

## "In Conversation: NICU Psychologists as Resources for Each Other"

### From Sondra Marshall to the group:

It was very inspiring being on the conference call with all of you.

I have spent the last 3 years working in our NICU follow-up and have availed myself to readings and trainings on this population addressing both the neurodevelopment issues and psychosocial challenges. Our community is just now getting a more organized postpartum flow and is working with Postpartum Support International to establish many different systems/points of access and trainings in our community.

I have spent the last 8 months shadowing various professionals on our NICU floor, learning and quite honestly developing relationships and trust with the nursing/respiratory staff. They are finally "asking" for me to be involved with some families, which has given us confidence to move to the next level of implementation, having me in a more formalized way meet with families.

I am wondering the following:

1. What algorithm are you all using to determine what and when families need to be seen. This perhaps speaks to the psychosocial assessment I think Steve is researching, but perhaps others are using something as well.
2. Are there "Go to" handouts you routinely provide families and if so....would you be able/willing to share.
3. Are there handouts or other materials you may share with staff to support them in their work and/or their relationship with the families.

I know I have a lot to learn, there are many more questions and will look forward to your insights, guidance etc.

Warmly,

Sondra

Zina Steinberg replied to Sondra Marshall with a beginning set of tentative thoughts based on her experiences. Michael Hynan, thinking it could be useful to other psychologists starting their work in the NICU, posted it on the NPA website. Recently, Zina made some small changes in her original personal email to Sondra. Below is her revised email.

## Reply from Zina Steinberg:

Hi Sondra,

I resonate with how you are approaching the NICU. I too spent about 6 months “shadowing” NICU nurses and feeding specialists and do believe that it was the best thing I could have done. I am sure that you will also find that this time was well spent.

Your questions are good ones. I don’t have an algorithm and do wonder if the focus on screening tools will be sufficiently helpful, especially if they are checklists/scales that are filled out by parent alone and not in context of open-ended clinical conversation with psychologist/social worker. It is my impression that parents are extremely concerned that they not be ‘labeled’ and work extremely hard to manage their presentation in the NICU.

Social workers are required to talk with all parents within a short time of admission and do their assessment in person or on the phone but not necessarily with a standardized tool that probes for symptoms of disorders, (i.e. Beck, Edinburgh).

So usually it is only if a parent offers her own history of depression or other major psychiatric disorder that it is noted. Other symptoms of acute stress, potentially post-traumatic reactions are not regularly noted. (And the field, in general, I believe, pays little attention to the important psychological reactions of fathers, though these have an enormous effect on the mother and therefore the baby.)

If parents are distressed, the social worker assessment might say something like, “their affect/behavior is appropriate to the experience”, which may be the whole story, but also may not be.

Social workers have the time-consuming task of doing all the often complex discharge planning. This overloads their days and limits their time availability for clinical interviews that might need to take place again after the initial intake.

When serious problems arise, social workers might try to hook a parent up to psychiatric services, but the task is very hard. Between insurance problems and distance traveled to get to the NICU and the multiple stresses in the parent’s life, these referrals, if made, don’t often “take”. And as noted before, there is also the question of when a screening is done. If it’s shortly after admission the parents are in what has been called an “affectless shock”. Parents describe their state of mind as “surreal”, “underwater”, “people talking but I can’t understand or even hear them”. It is a state of depersonalization and derealization. This can get a lot better in a week or two, depending greatly on how the baby is doing and the relationship that the parents create with the medical staff (and of course, the support the parents have in their lives). So if another clinically oriented conversation takes place after the first 2+ weeks (and importantly before discharge), the picture could look a lot different, though not always less worrisome. But even if the parent is far more ‘connected’ and present, any downturn in the baby’s condition can bring him/her right back to the initial traumatized state.

We find that meeting parents in a variety of ways - following their lead as to what they can tolerate and/or use is important. Always, we look for the parent's edge of resilience and their coping skills. We both want to help them tell their story as well as infuse this story with agency.

So the other psychologist and myself primarily figure out who to see in the following ways. (By the way, we are each on the unit two 1/2 days a week. I try to make one of my half -days bleed over to the evening so I can see parents that only can come later and also to see night nurses.)

1. We have a letter of introduction that we tape onto every isolette when baby is admitted. Sometimes this letter seems to coax a parent to find us, but this is rare. Parents seem very reticent to say that they need help and are guarded about having someone think they might need help. But when we introduce ourselves at the bedside, a parent often lets us know that the letter interested them and that they had been thinking of finding us.

2. We circle the large unit many times during the days we are there and we introduce ourselves to families saying something like "Hi, I am \_\_\_\_, the psychologist, and I meet all the new families and so happy to meet you and your baby." We emphasize "all the new parents" as, again, we don't want any parent to feel singled out as needing psych services. Then we proceed to say things like - when was your baby born? How is he doing? And how are you doing? We ask about their pregnancy, the labor, the delivery, the diagnosis and when they knew it. We are guided by the CLIP interview - though we really follow our own instincts and the parents' thread. If the parent seems to want to talk more, we'll pull over a chair and just engage in a conversation. We often find out things that might never come out in a screening, i.e. their prior reproductive history and their feelings about it (how long they have tried to become pregnant, number of ART trials, miscarriages, still births,) and other important life traumas and significant events (their own illnesses, experiences with doctors, accidents, recent deaths and serious illnesses of loved ones), people they have known that have had children with disabilities, their situation during the recent economic crisis and in New York especially, their relationship to 9/11 – where they and others important to them were. These events (and these are just some of the things we look for) and the mom/dad's ways of making meaning of these events could increase their risk for PTSD and PPD.

We are interested in helping the parent construct a narrative in this confusing and traumatic time. Often how the parents describe themselves would be 'sub-clinical' i.e. depressed, but not necessarily needing meds, traumatized and shocked, but also functioning in many areas. We talk to them about how to help create a team of nurses that will support them, the inevitability of communication snafus and how to deal with them, etc. Mostly we aim to try to find out what if anything is keeping the parent from being engaged with their infant. Are they scared to touch him? Do they think that they are toxic and guilty? We ask the parent to introduce us to their baby - and we notice things - eyes, eyelashes, fingers etc. And we try to always remember to congratulate the parent on the birth -- these parents haven't been congratulated, the birth has been a shock.

We follow the parent's lead, keeping in mind all that we know about the NICU experience. If a parent hasn't been shown 'safe' ways to touch their baby, we do that. We remind the parent how important they are. We validate the parents' fears and sense of shock and we offer anticipatory guidance when appropriate (i.e. why couples might argue during this time, how friends might back away, what to look for in a pediatrician, why discharge can seem so scary). Mostly the parents (mothers/fathers and grandparents) find it very helpful. We ask about how they are communicating with each other, with friends, with people at work. We inquire about how things are going with nurses, doctors etc? And depending on the families' desire to talk more, we meet it as best we can. With some parents we will make a specific appointment to see them again; others we will check in with the next time we are in the NICU.

When and if a difficulty occurs with the medical staff - say, a communication problem, a medical error, or if the parents' resources have been sucked dry, we already know the family and can try to be helpful. Some parents are wary in our first conversations. We then keep it short and make sure to touch base again and again. So often the same parent that was hesitant and even curt, will begin to use our services when they see us more often.

3. Nurses are our best source of referrals. The nurses often know when the parents are not communicating well, when parents are not showing up or showing up, say, to get a subway card but not spending time with baby. They know when parents are afraid to touch the baby etc. So we spend ALOT of time creating relationships with nurses. We also try to help nurses when they are finding themselves exasperated with a family - and this happens regularly.

4. I run a weekly group and thru this group I meet parents that then want more psychological input. I also find that because my time is limited and it is impossible to meet all families, the group serves to help me meet larger numbers of parents. I like to find ways that parents can begin to help each other. In the group, the parents feel that their concerns are 'normal', that they probably aren't going crazy but that they may need to figure out how to express their needs in a way that is more likely to be responded to by a medical staff that can seem to speak a very different language.

Depending on who is participating in the group on any given week (I co-run the group with a wonderful nurse), we may talk about signs of PPD or PTSD, how to care for your baby, how to touch etc, how to develop a 'team' with your nurse. We spend a lot of time encouraging kangaroo care and helping parents become advocates for it. We talk about how to handle friends, family, and other children. Parents share the insensitive things people say to them - even good friends - and their feelings of jealousy and envy that they are ashamed of. They are reassured that other couples are having trouble coping and feel less critical of their partner. And death.... it is not uncommon for death to be raised - a parent who gave birth to twins may only have a surviving twin in the NICU, a baby may be close to death, or another baby recently died and everyone is in a heightened panic. We make room to talk about the unthinkable in group. It seems like a profound relief.

You ask about handouts-- I have many things -- mostly taken from other people's materials - all found on line. And although I have a lot of things, frankly, I don't hand them out very often. I am always amazed that I may have brought something to the group, but the parents own experiences and their desire to be with each other and learn that way seems to make any handout extraneous.

We do a lot of staff inservice-- I have given several workshops -- twice to full staff (nurses, drs, social workers, PT and OT etc) and then 4 times to just nurses that have been on staff for less than 5 years. (There are about 200 nurses at our NICU.) I didn't really use handouts, though I had power point slides. In addition to these formal workshops, bedside and 'corridor' conversations that are patient/family specific seem to be the bulk of our 'teaching'/consulting.

I do one other thing: recently one of the nurse educators decided to put together a weekly newsletter for nurses. Much of it lists new regulations, conferences, announcements, etc. I asked if we could post a column from time to time and we have. We've posted columns on how nurses could recognize PPD and PTSD, how to deal with angry parents, the parent that never visits, kangaroo care, etc.

I hope this is helpful. One other thing is that we tend to focus on the families where the baby will have a longer NICU stay - very premature babies, serious congenital defects, etc. This gives us a chance to really work with the family-medical team. We also tend to stay in email contact with some of these families.

I will send some articles/talks soon. But here are two recent blog postings in Psychology Today that emerge from our NICU work.

<http://www.psychologytoday.com/blog/psychoanalysis-30/201209/labor-day-exposes-cruel-choice-facing-mothers-premature-infants>

<http://tinyurl.com/86q19n4>.

Good luck,  
Zina