Pediatric Nutrition
CONTINUING EDUCATION FOR CLINICIANS

TRANSCRIPT

Bridging the NICU to Home: A Team-Based Approach to Infant Discharge and Follow-Up Care

Part 3: The Parent Experience in the NICU

Editor's Note: This is a transcript of an online course released in September 2026. It has been edited for clarity.

The Parent Experience in the NICU

Heidi: Welcome to part 3 of the program, Parent Support and Advocacy. I'm Heidi Gates and I'm a NICU nurse, but I also serve as the discharge coordinator for our NICU. In a few minutes, you'll watch a conversation between me and Molly Fraust-Wylie who I have worked with for many years supporting families from admission to the NICU through the transition to home. Before that conversation, I want to spend a few minutes grounding us in 3 concepts you'll hear us reference throughout: family-centered care, family-integrated care, and what we simply call the parent experience. These philosophies shape how we teach, how we hand off caregiving tasks and how we prepare families to advocate for the infants long after they leave our unit.

A NICU admission is a family crisis as well as a medical one. If you think back to how NICUs operated 2 or 3 decades ago, visiting was often restricted and parents were treated more like visitors than participants in care. That's shifted substantially, and the evidence base has shifted with it. Three concepts reflect that evolution: family-centered care, the philosophy that got us started down this path; family-integrated care, the more structured model many, including ours, have since adopted; and the parent experience itself, which is the true reality of what families live through during a NICU admission, connecting the other 2.

Molly: I'll add, Heidi, having been on the other side of this, from a parent perspective, that this evolution in how we see and handle the role of parents in this setting in the NICU is not abstract or just a concept to me. The difference between being told as a NICU parent what was happening to my son and being invited to actually participate and do something for him really changed how I experienced those weeks in the NICU entirely.

Heidi: That's really good to hear, Molly. The family-centered care is a philosophy of care built on a partnership between clinicians and the infant's family. And it was formalized by the American Academy of Pediatrics in 2012, and it also rests on 4 principles: dignity and respect, information sharing, participation and collaboration. In practice, that means honoring a family's values and cultural backgrounds in every interaction, giving them complete unbiased information that is actually useful, not just accurate, supporting their participation in care and decision-making at whatever level they're able to engage in and, at the institutional level, involving families in how we design programs and train our staff. Family-centered care sets a philosophical foundation for how to bring families closer to the care of their infants and how to consider such things as the family's culture, values, priorities and learning preferences. What it didn't originally specify was exactly what day-to-day participation looks like. That's where family-integrated care comes in.

Family-integrated (FI) care takes the principles of family-centered care and operationalizes them. Instead of general expectations that parents participate, FI care defines the specific caregiving and decision-making responsibilities, such as feeding, providing certain care, charting, being present on rounds as part of the parents' defined role on the care team. This isn't only a conceptual distinction, we have an evidence base to support its adoption in neonatal ICUs. In 2018, in a multicenter, multi-cluster randomized trial, led by O'Brien and colleagues, published in *Lancet Child and Adolescent Health*, it was found that FI care reduced parent stress and anxiety and improved discharge readiness compared to standard family-centered care. Frank and O'Brien had a paper in 2019 that traces this evolution in more detail for anyone who would like a fuller history. Other published studies have found numerous clinical benefits of an approach that prioritizes family-integrated care related to weight gain, reduced nosocomial infection rates, higher rates of breastfeeding, shorter hospital lengths of stay and less use of emergency services after discharge. The benefits of FI care are clinically important and have been shown to directly impact the outcome of the preterm infants.

Do you want to give us some thoughts on this, Molly?

Molly: From where I sat, Heidi, the transition from watching your NICU and the infant to actually be able to do something specific for my son was one of the single biggest

turning points in how I felt, and how confident I was by the time we were ready to go home.

Before we get into our discussion, I wanted to say a few words about the experience of parents at the bedside. Everything just covered translates into 3 things I hear from families constantly and that I lived myself. We found these 3 principles to be highly effective in guiding clinician and family interactions and conversations in the NICU. First, remember that while a day in the NICU is truly ordinary for those that work there, finding yourself there as a parent is a traumatizing experience. That acute stress and anxiety absolutely influence our ability to listen, learn and retain information. In those early days, don't expect a parent to retain very much. The stress is simply too high. Second, our ability to absorb and process information, whether it's a clinical summary of what's going on, or the status or the update of the baby is more dependent on a parent's emotional state than the actual content that's being shared. The same information that means nothing might be clicking with 1 parent on a day that might not be clicking with a parent on day 2, might be exactly what they're ready to absorb and take in on day 12. And finally, third point, advocacy isn't something that parents just walk in with. It's something that gets built over time, conversation by conversation, when clinicians create room for it. If we can think about it as a skill that needs practice, coaching, encouragement and, most importantly, patience, I believe that we can transform NICU parents into strong, confident and knowledgeable advocates for their children.

Heidi: That's great information. Those 3 ideas, stress and information processing, readiness and advocacy as a skill, are exactly what you and I are going to dig into in the conversation that you're about to watch. Let's go to that now.

We're going to talk about the parent experience in the NICU from the perspectives of a NICU discharge coordinator and a NICU parent. Our 3 goals for today's conversation are to provide learners with direct, first-person perspectives on the parent/caregiver experience of concurrent education and advocacy during a NICU admission, to educate clinicians on best practices for supporting parents as both learners and advocates and to identify resources for enhancing family-centered and family-integrated care practices in the NICU.

The first topic for discussion is parent information processing during the acute first few days of admission. And we know that acute stress affects the parents' capacity to retain and act on critical information, particularly during the first few days of admission. Educational approaches that might work later in the NICU stay are often not successful early on. In the first few days, parents are overwhelmed, they're stressed, and yet there is information that needs to be conveyed. There's a lot happening. As a person at the bedside, a clinician, we try to limit the amount of information that we give to just crucial information that parents really need to know about the care that their babies are being given. We try to do it in small doses, knowing that parents get overwhelmed, and then we just answer questions because we know parents may have a lot of questions or they may not have any questions, but if they do, we try to answer specifically the questions that they're asking.

That's the clinician's side of it. What are parents feeling and how can we make this better for them during that highly stressful time?

Molly: It's really important to think about how much information a NICU parent, and particularly a birthing parent, can retain in that first 24 or 72 hours, knowing that most likely they've never even been in a NICU before. At best, they might have had a NICU tour if they were anticipating a high-risk pregnancy or delivery. They're getting so many new words and concepts after their baby was admitted and also they're recovering or still in process from what might have been a really traumatic delivery that they have experienced or that their partner has experienced. I think it's really important to honor that experience and know that there's kind of 2 different crises happening. There's what's happened to the baby and what's happening to the birthing parent, and all attention went from a pregnancy to a baby, and there's a lot of whiplash with that. The ability to retain any information is pretty limited, and also the ability to retain information that's given to you orally is really tough while you're recovering. We're given a ton of paperwork, we're given information in bits and pieces, our partner might be giving us information. The way that we're able to discern what's important in those moments is really difficult. I think we ask for a lot of grace and a lot of patience because it's really difficult to know what the most important information is, whether it's the parking at the hospital, whether it's how your baby's breathing, all of those things feel really overwhelming when they're being given to you in the same 15-minute window.

Heidi: That's really important to hear from a parent's perspective, but there are times when communication does go well and, in my experience, I've noticed that

communication that does go well has a few basic communication skills and 1 is to sit down with the parent and be on the same level, face to face. Two, as I said before, small chunks of information that can be given in a short period of time so as not to overwhelm. Using simple, understandable language, oh my goodness, the NICU is full of big words and acronyms and lots of initials. Especially in the beginning, before parents have learned the lingo, if you can avoid using those, I have found that communication goes better. And lastly, just giving parents some time. The NICU's busy, people are always rushing around and if you can sit and give them the time to just listen or ask questions or you can just sort of tell or ask them are you understanding, that seems to be helpful. But, from a parent's perspective, what kinds of things would you find helpful from a clinician?

Molly: Thanks for asking that, it's really important because I think there's honestly often a difference between what clinicians think we want to hear and what we actually want to hear as NICU parents. And sometimes we just need a little time to absorb the environments and to understand what all of the different tubes and wires and alarms really mean. One really meaningful interaction that I had with a neonatologist in the NICU was when she came to the bedside and she rounded with us at the bedside and she explained what each alarm meant and she explained to us the sort of abbreviations. When people were using the term "spells" or "As" and "Bs," that was language I was very unfamiliar with at the time and my son was quite small and that was just language I was totally unfamiliar with and so she helped us get really comfortable by just talking to us on a one-to-one basis. And our nurse was there and it was a moment where we could be vulnerable with her and ask questions and we could ask questions of the nurse. It felt private. We weren't as exposed as we would've been at the rounding desk and we could really kind of share what our worries and fears were about our son and she could answer them honestly and openly, but we didn't have to leave our son's bedside. But she was also able to be very frank with us about what they were watching for, but also just understanding the technology in the room, what they were looking for, what concerns they had, really helped us feel like we were part of the care team.

Heidi: That's very insightful information and what I hear you saying is that picking the place where you're going to convey this information may have a big impact and the fact that you were able to hear the information at your baby's bedside and could relate what was being told to you with your baby and what was happening to him made a difference in how you heard the information. That's amazing insight that I think, as clinicians, we can use going forward, so thank you so much for that.

One more question on the processing of information. The first few days we've talked about are overwhelming and stressful, but as time goes by and you become more accustomed to the flow of the unit, the sounds, the routines that happen every day, how does that change your ability to understand communications and learn information that's given to you?

Molly: I think that as you become more familiar with the NICU environment, you never really grow comfortable in it, you never want to grow comfortable in the NICU. That's why I call it the best worst place and the worst best place. But I think you gain more confidence in understanding which alarms, for example, you need to be more worried about, and which ones are just the end of a tube feeding, for example. And being able to build that confidence I think is really important. The other thing I will say is, for example, my husband took every piece of paper that was handed to him and just absolutely digested everything in full. He wanted every scrap of paper, he kept it, he probably pored over it 3 and 4 times. I honestly am not sure I read any of it, to be completely candid. I think there needs to be multimodal communication. There needs to be visual things for people who are visual learners. There needs to be verbal communication so that you can build a relationship with families, and there needs to be written documents for people who are more comfortable with that. And, obviously it goes without saying, those need to be in multiple languages because not everybody speaks English. I think, in time, all of that confidence is built but also that not every family will feel comfortable asking questions. Not every family will feel comfortable going to rounds. Being able to provide them with the information that they need about their baby in different ways is really, really important, because also not everybody can come in to the NICU.

Heidi: Really important information to remember. That, even though they're parents of the same baby, they may learn completely different and they may need different things to absorb information and learn things. That is very important feedback, and I thank you so much for that. But, moving on, I want to talk a little bit about the parents' role in family-integrated care. Family-integrated care models assign to parents specific, defined, caregiving and decision-making responsibilities rather than the general "you can participate in your baby's care." This is what we talked about that distinguishes family-integrated care from the

earlier family-centered care approaches. I'm just curious, as a parent in the NICU, how do those things feel to you? What helps to make the parents transition from an observer watching how the nurses take care of the baby to, oh this is my job, I can take over this role? How does that happen?

Molly: I think that a really good, strong relationship between a parent and the clinical care team, starts from day 1. You and I know, Heidi, that admission begins on day 1 in the NICU, right? We're already preparing for admission. We're trying to build a family's confidence in caring for their baby. Getting them as involved as possible from those very early days, even in the acute days, sharing with the family what they can do, even for the most tiny fragile babies, there are still things that their families can do for them and making sure that they know that they are the most important member, they are the most important thing in their child's life. I think that once those connections are made, as a parent you really start to feel that and to understand that you aren't an observer. You are their parent. You are their first home and now you have this important role to play in the NICU and to be involved. At first, it's really scary, changing the diaper on a teeny, tiny baby. You've never seen diapers so small. Who had any idea that we brush a 3-pound baby's hair with a toothbrush, like a teeny, tiny, tiny toothbrush, but it's one of my absolute favorite memories and I'm so glad that someone showed me how to do that. All of these things are so central to the bonding that needs to happen. I think being able to have those connections and being able to take over that care is so important because it helps us build the confidence that we need and it's also part of our healing.

Heidi: I appreciate your insights. As a clinician, providing parents the opportunity, at the bedside, to actually do the care, I think, as the days and weeks go on, it engages parents. They actually learn better. They absorb things more when they're actually doing them on their baby. You and I know from years of follow-up phone calls, parents tell us that what helped them the most to learn to care about their babies was actually practicing, doing it at the bedside with the nurses present. And it's important to take time. NICUs are busy places. Nurses are running around, answering alarms, doing all kinds of things, but, as a clinician, I think it's really important to take the time to be there at the bedside, but allow the parents to do whatever it is, the diaper change, the temperature, preparing the feeding. From a clinician's point of view, that's the thing that I think we work really hard to do is to give the parents the support so that they can do it themselves.

What is it like once you, as a parent, have sort of accepted that role and how does it make you feel, as a parent? What does it do for your long-term caring for your baby once you've accepted the fact that these are your responsibilities and you can handle them?

Molly: From first-hand experiences, there's no better feeling than being able to care for your baby. It gives you that confidence that you can do it. It's so empowering. And being able to observe, so many of the families that I help support in the NICU, you can just see whether they're holding a baby skin-to-skin or they're seeing something on the monitor, they're just observing something on their baby that they're catching early, that maybe the care team hasn't seen yet. Or they're learning how to put something in if their baby is going home with an NG, learning how to use the oxygen, all of those things. It's so important and it really helps establish their confidence and their comfort because they're the parents, they're not visitors. The goal of the NICU is to get these babies well so they can go home and I think it's really, really important that the goal and the language and the communication that we focus on is that. There's nothing that's more beautiful than being a parent who gets to care for your baby because it's not what we expected. No one wants to be in the NICU and no one expects to be there, but what an honor to be able to witness that.

Heidi: That's really powerful and I thank you. And I hate to bring this up, but there are always some barriers. No matter how hard we try, we're always going to run into some barriers. From the clinical side of it, I do see there are some things that nurses have a hard time letting go of. Feeding happens to be a big one and nurses have had years of experience feeding babies and sometimes it's hard to let a new parent take over and make the decisions. Is the baby ready to eat? When does the baby need a break? What are the cues that the baby's giving us? So, acknowledging that, I really think it would be helpful to hear from a parent what kind of barriers that you encountered that made it a little bit more difficult to take over and really feel empowered to care for your baby?

Molly: This is a tough one, right, because I think everyone has the best of intentions. But there are barriers. I think sometimes it's just easier to do it yourself when you've been doing it and it's your job. I think timing is sometimes, if you are caring for multiple babies and your family is coming in late. It's not always easy to get to the NICU and I think, oftentimes, we forget that families have whole lives outside of the NICU. It's not their job! This is something that

happens, that blindsided most of us and so there's a lot of obstacles to getting to the NICU. You have to pay for parking. Oftentimes, you're navigating a distance. Maybe you have childcare that you have to navigate. You're on leave. Maybe you don't have leave because you have to save it for when your child comes home. Coming in for a certain time, if you are in a NICU that has dedicated care time, if you're in a NICU that has visiting hours, I hate even saying that out loud, but these are some of the obstacles that NICU families face in being able to be, to come in for various reasons. There's also a very real fear. It is very scary to change the diaper of a very, very tiny baby who you feel is very fragile. There's also postpartum. Sometimes we just don't feel well. Sometimes it's our mental health; sometimes it's our physical health. Those are things that we really do have to navigate because having a baby in the NICU takes a real toll. Sometimes it's just really, really hard to overcome those things too, and those are just the realities of having a baby in the hospital.

Heidi: That's a great segue into our next topic which is trying to align education and emotional readiness. Retention of clinical information depends on a family's emotional state at the time it's delivered, right? And information provided at a time that they're not ready to hear it or to understand it is often not retained and needs to be repeated. We need to be aware of that and looking for clues to see about a parent's emotional support, if they need more emotional support or where they are, before we embark on a whole lot of education and information. You bring up some really, really valid points that they have a whole world outside the NICU that, for the most part, we don't know a lot about if we don't care to ask and find out. But what kinds of things should we be looking for that tell us that maybe there's some emotional things that need attention before we get into a whole lot of teaching to get a baby ready to go home?

Molly: I think it can vary, but I think when a parent is withdrawn or not feeling excited, they're not engaging, any changes in mood, behavior, when their interaction with their care team shifts or even if their patterns of coming in shift, I think this is why the relationship building is so important because I think, to your point Heidi, you have to be able to be asking—and not every family will be willing to share what's going on in their life certainly nor do they owe you any answers—to be clear, but I do think that there are certain things that are happening in a family's life that are pertinent. It's not in every family the only thing that's happening is the baby, right? There are sometimes little earthquakes everywhere for a family. We never know if they're caring for someone else in their family who's sick or they have other things going on. I think just having more awareness and just asking how they're doing, understanding from the very beginning of the admission, like who are the people who are supporting them, finding out who their networks are and having a cadence of check-ins. That's where the social work team is really great. That's where peer support and mentorship is really important and support from other people who have been through it is really essential because that is going to help with understanding what emotional readiness looks like, because the other thing is that one day looks totally different from the next day for a NICU parent. When you've got good news, you may be great and when, you know, some days feel like a setback or some days feel like an eternity. It really varies.

Heidi: There's a lot of emotional things that could be happening and I totally agree with you that there has to be a relationship, and you need to check in. And you need to listen because it may not be what you think it is. It might be that they're afraid to take their baby home. It might be totally unrelated. They could have childcare issues at home. They could have transportation issues. They might be worried that they don't have the equipment to take care of the baby at home. They don't have a car seat, or they don't have a bed for the baby to sleep in. I think it's a good point to talk about there are resources. Our NICU has a ton of resources. You mentioned social work. We have a community resource specialist. The NICU itself will provide gas cards and food, gift cards to grocery stores, and things to help parents if we can determine that that's what the problem is. But you're right, it starts with a relationship and then the willingness to sit and listen to them. Lastly on this topic, sometimes the timeline doesn't always line up. You may have a parent that's still very emotionally needing support and yet the baby is getting ready to go home. We need to figure out a way to support the parents and yet still get that education and information across because the babies are getting ready. I think that, as a clinician, everything that you've said is really helpful. I'm just wondering if you have any other tips for clinicians who need to get some teaching and education done with a family that's still struggling and in an emotionally uneasy place.

Molly: I think normalizing that is helpful because I think that, for some NICU families, going home is not only wonderful but also quite scary. I think normalizing that and that's where I think community resources are really, really helpful. Connecting them to, potentially, a peer mentor in the community who can also check in. This is where the

pediatricians will be really helpful and that hand-off is really essential. I think again reminding them of the journey that they've had, reminding them of what they've overcome, how their baby has improved, reminding them what they have learned and that it won't always feel this way. And then also just making sure that there's a follow-up plan. If it really feels like there is an emotional concern, making sure that there's a follow-up plan because it is really hard to be postpartum and take home a baby.

Heidi: That's really great advice. As far as the transition from the NICU to home, we have to make sure that there is a safety net out there for them, that they are going to get the support they need continued outside of the NICU. Great information. And it brings us to the last topic here, which really goes along with this getting ready to take your baby home, which is advocacy skills. And advocacy skills are things like asking questions, raising concerns, providing information that you've noticed and coordinating the care. A lot of our more complex discharges have multiple providers, so coordinating care among multiple providers. These things can be taught and reinforced during the NICU stay and they're critically important and directly relevant to the outpatient follow-up and care coordination. But the question is how do we foster that and how do parents step into that role and accept that they will be the ones advocating for their baby? As a parent, how would you advise clinicians to help to support parents in their development of advocacy skills?

Molly: I think one of the ways that's most important is to be really clear and to tell parents you are your baby's first and most important advocate. Be really clear about that so that they understand that that is the role that they play, because I think a lot of families feel—and not all families—but especially in those early days in the NICU, you defer to your care team, the clinical care team. You defer. White coat syndrome is very real, and we don't necessarily feel comfortable questioning the people who are providing the clinical care to our infants. But that doesn't mean that we shouldn't; it just means that we don't have that comfort and that confidence yet. To hear from the people who are providing that clinical care that that's our job, actually, and our role, and one of the most important roles that we'll play, and not just in the NICU, but throughout the duration of our children's lives really. That's our job as a parent. It's to advocate for our children and so to be really clear in that messaging I think is really important. And to give opportunities for parents, rather than starting rounds with the clinical voice, to start rounds with the parent voice. To ask the parents what they have noticed, what they've observed, what are they feeling good about, what are their concerns, to give them the opportunity to play that part day to day because they are the parents. It's their goal to bring the baby home. No one is rooting for your baby more than you. It's just a simple matter. This is your job, this is the clinical team's job, this is not our job. We're the parents and so to make sure that our parents in the NICU feel that and to remind them that there's nobody who cares more about the outcome than us. I'm sure of it. Nobody cares more about that outcome of that NICU baby than the NICU parents and that's not to say that the clinical team doesn't care. They just don't care more than the parents and so to remind them that their job is to be the advocate and to use that language and to be so clear about it and to reinforce that, I think really, really helps.

Heidi: I think you're right on about that and I think, as clinicians, we can find opportunity to encourage parents. Ask them what they see that's different, what do they notice about their baby, how things have changed, what's the baby doing this week that they weren't doing last week, and really supporting their observations and what they notice about their baby and if they have a concern, absolutely encourage them. What would you like to do about it? Shall we talk to the team on rounds? We haven't rounded yet and encouraging them to formulate a plan. Yes, I'd like to talk about this on rounds because that builds confidence and when parents are taking babies home, like you say, I often talk to them about speaking up. If you have a question, if you have a concern, and my thing that I always tell them is nobody knows your baby better than you do. You're there every day. Nurses come and nurses go. The NICU teams change every couple of weeks. You're the consistent one. You know your baby. If something seems different, if something is unusual, speak up about it because you're probably noticing something that's important. Again, finding opportunities and giving them positive reinforcement, that's great, I hadn't noticed that but you're right, last week that wasn't there and now the baby's got a rash, or that kind of thing I think can really go a long way to building the parent's confidence. I think you're right about parents needing to practice in the NICU before they go home.

Lastly, I guess, what types of skills in parents do you think is predictive of successful advocacy once they leave the NICU? I know what my thoughts are, but I'd like to know what, as a parent, what you would consider the most important thing that a parent needs to do before they leave.

Molly: I think that's an interesting question because I think it really is parent-dependent, but I think confidence looks a

lot of different ways for NICU parents. I think a comfort with their baby, a comfort being vulnerable, is not necessarily something that's considered advocacy, but to be able to ask a question that's maybe uncomfortable is an important thing because then that the parent is going to pick up the phone and call if something is a concern. I think that an awareness about not just the baby but about what to expect. I think when parents have a connection and are engaging with their baby and are engaging with their care team, I think when they feel comfortable speaking with their care team, I think that's always a great sign of that advocacy. I would love to hear what your thoughts are, Heidi.

Heidi: Very similar, although you said it a lot better than I probably would. Mostly what I'm looking for is just that parents are willing to speak up, to ask a question, to talk about something they've noticed, to engage in a conversation about how things are going to look at home and that, to me, just says, okay, this parent is going to be able to express concerns or problems. And, as you said, that is so important that they understand they don't have to know everything. They're not supposed to know everything. That's why you have a pediatrician and you have a care team outside the NICU, and you should ask because no parent knows everything. That's what your team outside the NICU is going to be there for you. So, ask a question. As you said, pick up the phone. You're a new parent. They're happy to talk to you, answer your questions. They don't expect you to know everything. Those 2 things are what I really look for in parents getting ready to go home.

I thank everyone who has joined us today.

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