Developmental TIPS

PAIGE E. HARDY DNP, APRN, NNP-BC

Many NICU graduates are at high-risk for developmental delays in their early childhood years. There is also concern for the outcomes of their families.
Importance of Developmental Follow-up

- Monitor infant’s development through developmental surveillance to assure early identification of developmental problems
- Provide ongoing support to families of young children
- Identify outcomes of this population of children

Purpose

- To implement a statewide program to provide specialized developmental follow-up for babies who have been patients in the NICU
Developmental TIPS
Tracking Infant Progress Statewide

Program Goals:
- Standardize the system of developmental follow-up
- Gather outcome data for this population of young children
- Child Find for Early Development Network

Developmental TIPS
Tracking Infant Progress Statewide

- Collaborative Project
  - Hospitals
  - NE Health and Human Services system
  - Nebraska Department of Education
  - Local Planning Regional teams
  - Family members
  - Community providers
Funding

- Provided by:
  - Nebraska Department of Education
  - Nebraska Department of Health and Human Services
  - Local hospitals
  - Munroe-Meyer Institute

Concerns regarding developmental outcomes

- Cerebral Palsy
- Mental handicap
- Blindness
- Deafness
- Speech-language delays
- Decreased executive functioning skills
Who is eligible?

- All infants that were admitted to a NICU for 72 hours or more
- Infants in one of 11 Nebraska hospitals
- Nebraska resident infants hospitalized in Denver, Rapid City or Sioux City
- TIPS is voluntary

Clinic Staff

- Developmental Pediatrician
- Neonatal Nurse Practitioner
- Psychologist
- Developmental Specialist
- Physical Therapist
- Staff nurse
Three-Tiered Model of Follow-up

- Level I (low risk referral)
- Level II (at risk for developmental problems)
- Level III (has a diagnosis that may be associated with developmental delays)

Level II Criteria
Children with one or more of the following criteria will typically be followed in TIPS clinic

- Birth Weight of < 1500 grams
- Five minute Apgar of < 6
- Oscillatory ventilation
- ECMO
- Cooling Therapies
- Grade III - IV IVH
- Grade III retinopathy / laser surgery
- Seizures
- Cystic PVL

- Surgical Conditions
- Syndromes or multiple congenital anomalies which may or may not be associated with developmental problems
- Congenital Heart Disease
- Failed hearing screen at time of discharge
- Multiple birth siblings of identified high risk infant
- Exchange transfusion
- Physician referral (clinical judgment – please indicate your concern on enrollment)
- Social / environmental risk (please indicate your concern on enrollment)
LEVEL III Criteria
Children with one or more of the following criteria are typically accepted for school services

- Syndromes or congenital anomalies associated with known developmental delay, e.g., Trisomy 21, CHARGE.
- ROP requiring therapy beyond laser treatment
- Confirmed hearing impairment
- CPS Referral (CAPTA) Referral is indicated; may or may not be accepted
- NG or GT feedings (if the NG or GT is used for 75% or more of child’s nutrition)

TIPS visit at 6 months (CGA)

- Bayley Scales of Infant Development III (BSID-3)
- Bayley Screener Test III (BSID screener)
- Survey of Well Being of Young Children
- Edinburgh Post-natal depression screen
- Developmental interview

- AIMS (not at all locations)
- Gessell Developmental Scale (not at all locations)
TIPS visit at 16 months (CGA)

- Bayley Screener
- Modified Checklist for Autism in Toddlers (MCHAT-R)
- Communication Symbolic Behavior Scales Development Profile (CSBS-DP)- Infant/Toddler Checklist

TIPS at 2 years chronological age

- Bayley Scales of Infant Development III
- Developmental Interview
Unable to access a TIPS clinic

- Ages and Stages Questionnaire 3
- Follow up phone call with the Developmental Specialist

What have we learned about our NICU graduates?
1719 infants were enrolled in Developmental TIPS.

Methodist WH
Children's MC
CHI- Bergan Mercy
CHI- St Elizabeth
NE Medical Center
Bryan Health
CHI- Lakeside
Good Samaritan
Bellevue MC
Kearney Regional MC
Other

# of Children Referred by Hospital

69% of the children were born prematurely

The majority of the premature babies were 34 to 36 weeks gestational age.
The highest percentage of children who need further assessment is at 16 months corrected age. Across developmental screeners, the data demonstrates a need for consistent, long term follow-up.
Half of the families had private insurance.
Less than 1% were uninsured.

Results of the BSID

- Gross Motor: 77% (n=541)
- Fine Motor: 75% (n=539)
- Expressive: 70% (n=253)
- Receptive: 26% (n=251)
- Cognitive: 81% (n=253)

Fine Motor n=539
Cognitive         n=258
Expressive       n=253
Receptive         n=251
Gross Motor   n=541

Results of BSID -III Screening
0%  Competent
50%  Emerging
100% At-Risk
16%  At-Risk
Moderate risk children scored higher in both their language and cognitive skills than their high risk peers.

<table>
<thead>
<tr>
<th></th>
<th>Language</th>
<th>Cognitive</th>
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<tr>
<td>Moderate Risk</td>
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<td>n=221</td>
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<tr>
<td>High Risk</td>
<td>n=53</td>
<td>n=52</td>
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TIPS Clinic Follow up

- At 3 years of age an Ages and Stages questionnaire is sent to the family
- A Developmental specialist reviews the answers and follows up with the family as necessary
Early Development Network
2017-2018

- TIPS program found 448 infants to be eligible for referral
- 91 children were referred
  - 85% were referred after discharge
  - Half of those referred were considered to be at moderate risk

Early Development Network
2017-2018

- 52% received Physical Therapy
- 41% received Occupational Therapy
- 31% received Speech and Language services
- 30% service coordination
- 23% home based educator
TIPS research


Summarize

- Developmental TIPS has successfully instituted and maintained a statewide enrollment process for infants with a NICU experience.
- The majority of the children were considered low risk at the time of discharge.
- This three-tiered model of follow-up has provided a mechanism for early identification and referral to the Early Development Network and Early Intervention services.
References

- Needelman, H. (2018, February). Follow Me Through the Follow-Up Clinic: Clinic Care Experiences and Neonatal Developmental Outcomes. Panel discussion at Neonatal Developmental Care Conference, Children’s Hospital and Medical Center, Omaha, NE.