institution where you’re being cared for, there’s the race and ethnicity of the family and the family members, there’s the age, and there’s how they identify. So, there are a lot of different layers. These were some of the emotions when I spoke to some of the parents, where there were two moms or two dads. These are some of the feelings that came up.

The non-birth parent is envious or jealous. They feel like the baby might not like them and might like the birthing parent more because of breastfeeding and that closeness. In a family where there were 2 Dads, one of the dads in the family talked about feeling unimportant or invisible, or unequal as an outsider. Many times they felt that they were being judged as not one of the families that might ordinarily come into the hospital. Dads who were in situations where there was a donor, a surrogate, or gestational carrier. They talked about being worried or scared about the donor egg. There was some background in genetic testing. But what is this donor egg going to bring into the family? What is it going to be like in terms of the donor? It was the same idea with donor sperm.

When thinking about the surrogate, they think, how is the mental health or the physical health of the surrogate going to impact the birth or gestational period of their child? So again, there’s a lot of worries when a mother and father are genetically connected to the family. When we have families with two moms or two dads, there may or may not be a genetic connection.

Some of the worries that come up are a fear of genetic complications when families are choosing between which mom’s egg to use or which donor sperm to use. For the donor egg or donor sperm, what is that going to mean in terms of the genetic makeup? How is it going to combine with the egg or the sperm? When I talked with two moms, we talked about empathy in this process.

In terms of going through the process of birthing together, the non-birthing mom had a special empathy to the birthing mom. This was in terms of also having a woman’s body and knowing the changes occurring to her body if she had carried a child. That doesn’t always happen in families with a mother and a father. There’s the stereotype that it might be harder for the non-birthing parent to ask for help because all the focus is on the birthing parent.

Maybe there’s hesitation to express the emotion for fear that there might not be any support. In the cases with two dads or with two moms, we talked about being overwhelmed by the financial investment and commitment going through the process of finding a gestational carrier and an egg and sperm donor. There’s a lot of things that go along with all families and have to be managed in some of my conversations.

We talked about the range of interactions, and it can vary depending on race, ethnicity, where you are, and the people you’re dealing with.

“But in the best-case scenario, when I spoke with the dads, I was very surprised that they had a surrogate coordinator. So their experience was amazing. From the day that they connected with the hospital and said they wanted to have their child there, they were connected with the surrogate coordinator, who walked them through the whole process.”

But in the best-case scenario, when I spoke with the dads, I was very surprised that they had a surrogate coordinator. So their experience was amazing. From the day that they connected with the hospital and said they wanted to have their child there, they were connected with the surrogate coordinator, who walked them through the whole process.

With the two moms, in their experience, the hospital was very welcoming, which was really wonderful. They also found the same thing as the dads. These are best-case scenarios. The worst-case scenario was from my conversation with another set of dads. They talked about the staff and some interactions where their role as a parent was trivialized.

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The staff didn't truly recognize that these were the dads of the baby, and there was some homophobia that came with that. It was interesting that even though there was a biological connection to the baby, they still felt like they were outsiders to that process.

Again with the two moms, there was some phobia involved. There was a hard time understanding that they were two moms and not sisters, or one wasn't an aunt. They felt like they had to come out every time they had an interaction with a new provider. They had to explain who they were and what their relationship was to the child.

With the mom and dad, there was the idea that everything was focused on the mom, and the dad was an afterthought like he was disregarded and not part of the process and didn't have a role to play. It was very interesting in my interviews with some of these families. If we do have some non-birthing parents in the audience, what can you do?

As a non-birthing parent, some of the things are to wash the pump supplies and help the nurse, staff, or birthing parent. Also, watch the baby, hold the baby, change the baby, take time to sing, read, and talk to the baby. Support your partner, talk with your partner, and see how your partner is managing all the ups and downs. For the partner, it's important to be there for some of those bumps along the road in terms of non-specific things.

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This includes trying to be a buffer with staff, other families, relatives, and friends. Helping with health insurance if that's something that's needed. Helping care for other children, if you do have other children. If you need to go to work, it's okay. Play your role in the larger family. If you can, manage the food train or the meal train, that is always great. Also, encourage self-care both for yourself and for your partner.

In terms of providers, the list goes on. These are some I want to highlight, but as a provider, if you're not sure about who's in the room and their relationship with the baby, just ask. How are you related? How are you connected with the baby? They will say I'm mom, or I'm dad, or I'm Ted. Try to explain the role of the team. Everyone is not medically savvy and may not know what a fellow NP, PA, or even attending is. Explain the roles of the team.

Offer some anticipatory guidance about what this experience might look like. Try to help connect the family with the appropriate staff within the hospital or within the unit. I certainly encourage self-care for all family members. Help them find folks from the extended family that can help support the family. Always take pictures to mark the milestones that the infant makes and that the family makes. When you're working with family, acknowledge the trauma and the emotional impact that this experience has on the child. Try to offer social media links, Instagram posts, and podcasts. There is a lot out there that these families can connect with so they don't feel isolated. During COVID, families felt really isolated, and I tried to connect them with online resources where they could feel connected and recommended community support if that is something the family is interested in.

"When you're working with families, always remember that they're not always on the same page and they're experiencing this hospitalization differently. They all react differently in terms of sadness, post-traumatic stress, and perinatal mood and anxiety."

When you're working with families, always remember that they're not always on the same page and they're experiencing this hospitalization differently. They all react differently in terms of sadness, post-traumatic stress, and perinatal mood and anxiety. It can come out in many different ways, like being tired, being sad, being exhausted, getting angry easily, or being hyper-vigilant.

As staff and as a partner, we need to remember that. Discuss the impact of grief and loss of the normal pregnancy that they might have imagined, or even had, with the previous child. Certainly acknowledge society's message related to gender, the couple, the family structure, race, and ethnicity, because all that plays a part, and sometimes it's the elephant in the room. Nobody wants to talk about it, but everybody knows that it plays a role. Encourage families about different ways to communicate when words fail, so it can be tough, art therapy, journaling. Talking is great, but there are also other ways to communicate how you're feeling and express your emotions. Create special moments for the non-birthing parent, like encouraging them to hold the baby, speak to the baby, bathe them, change them, participate, and take pictures.

I really liked this quote and will use it to end this presentation. "The inability of some people to verbally express their pain and emotional reactions should not be taken as a sign that they suffer any less." I think sometimes people fall between the cracks or suffer in silence. We need to work harder on reaching out and checking in with people more often. Thank you again to everyone for their time and attention. Thank you for the invitation, and also, thank you to the families that I was able to interview to collect the information for this presentation.

Caroline Toney-Noland (she/her):

Thank you so much for sharing that. I would love to open it up to see if there are specific questions that folks have for Dr. Patterson.

Do you offer a psychologist in the NICU for parents at CHOP?

Chavis Patterson:

Thank you very much for your question. At CHOP, yes, we're very fortunate to have a few psychologists. I'm one of the psychologists that has 50% clinical time in terms of working with parents, and the other time is academic. We also have other psychologists who split their time between the NICU and other units within the hospital. So again, we're very fortunate to be able to have psychological services in our queue.

Colby Day:

Dr. Patterson, that is wonderful that you are able to have those services. I think it's something that many of us aspire to in our hospitals. I'm curious about the logistics of how you use the psychologists in your unit, particularly whether you approach or your group approaches all families. Or do you wait for families to reach out, saying that they need help? Or are there specific screens that are done? If so, who performs those screens?

Chavis Patterson:

Thank you for the question. In our NICU, referral comes in a number of ways. The medical team, will usually connect with the social worker. Then the social worker will do their assessment and talk to the families. They ask the family about having the psychologists come and speak with them.

> ***"We don't screen, but we're working on a universal screening. We have not nailed that down in terms of logistics. We're a freestanding pediatric hospital, and we don't have a system of support for adults. So if one of the family members needed adult care, we would have to refer out."***

We don't screen, but we're working on a universal screening. We have not nailed that down in terms of logistics. We're a freestanding pediatric hospital, and we don't have a system of support for adults. So if one of the family members needed adult care, we would have to refer out. We don't have adult psychiatry to manage medication. So, we're a little limited in that way, but we do have psychology.

Social work connects with all families and does the assessment. They do a great job, and they usually reach out to us in psychology as a result. Sometimes we get referrals from bedside nurses or other medical care providers. But we usually have the social workers go out and do an assessment. There are other families who come in and ask to speak with a psychologist on staff. Then we would get connected in that way. Now, to go back to the first part of your question. It is unique that some institutions have a psychologist. There is some information on the web about how to encourage your hospital to get a psychologist.

There's information on the National Perinatal Association (NPA) with a link to support NICU parents. It gives a job description and a whole PR package about how to ask your institution to support a psychologist in the hospital. Is there anyone from that group that can put the link to that information in the chat? It really helps to bring a package of information to your organization to help convince them.

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I'm going to do some sleuthing because I don't think any of us are very good at that. I can send you a packet of information. It's a really great website. I know Sue Hall, and some folks from NPA did a lot of work to pull this information together because we were really trying to get the word out about psychology, what we can do, and how we can be helpful.

Colby Day:

That would be wonderful. We can put it on our tablet resources for everyone to see. Thank you.

Caroline Toney-Noland (she/her):

We have another comment about a really great idea about using EPIC to allow sticky notes so you can make the different family member roles clearly visible to all staff. Another question from Sara. Can you talk about how you bridge psychology and care after discharge?

Chavis Patterson:

Yes, that's a great question. It's very challenging because providers are very difficult to find. We work really hard to create a list of providers. We take advantage of the Postpartum Support International (PSI) link. You type in the zip code, and then you get providers in certain areas of the country, and I think they're moving towards the world.

It's really trying to create a network. I think PSI is a good place to start, but just creating a network. Many hospitals treat not only families in their area but sometimes out of state, and it's really hard to find those providers. But usually, when families are midway in, I start thinking about where they live and encouraging them to look into it, or I help find them providers in their area. There is a national network of NICU psychologists.

Caroline Toney-Noland (she/her):

To add, for families who lack insurance or may not be able to afford psychosocial support after discharge, are there any resources that CHOP has for them?

Chavis Patterson:

Well, not necessarily CHOP. But I usually try to link them to the Internet because there are a lot of organizations and foundations that have mentors. Graham's Foundation is run by Nick and Jen Hall. They have mentors. I know PSI and NPA also do that. There are a lot of foundations and organizations that help because not everyone is local. If they don't have insurance, I usually try to again find things on the Internet. But I also try to go through local city agencies to find community groups that offer a free or low-fee service.

> ***"Then the HOPE Family Project also has a social worker on staff for therapy services. PSI has a lot of online support groups across the U.S. There's also a shortage right now of mental health providers. I think finding support may be even more challenging for families."***

Caroline Toney-Noland (she/her):

Another comment about Project NICU, it has connections with better health online. I have seen them advertise on Instagram, so they're able to get free counseling for NICU families. Then the HOPE Family Project also has a social worker on staff for therapy services. PSI has a lot of online support groups across the U.S. There's also a shortage right now of mental health providers. I think finding support may be even more challenging for families. I've been trying to waitlist some for 2-3 months.

Chavis Patterson:

And families can't wait 2-3 months.

Caroline Toney-Noland (she/her):

Any other final questions for Dr. Patterson before we move on to our family panel?

I just want to say from my part. This has been really great to see and hear so many different family structures represented and celebrated. Then making sure that we, as health care providers, are doing our best to ensure that family is still welcome into the NICU. It's hard enough to align transportation, time off work, and care for other children or other responsibilities. It's hard enough to make it into the NICU and have family members come. We really want to make sure that we're doing our best and they are supported. Thank you so much for your talk.

Colby Day:

Wonderful, and I echo those comments. Thank you so much for that talk, Dr. Patterson.

Disclosures: No conflicts have been identified. .

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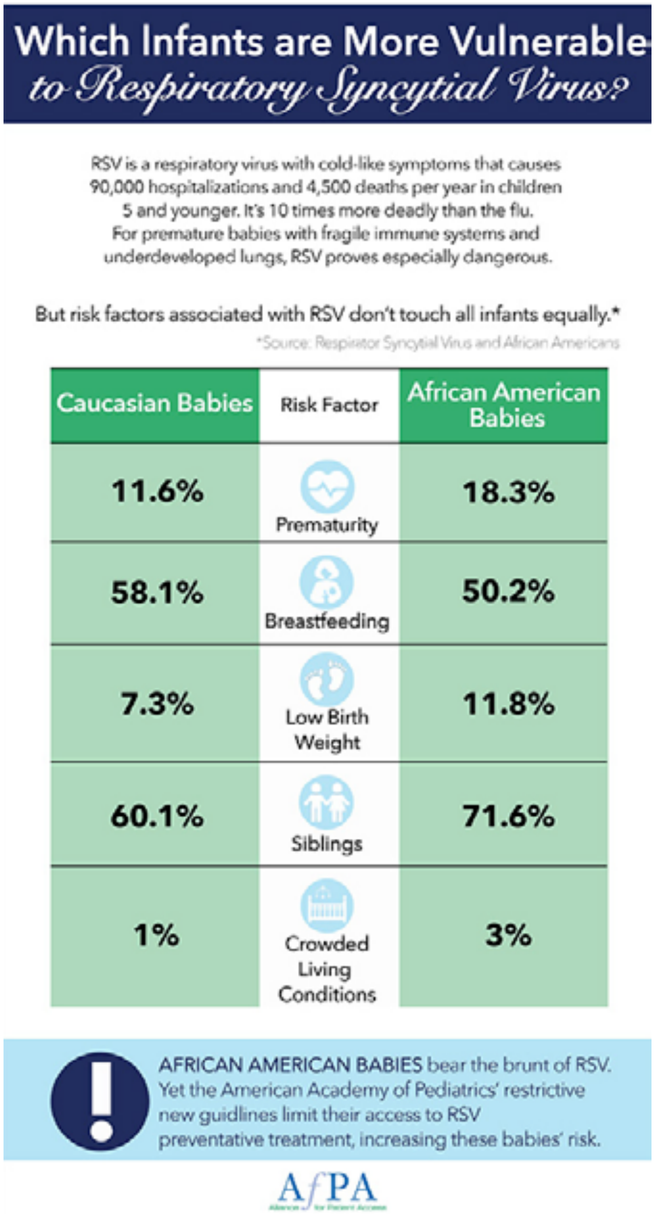

Which Infants are More Vulnerable to Respiratory Syncytial Virus?

RSV is a respiratory virus with cold-like symptoms that causes 90,000 hospitalizations and 4,500 deaths per year in children 5 and younger. It's 10 times more deadly than the flu. For premature babies with fragile immune systems and underdeveloped lungs, RSV proves especially dangerous.

But risk factors associated with RSV don't touch all infants equally.*

*Source: Respirator Syncytial Virus and African Americans

Caucasian Babies	Risk Factor	African American Babies
11.6%	Prematurity	18.3%
58.1%	Breastfeeding	50.2%
7.3%	Low Birth Weight	11.8%
60.1%	Siblings	71.6%
1%	Crowded Living Conditions	3%

AFRICAN AMERICAN BABIES bear the brunt of RSV. Yet the American Academy of Pediatrics' restrictive new guidlines limit their access to RSV preventative treatment, increasing these babies' risk.

Interpreting Umbilical Cord Blood Gases: Section 9: Deciphering Multiple Issues

Jeffrey Pomerance, MD, MPH

"In clinical practice, accurately interpreting umbilical cord blood gas values may be quite difficult. Following are two cases in which the issues are multiple but, in the end, mostly decipherable."

In clinical practice, accurately interpreting umbilical cord blood gas values may be quite difficult. Following are two cases in which the issues are multiple but, in the end, mostly decipherable.

Case 26: Cord Occlusion with Release Just Before Delivery

The mother was a 27-year-old, 226 lb, gravida 3, para 2, aborta 0, with an intrauterine pregnancy at 40 5/7 weeks gestation. The mother had two previous difficult vaginal deliveries. One required vacuum extraction (birth weight 3034 g) and the other suprapubic pressure for shoulder dystocia (birth weight 3289 g). One day before admission, the mother complained of decreased fetal activity; however, an NST was reactive. On admission, the FHR tracing had a baseline heart rate of 145 bpm with good variability. Over the next six hours, both late and variable decelerations occurred with increasing frequency.

"Thirty-five minutes before delivery, Tucker forceps were applied. The FHR declined slowly from 180 to 40 bpm. This was followed by a rapid increase to 140, a rapid decrease to 75, an unstable heart rate between 75 and 130, a return to 180, and finally, a deceleration to 80 bpm without variability."

Thirty-five minutes before delivery, Tucker forceps were applied. The FHR declined slowly from 180 to 40 bpm. This was followed by a rapid increase to 140, a rapid decrease to 75, an unstable heart rate between 75 and 130, a return to 180, and finally, a deceleration to 80 bpm without variability. Further attempts at vaginal delivery were abandoned, and an emergency cesarean section was ordered. Twenty-five minutes later, the infant was delivered. The FHR was 145 bpm three minutes before delivery, still without variability. Apgar scores were 2, 4, and 4 at one, five, and 10 minutes, respectively.

Cord blood gas results were as follows:

	Umbilical Vein	**Umbilical Artery**
pH	7.00	6.75
Pco$_2$ (mmHg) *(kPa)*	71 *9.47*	132 *17.60*
Po$_2$ (mmHg) *(kPa)*	35 *4.67*	5 *0.67*
BD (mmol/L)	14	17

At delivery, the umbilical cord was wrapped tightly around the shoulders "like suspenders." Thick meconium was present. Resuscitation included intubation, suctioning, positive pressure ventilation, and oxygen. Oxygen was increased to 100% when the baby was slow to respond. The Birth weight was 3318 g.

Follow-up arterial blood gases from the infant at 37 minutes of age were:

	Infant's ABG
pH	7.13
Pco$_2$ (mmHg) *(kPa)*	37 *4.93*
Po$_2$ (mmHg) *(kPa)*	48 *6.40*
BD (mmol/L)	17

A CBC at age 42 minutes had a hematocrit of 49.3% and a WBC count that was mildly elevated with a shift to the left. A follow-up WBC count at age 18 hours was normal; the hematocrit was 47.6%. The blood culture was negative.

The infant was found to have a right non-depressed parietal skull fracture, developed seizures that resolved, and had an MRI that was compatible with a hypoxic-ischemic event. Intracranial hemorrhage was absent. Subsequently, the infant was found to have cerebral palsy, spastic quadriparesis, and moderate to severe