InReach: A Collaborative Model to Support Moms and Babies in the NICU and Beyond.

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Rationale

- An increasing number of extremely low birthweight infants are surviving. Many are eligible for Early Intervention (EI) services (also known as Part C).

- When an infant is born early, the relationship between parent and infant may be disrupted:
  - Extended separation caused by the infant’s stay in the Newborn Intensive Care Unit (NICU)
  - Atypical response patterns and cues of the infants
  - Parental stress

- Most states do not have effective mechanisms to ensure a smooth transition from the NICU into EI services.

- EI service providers are looking for ways to support the parent-infant relationship and the parent’s confidence in carrying for the child.
Insert Video clip of Parent’s Perspective
How did we start?

- Interviewed parents who had infants in the NICU and then EI
- Observed of EI Home Visits and NICU interactions with parents
- Held Focus Groups
  - Parents
  - NICU nurses
  - NICU support staff (OT, PT, social workers)
  - EI staff
How did we use information?

- Advisory Council formed
  - NICU staff
  - EI staff (state and local)
  - Researchers
  - Parents
- Sub-group, using information learned, designed new transition procedures
- Advisory Council approved procedures
Who were the Babies?

- Infants in NICU who meet Early Intervention (EI) eligibility requirements
  
- Intervention group: Infants going to EI program using InReach

- Comparison group: Infants going to EI program not using InReach
InReach Transition

Traditional Discharge to EI Services from the NICU

NICU
- NICU Discharge

Home
- Evaluation
- IFSP
- Home Visit

InReach Transition to EI Services from the NICU

NICU
- Support Parent Observation
- Evaluation
- IFSP
- NICU Discharge

Home
- Home Visit
InReach Procedures (Overview)

- NICU staff supports parent observation of infant behaviors, using *My Needs and Goals*
- NICU staff makes referral to community EI agency
- NICU staff provides information and documentation of infant’s medical concerns and development for IFSP assessment
- Individualized Family Service Plan (IFSP) Care Conference is held in NICU or via desktop video-conferencing
My needs and goals video clip
# My Needs and Goals

**My Date of Birth:** ________________       **My Mother's Name:** __________________

**My Birthweight:** ________________       **My Father's Name:** __________________

**My Gestational Age:** ________________       **My Primary Care Nurse's Name:** __________________

### Signs That I Am Calm...
- [ ] Sucking
- [ ] Hand to Mouth
- [ ] Flexed Arms and Legs
- [ ] Hand Clasp
- [ ] Grasping
- [ ] Leg Bracing
- [ ] Alert and Focusing
- [ ] Other

### Signs That I Am Stressed...
- [ ] Finger Splaying
- [ ] Stretching Out Arms & Legs
- [ ] Crying/Fussing
- [ ] Color Change
- [ ] Yawning/Sneezing
- [ ] Gagging & Hiccups
- [ ] Looking Away
- [ ] Staring
- [ ] Glassy-Eyed
- [ ] Difficulty with sleep/awake states
- [ ] Other

### Now that I am ______ weeks old:

**I need:** ________________

**I show stress by:** ________________

**I help myself calm by:** ________________

**My parents help me calm by:** ________________

**I show that I am content when:** ________________

**I like it when:** ________________

**I show stress by:** ________________

**My parents would like me to:** ________________

**Ways my parents can help me reach this goal:** ________________

**My parents want to learn:** ________________
My Needs and Goals

Feedback

- **Parents:**
  - *Recognize infant cues:* “It was really informative to know the signs and recognize what things he liked and what calmed him and what stressed him. That was really helpful.”
  - *Put observations into words:* “I was able to put into words what I thought I knew anyway. I had ideas about what she needed, but it helped to be able to list them.”
  - *Communicate with nurses:* “It is a good tool to use in the NICU. A note isn’t a good tool for parents to use to communicate about their baby to the nurses, but this form lets nurses know what the parents are seeing. Nurses take notice of it quickly and respect it.”
My Needs and Goals

Feedback

- **NICU staff:**
  - **Supported mom’s observational skills:** “I think it really helped mom see some different things about her child. Mom was very positive about it. It helped her feel more connected with the care of her child.”
  - **Generated discussion about baby’s cues:** “It went great: mom took it, we went through it; I had her write. She pinpointed baby’s cues, etc. She’d write it and then ask the dad, what do you think?”
  - **Affirmed parent’s competence:** “She seemed pleased to complete the sheet. She knew her baby well and enjoyed verifying what she knew.”
Before Discharge

Baby grows; is ready to go home

Mom can talk about baby’s strengths and needs

NICU staff provides assessment information

IFSP Care Conference with Community EI Agency
In Hospital IFSP Care Conference
InReach Support Across Distance

- Desktop Video Conferencing
  Allows family, NICU staff and Early Intervention staff to work together to plan community service goals before discharge, even when the home community is far away
# FAMILY AND INFANT STRENGTHS AND NEEDS

**Baby’s Name:** ____________________  **Current Date:** ____________

<table>
<thead>
<tr>
<th></th>
<th>Our baby’s likes/abilities with hospital team observations</th>
<th>Our baby’s dislikes/difficulties with hospital team observations</th>
<th>Our concerns/goals</th>
<th>Update (Date___________)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Feeding</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Sleeping</strong></td>
<td></td>
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<tr>
<td><strong>Social Interaction</strong></td>
<td></td>
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<td></td>
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<tr>
<td><strong>Self-Calming techniques</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Movement</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sensitivity to light, sound, &amp; touch</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Health/medical</strong></td>
<td></td>
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</tbody>
</table>

Portion of the Individualized Family Service Plan, adapted from *Colorado Beginnings*
Case Study

- 29 weeks
- 920 grams at birth
- Apgar scores: 4, 5, 8
- Hispanic family in suburban area
- Retinopathy of prematurity
- Feeding difficulties
- Brain malformation
IFSP Care Conference

- All medical and developmental records are shared with EI
- Therapists and occasionally physicians from the NICU discuss specific concerns with EI
- Parents feel comfortable enough to share their observations, hopes, and desires
- EI uses current NICU information rather than starting from scratch or duplicating
- EI is able to provide services to the infant and family sooner after discharge
## FAMILY AND INFANT STRENGTHS AND NEEDS

<table>
<thead>
<tr>
<th></th>
<th>Baby’s Name: <strong>John Doe</strong>______________</th>
<th>Current Date: <strong>02-14-05</strong></th>
<th>Update (Date__)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Baby’s likes/abilities</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeding</td>
<td>Enjoys pacifier</td>
<td>Receives supplemental feedings from NG tube</td>
<td>Able to breast feed and take a bottle</td>
</tr>
<tr>
<td></td>
<td>Takes 35 cc from bottle</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sleeping</strong></td>
<td>Sleeping well</td>
<td>No concerns</td>
<td>None for now</td>
</tr>
<tr>
<td></td>
<td>Awake for mom</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social Interaction</strong></td>
<td>Calms to mom’s voice</td>
<td>No concerns</td>
<td>Will look at parent’s and brother</td>
</tr>
<tr>
<td></td>
<td>Looks at mother’s face</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Self-Calming Techniques</strong></td>
<td>Calms with pacifier</td>
<td>Overstimulated with movement</td>
<td>Become more accustomed to gentle movement</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Movement</td>
<td>Baby’s likes/abilities</td>
<td>Baby’s dislikes/difficulties</td>
<td>Our concerns and goals</td>
</tr>
<tr>
<td>----------------</td>
<td>------------------------</td>
<td>-----------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Tries to bring hands to mouth</td>
<td>Strong extension</td>
<td>Bring hands to midline</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bring hands to mouth</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Begin to use some flexion</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sensitivity to light, sound, touch</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Health/Medical</td>
<td>Passed hearing screening History of laser surgery for both eyes No special medical equipment needed at discharge</td>
<td>To be followed by ophthalmologist</td>
<td>Information will be given to family on ways to stay healthy</td>
</tr>
</tbody>
</table>

Baby’s Name: __John Doe__________ Current Date: ___02-14-05____
Feedback

NICU Staff:
- “I was really attached to this mom and it made me feel glad that she felt supported and that she understood that they would be supported when she took her baby home.”
- “The mom really liked talking about her baby. It really put her at ease that the EI staff were listening. She was more confident in the program and excited about the early intervention program.”

Part C agency staff
- “The care conference was great. We feel like we know [the baby].”
- I learned about [the baby] from the information the NICU sent me. It helped to know what questions to ask in the IFSP. I used it as background medical information to understand the health needs when I made the first visit
Feedback

■ Parents:
  − “It was definitely helpful for me to meet the community EI staff before taking him home. I was really glad to at least know somebody. It was good to know about EI and who was going to come into my home.”
  − “It was nice to have the [early intervention agency staff member] know first hand what had gone on and having her prepared when she came to visit us.”
  − “All the questions I had got answered really well. I felt confident in my knowledge of my baby. The NICU staff was really helpful, and the early intervention person. They answered all my questions and were very helpful and friendly. It gave me reassurance.”
Findings
Comparing Traditional v. InReach Transition

InReach families received EI services sooner than traditional discharge families

<table>
<thead>
<tr>
<th></th>
<th>Traditional Discharge (n=15)</th>
<th>InReach (in-hospital) (n=29)</th>
<th>InReach (w/computer) (n=17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average # of days from discharge to first home visit</td>
<td>90.7</td>
<td>17.9</td>
<td>30.8</td>
</tr>
<tr>
<td>Range of days</td>
<td>15-312</td>
<td>3-60</td>
<td>3-70</td>
</tr>
</tbody>
</table>

The difference between the traditional discharge and InReach (in-hospital) discharge is statistically significant ($p < .01$)

The difference between the traditional discharge and InReach (w/ computer) discharge is statistically significant ($p < .013$)

* One infant who had the Traditional Discharge never received EI services.
Summary

- Infant development and well being can be supported in a continuous way across the transition from NICU to home and community EI

- The IFSP process can be strengthened:
  - With parents being supported in their ability to recognize and articulate their infant’s strengths, they become...
    - More competent (and confident) in understanding and meeting infant’s needs;
    - Empowered to more fully participate in setting developmentally realistic IFSP goals
  - With NICU staff sharing knowledge about infant’s needs and strengths
InReach procedures reduce number of infants who are not referred to EI.

Community EI services and support can be initiated in a more timely and cost-efficient manner.

Parents can be more consistently supported during the transition and the first weeks at home.

To make the InReach transition work, procedural changes need to be made collaboratively by the NICU and EI.
For more information, or for a copy of this presentation or other project materials, please email Lisa Boyce

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