The Role of Family Resource Specialists as Key Players in the Research Team

Jennifer Silva, BSBA FRS
Family Resource Specialist
FRS

- Trained parent paraprofessionals who share the personal experience of having had an infant treated in a Neonatal Intensive Care Unit.

- Provide emotional support to parents and help them navigate the NICU journey in ways unique to an experienced NICU parent.

- Comprehensive training in how and when to utilize personal experience in an appropriate way enables FRS staff to play an invaluable role in supporting families during their stay in the NICU and with the successful transition from the NICU to home.
Models Demonstrating Effective Peer Mentor Support

Recent studies have demonstrated ↑ usage of this innovative peer/mentor approach. The findings demonstrate that PM/FRS relate well to patients and provide a cost effective measure to attain favorable outcomes.

- Using breastfeeding peer counselors, mothers rated peer support as the most supportive aspect of developing their maternal role in the NICU. (B. Rossman et al J Obstet Gynecol Neonatal Nurs. 2015 Jan-Feb;44(1):3-16)

- For asthmatic minority children, it was concluded that using parent mentors provided an approach which ↓ wheezing episodes, ED visits and missed parental work days. (G. Flores et al Pediatrics. 2009 Dec;124(6):1522-32)

- Parent mentors were utilized to successfully enroll and ↑ retention in a Head Start organization of an underserved Hispanic population. (B.A. Foster et al Contemp Clin Trials. 2015 Sept 4. pii:S1551-7144)

Women & Infants Hospital

- 80 bed single-room level 3 NICU opened in September 2009.

- Affiliated with Warren Alpert Medical School of Brown University.

- WIH Neonatal Follow-up Program is recognized as one of the best programs in the United States. The team evaluates >1,300 high risk infants and children each year.
Program Background

- Transition Home Plus program
  - Launched by our Neo-natal Follow Up Clinic in 2006.

- Provided transition care to very PT infants with public insurance.

- Recognized that a high percentage of mothers of NICU graduates have significant social and environmental stressors and may be more likely to suffer from post-partum depression and therefore may be less likely to be compliant with follow up care for themselves and their infant.

- Paired NICU families with a licensed social worker who provided transition support up to 7 months corrected age.

- Utilized a FRS in a supportive role to the social workers.

Program Background

- In 2012 Dr. Vohr was funded with a CMS Innovation Challenge grant, as part of the Affordable Health Care Act, for an expansion of the Transition Home Plus Program.

- Service was expanded to all NICU infants regardless of their gestation and inclusive of those with private insurance.

- Families would receive transition support through 3 mos corrected age.

- An important component of the grant was the creation of six positions for peer/parent para-professionals in the capacity of Family Resource Specialists (FRS).

- The FRS staff would be an integral part of the research team.
The overall objectives of the Partnering with Parents Study were to:

- Improve the transition home care for all infants in the NICU
- Provide added supports for families
- Improve families’ readiness for discharge
- ↓ Visits to the emergency room and ↓ re-hospitalizations in the first 3 mos post-discharge
Methods

❖ Parents receive one on one support and education from either the FRS or the social worker assigned to their family.

❖ Families receive a home visit pre-discharge and a call 24 hours post discharge to answer any questions and assess any needs in the home.

❖ All babies receive a NICU Nurse Practitioner home visit one week post discharge.

❖ Parents have 24-7 access to the PWP on call physician/NNP.

❖ All babies are seen in the Neonatal Follow-Up Clinic at 1 month post discharge and 3 moths corrected age.
FRS Criteria/Training

- Para professionals with experience as a NICU parent.
- Hired and Trained through Rhode Island Parent Information Network (RIPIN). A local non-profit and grant partner.
- All FRS staff were required to complete hospital orientation which includes:
  - HIPAA training
  - PHI handling
  - Security and risk management training.
- Required to complete CITI Program training.
- In addition, RIPIN provided the FRS staff with training in:
  - Creating effective boundaries
  - Cultural competency
  - Privacy and safety
  - Motivational interviewing
  - Assessing community resources
FRS Study Responsibilities-Enrollment

- Identification of eligible subjects.
- Meet with families to explain the study.
- Obtain informed consent.
- Retrieve demographic data.
- Obtain release of information to the families Pediatrician.
FRS Study Responsibilities-Enrollment

- Enroll families in Current Care, a medical record coordination program and tracking tool operated by Rhode Island Quality Institute.

- Collect data on maternal comfort via the Fragile Infant Parent Readiness Evaluation (FIPRE) questionnaire.

- Attend weekly team meetings to discuss successes and challenges.

- Enter all relevant data into the study database.
FRS Responsibilities-During Hospitalization

- Attend family meetings as a contributing member of the care team.
- Provide ongoing support to the family.
- Review a discharge educational binder with family members which includes information on:
  - RSV prevention/Synagis
  - Managing reflux and constipation
  - Safe sleep and bath safety
  - Infection control
  - Home and car seat safety
  - What to expect at the first Follow-Up Clinic visit
  - The impact of corrected age on developmental milestones
  - Early Intervention
  - Community resources (WIC, RIPIN, Family Planning, Warm line)
FRS Responsibilities-During Hospitalization

- Complete a pre-discharge home visit to assess any needs of infant and family.

- Document all interactions with the family and providers in the study database.
FRS Responsibilities-Post Discharge

24 hours post discharge

- Call the family 24 hours after discharge to check in, answer any questions, make sure they have scheduled their first pediatrician appointment and confirm the 1 month Follow-Up Clinic visit.

- Schedule the Nurse Practitioner home visit for one week post d/c.

- Confirm that the EI referral is in place.

- Complete documentation in the database.
FRS Responsibilities-Post Discharge

At the 1 month Follow-Up Clinic visit:
- Complete the Edinburgh Post Partum Depression Screening.
- Score the EPPDS and make MH referrals if indicated.
- Follow up on past referrals and determine if any further resources are needed.
- Complete documentation in the database.

At the 3 month Follow-Up Clinic visit:
- Collect data on maternal satisfaction with the NICU experience, support, and transition to home via the Family Infant Transition Summary (FITS).
- Gather feedback on the effectiveness of the study by having the family complete a satisfaction survey.
- Provide support and determine any ongoing needs.
- Complete documentation in the database.
Jennifer Silva
Mom of Katie, a full term baby with HIE, who underwent therapeutic cooling and spent 20 days in the NICU.

Jeanne Hebert
Mom of Ryan, born at 24 weeks, who spent 6 months in Women & Infants NICU.

Silvia Perdomo
Mom of Jeremy, a full term baby with severe meconium aspiration who spent 23 days in both Women & Infants NICU and Mass General PICU.

Corin Nava
Mom of Gabe, a full term baby with CDH. He spent 55 days in both Women & Infants NICU and Mass General PICU.
WIH Family Resource Specialists

Erinn Huetteman
Mom of Kristen, born at 25 weeks, who spent over 3 months in the Women & Infants NICU.

Leah Sperlongano
Mom of Kason, born at 29 weeks, who spent 8 months in Women & Infants NICU.

Stacy Quigley
Mom of Emma, born at 26 weeks, who spent 3 months in the Women & Infants NICU.
Accomplishments- 3 year period

### Recruitment & Consents

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<th></th>
<th>7 FRS</th>
<th>1 RA</th>
<th>4 SW</th>
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<tr>
<td>Total</td>
<td>711</td>
<td>118</td>
<td>522</td>
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<tr>
<td></td>
<td>(53%)</td>
<td>(8.7%)</td>
<td>(39%)</td>
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<tr>
<td>EPT</td>
<td>139</td>
<td>13</td>
<td>172</td>
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<td></td>
<td>(43%)</td>
<td>(4%)</td>
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FRS enrolled the majority of the sample
And 43% of EPT < 32 weeks

### % Follow-up @ 1 & 3 m

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<tr>
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<th>1 m FU</th>
<th>3 m FU</th>
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<tr>
<td>FRS</td>
<td>98</td>
<td>87</td>
</tr>
<tr>
<td>RA</td>
<td>100</td>
<td>92</td>
</tr>
<tr>
<td>SW</td>
<td>87</td>
<td>82</td>
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1 m FU 3 m FU
Lessons Learned

- Having shared personal NICU experience allowed the FRS staff to provide emotional support to parents and help them navigate the NICU journey in ways unique to an experienced NICU parent.

- Most FRS staff had their child enrolled in a study at some point during their NICU stay and can offer valuable feedback to research staff and families alike.

- Hiring FRS staff of varied NICU experience proved effective.

- The Family Resource Specialist can be an effective part of the research team model.

- The FRS enrolled, consented and followed the majority of study subjects.

- Despite a population of both in state and out of state residents achieved FU rates of 94% at 1 month and 84% at 3 months.
Based on the successful integration of the Family Resource Specialist role in the research model, positive patient feedback and the significant increase in the family compliance with follow up services, Women & Infants has incorporated the use of Family Resource Specialists into multiple upcoming research projects using a dual model approach:

- Active recruiters and participants in research projects
- Support to prospective research participants
- Complete study questionnaires
- Data collection and data entry
Broadening the Role of the FRS

- Data obtained through the CMS/Partnering with Parents Program demonstrated that 41% of Medicaid and 31% of privately insured mothers had a past or current history of adverse mental health.

- In response, WIH is seeking to expand the role of FRS by providing specialized training in skills and knowledge for assessment and treatment of perinatal mood disorders. This will be done as part of an intervention promoting enhanced mental health support for NICU families.
Questions