

Parental Perspectives of the NICU: Focus Group Findings

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Objective: Our goal was to find out what parents really feel and think about their NICU experience—from the hospital through home care—and how their expectations were or could be better met. Our paramount objective in these groups was to learn from parents' stories and observations and apply these to improve services and help families more in the future. A secondary goal was augmenting our capacity to provide meaningful feedback information to the hospitals, providers and health plans we work with.

Methods: We formed a Family Initiative Committee and conducted focus groups in two metropolitan areas with parents of NICU infants who had been followed by Paidos during the past year. Each of the focus groups totaled 12 families. Participants were recruited by phone, served dinner and received a \$50 cash gift. Each group followed the same discussion outline, but given the dynamics of the groups, the actual conversations were somewhat variable.

Results: The discussions produced evidence in several key areas for improvement.

1. Hospitals should offer a comprehensive orientation to the NICU, provided at a time when the parents can absorb it, including a parent checklist provided at the beginning of the NICU stay.
2. Hospitals should offer a pre-orientation for mothers pregnant with multiples, high risk pregnancies, or known infant conditions.
3. Parents would like an opportunity weekly to ask questions.
4. Hospitals should address the huge variability in practice and information from physician to physician, nurse to nurse, shift to shift. This included clinical specifics and policies on what parents are allowed to do with their infant.
5. Going home without their baby was the single hardest part of the NICU parents' experience.
6. Actual versus corrected age should be addressed more effectively.
7. Nurses should realize how much they can make or ruin a parent's day.
8. Doctors should be more communicative, not just available, in providing information.
9. NICUs should pad the rocking chairs.
10. In some hospitals, multiples were not always in the same room or near each other.
11. Case manager involvement early on and throughout the hospitalization had definite value and was appreciated by families.
12. Parents felt stressed, exhausted, confused and scattered during their experience.
13. There was a clear interest for a Family Information or Contact Center for a variety of resources.
14. Most parents found the discharge/home care preparation and process challenging.

Conclusion: Parental perspectives regarding their NICU experience are important in meeting the needs of the family. Specific suggestions or observations may be easy for hospitals to implement, or if nothing else, helpful to know and/or consider.