Driver 3: Transfer and Coordination of Care

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HOMEWARD BOUND

Vision: Integrate family into a "Family Centered" discharge process that encompasses Dignity & Respect, Participation, Communication, and Information Sharing. The process begins on admission, empowering families to collaborate with the clinical interdisciplinary team throughout their baby's transition from NICU admission to discharge home.

Primary Key Driver

Transfer and Coordination of Care

Secondary Drivers

- Orient caregivers to primary care/medical home
- Coordinate referrals to subspecialist/ rehabilitation services/mentoring programs
- Provide a comprehensive discharge summary to caregivers and care team

Family-centered care is a universal component of every driver & activity

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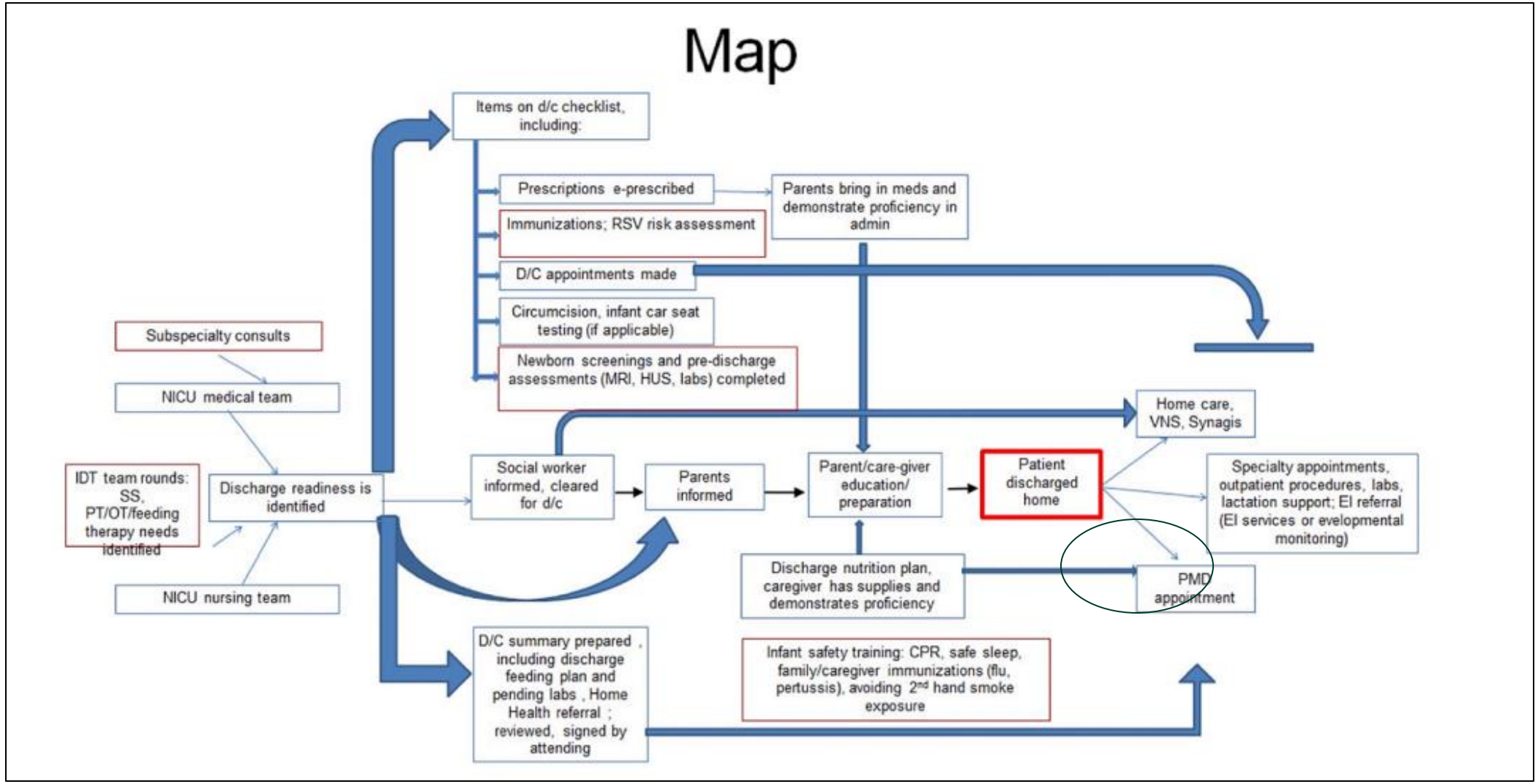
Secondary Driver 3a: Orient Caregivers to Primary Care/Medical Home



Secondary Driver 3a: Orient Caregivers to Primary Care/Medical Home

Neonatal Intensive Care Unit to Home Discharge Communication: A Quality Improvement Project

Priyam Pattnaik, MD; Suhas Nafday, MD†; Robert Angert, MD‡*

PCP Survey

- 67% of PCPs did not receive notification of infant discharge
- PCPs uncertain about subspecialists, need for follow-up labs and imaging
- Spend substantial amount of time gathering patient information
- Felt earlier contact having well-prepared discharge summary were helpful

Pattnaik, P., Nafday, S., & Angert, R. (2023). Neonatal Intensive Care Unit to Home Discharge Communication: A Quality Improvement Project. *Pediatric quality & safety*, *8*(4), e669. https://doi.org/10.1097/pq9.0000000000000669

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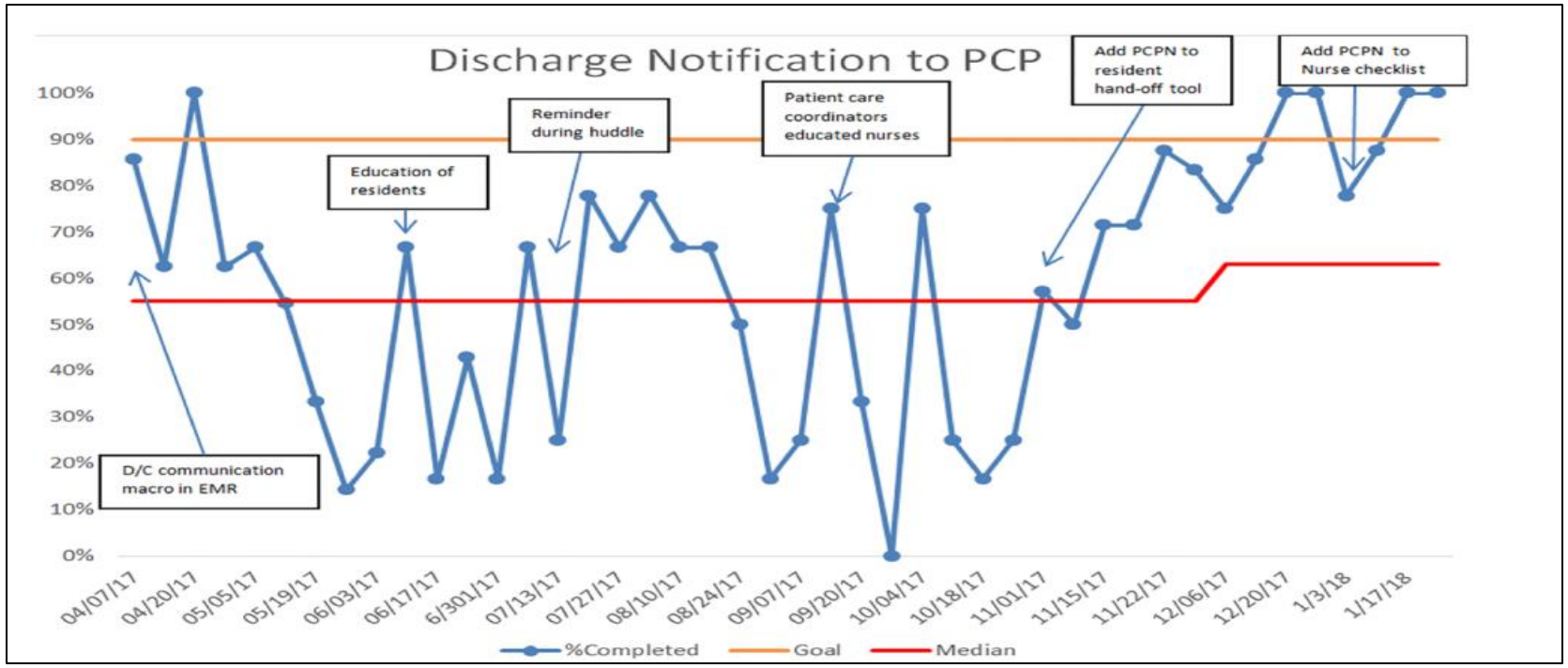

PCP Notification Template

- Short template containing all relevant medical information sent to PCPs
- Sent several days before discharge in complicated cases and for extremely low birth weight infants
- Improved communication with PCP
  - Be aware of relevant information and outpatient recommendations
  - Patient Safety

Pattnaik, P., Nafday, S., & Angert, R. (2023). Neonatal Intensive Care Unit to Home Discharge Communication: A Quality Improvement Project. *Pediatric quality & safety*, *8*(4), e669. https://doi.org/10.1097/pq9.0000000000000669

PCP Handoff Discussion Elements

After the NICU infant's caregivers have chosen a PCP, a warm handoff to the PCP/medical home is preferrable, especially for complex situations.

Within 48 hours of discharge, contact the PCP/medical home by telephone call. A text message, fax, email, or meeting may also be appropriate. Consider also providing important hospital contact information to be available for follow-up questions and ongoing communication about the infant's past health history.

Communication with the PCP/medical home should include the following **at minimum**:

- Infant's name in the hospital and after discharge (if they are different)
- Medical diagnoses
- Medical history and ongoing issues
- Discharge medications, home equipment, and administration instructions
- Nutritional recommendations
- Results of major procedures (e.g., Sleep studies, bronchoscopy, modified barium swallows, etc.)
- Test results and pending tests
- Follow-up appointments and referrals arranged and those that need to be scheduled
- Interpreter and communication needs (if necessary)
- Connections to resources for specific diagnoses or special needs
- Guidance given to family and discharge teaching that may benefit from reinforcement
- Resources for family's health-related social needs (if necessary)

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Choosing a Primary Care Provider: How Can Hospitals Assist Caregivers?

Before NICU discharge, families may benefit from assistance choosing an appropriate provider for their situation. The following questions can help guide this process:

- Does the provider accept the infant's insurance, **Medicaid health plan** or form of payment? Is the provider accepting new patients?
- Where is the provider located? Does the family have appropriate transportation to reach the provider?
- Does the provider understand the caregivers' culture and beliefs to easily talk with and educate them? Does the provider utilize interpreting services when necessary?
- Does the provider have the knowledge, skills, and resources to care for this NICU graduate? Is the provider willing to coordinate potentially complex care needs?
- Which hospital(s) or hospital network is the provider affiliated with? Which hospitals and emergency rooms does the provider refer to?
- Does the provider have separate "sick" and "well" waiting areas, or does the provider schedule fragile patients at specific times?
- How long does it take to get an appointment?
- What are the office hours? Are there appointment times that work with the caregivers' schedules?
- How do caregivers contact the provider after hours or on weekends? If the caregivers need advice, is there a "nurse line" they can call with questions?
- Does the provider offer lactation support after discharge through the office?
- Will parents always see the same primary care provider at every regularly scheduled visit? During urgent sick care visits?

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Choosing a Primary Care Provider: For Parents

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After you leave the NICU, your baby will need to visit a pediatrician. Use these questions to help you find a provider that is a good fit for your family.

- Does the provider accept your baby's insurance or Medicaid health plan? How much money will you have to pay at each visit?
- Is the provider seeing new patients? How long does it take to get an appointment?
- How close is the provider to your home, work, or daycare? Do you have an easy and affordable way to get to the provider's office?
- Does the provider understand your culture and beliefs? Can they easily talk and share information with you?
- If your baby is sick, does the office have a separate waiting room for them?
- Will your baby see the same doctor at every visit?
- When is the office open? Do the hours work with your family's schedule?
- If you have questions, can you call the provider's office for help without making an appointment?
- Is there a provider available 24 hours a day for 7 days a week if there is an emergency or need you need help right away?
- Does the provider offer breastfeeding support or other resources to families?

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Primary Key Driver

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Secondary Drivers

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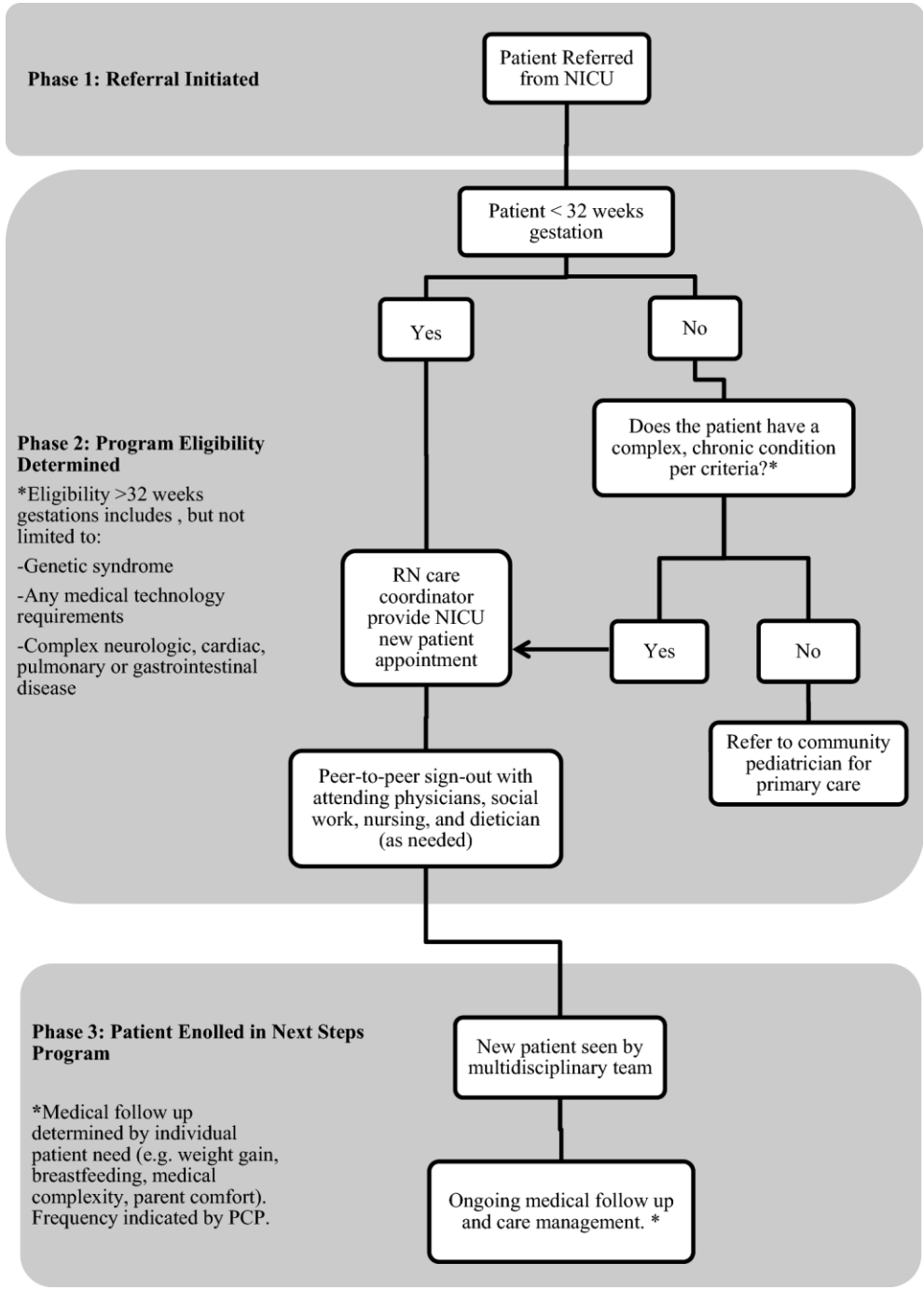
Secondary Driver 3b: Coordinate referrals to subspecialist/ rehabilitation services/mentoring programs

Care coordination addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes (p. e1452).
- AAP Policy Statement: Council on Children with Disabilities

3. Transfer and Coordination of Care

Development of a Multidisciplinary Medical Home Program for NICU Graduates

Katie Feehan[1] · Folasade Kehinde[2] · Katherine Sachs[1] · Roschanak Mossabeb[3] · Zek Berhane[4] · Lee M. Pachter[5,6] · Susan Brody[7] · Renee M. Turchi[1,4]



Feehan, K., Kehinde, F., Sachs, K., Mossabeb, R., Berhane, Z., Pachter, L. M., Brody, S., & Turchi, R. M. (2020). Development of a Multidisciplinary Medical Home Program for NICU Graduates. *Maternal and child health journal*, *24*(1), 11–21. https://doi.org/10.1007/s10995-019-02818-0

Secondary Driver 3b: Coordinate referrals to subspecialist/ rehabilitation services/mentoring programs

Next Steps Program

Table 2 Health care utilization in the Next Steps Program (2011–2016)

Year	Total patients in the program	New patients/ year	Average new patients/week	Transi-tioned patients[a]	Total well-child visits	Total follow up visits	Palivizumab vaccine (n received/n eligible)	Inpatient admissions/ year[b]	ED visits/year[b]
2011	85	85	2–3	6	107	136		21	77
2012	179	116	2–6	30	405	650		18	161
2013	264	111	3–7	53	433	584		21	146
2014	293	89	4–8	47	607	609	82/82	20	174
2015	324	99	4–8	31	646	616	118/120	15	128
2016	355	108	3–8	18	746	781	103/104	13	60*

*Statistically significant decrease in emergency department visits from 2015 to 2016 ($p < 0.001$)

Feehan, K., Kehinde, F., Sachs, K., Mossabeb, R., Berhane, Z., Pachter, L. M., Brody, S., & Turchi, R. M. (2020). Development of a Multidisciplinary Medical Home Program for NICU Graduates. *Maternal and child health journal*, *24*(1), 11–21. https://doi.org/10.1007/s10995-019-02818-0

Patient-Specific Care Plan Elements

1. Identification and preparation of the in-home caregivers
2. Formulation of a plan for nutritional care and administration of any required medications
3. Development of a list of required equipment and supplies and accessible sources
4. Identification and mobilization of the primary care physician, on-going specialty care physicians, and necessary and qualified home-care personnel and community support services
5. Dates of scheduled follow-up appointments
6. Assessment of the adequacy of the physical facilities within the home
7. Development of an emergency care and transport plan
8. Assessment of available financial resources to ensure the capability of caregivers to finance home-care costs and transportation to appointments

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Add lines as needed for additional service providers in your community. For help identifying and connecting with local partners, consult the Florida Birth Defects Surveillance Program Statewide Resource Guide or contact your local Healthy Start Coalition.

Florida Healthy Start Resources

- CONNECT https://connect.healthystartflorida.com/ One-stop coordinated intake and referral for resources by county
- RESOURCES https://www.healthystartflorida.com/resources/ General resources for families
- LOCATOR https://www.healthystartflorida.com/about-us/coalition-map/ Find your local Healthy Start Coalition

Early Learning Coalitions

- DIRECTORY https://www.fldoe.org/schools/early-learning/directory/ Every county has an Early Learning Coalition that includes a Child Care Resource and Referral Department

Early Steps

- LOCATOR https://floridaearlysteps.com/contact/ Every area has an Early Steps office that provides early intervention services

211: Your First Call for Help

- Most areas have a 211 line for help finding local resources

Substance Use and Mental Health Resources

- LOCATOR https://www.myflfamilies.com/SAMH-Get-Help Find local substance use and mental health resources by county

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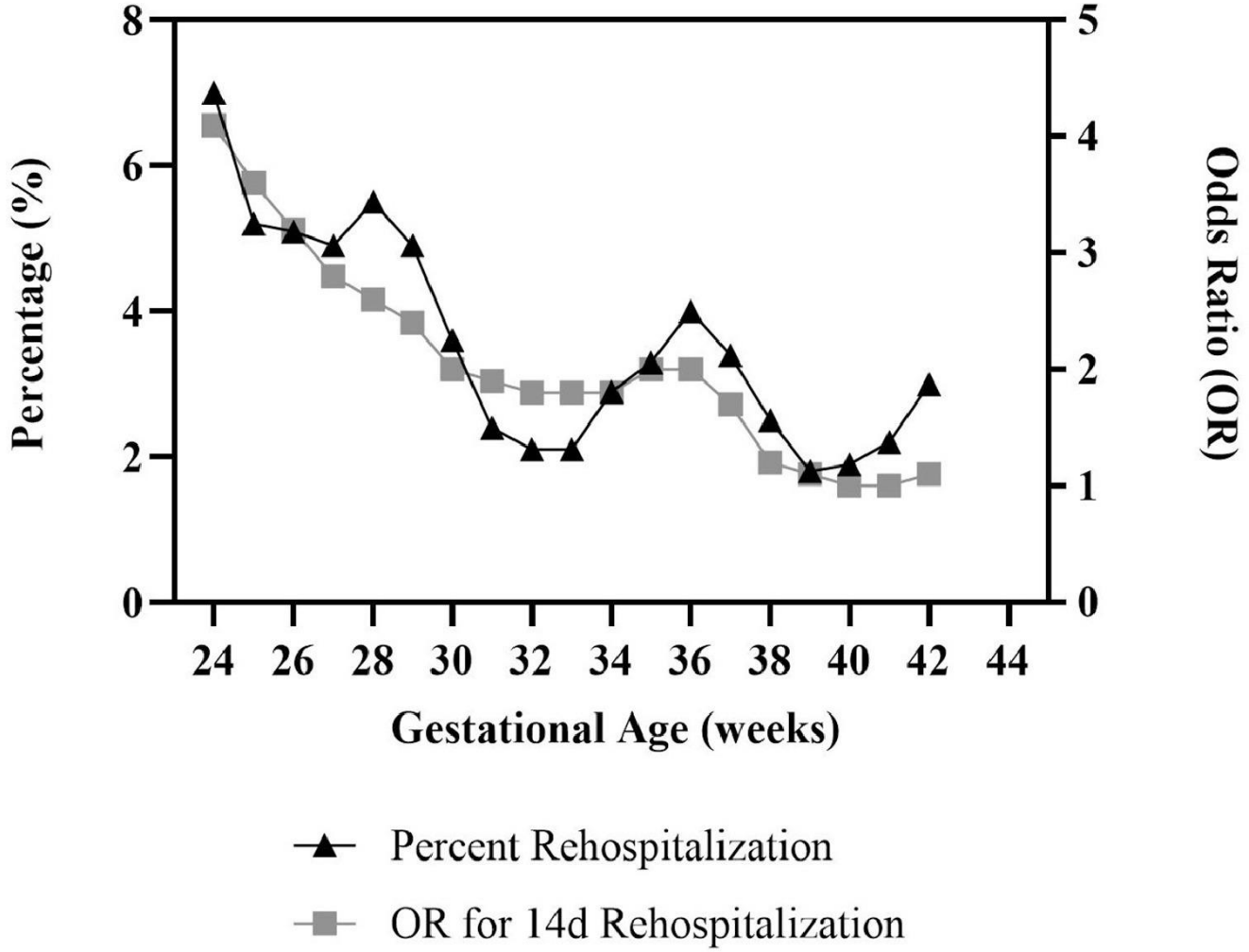
Secondary Driver 3c: Provide a comprehensive discharge summary to caregivers and care team



Hannan, K. E., Hwang, S. S., & Bourque, S. L. (2020). Readmissions among NICU graduates: Who, when and why?. *Seminars in perinatology*, *44*(4), 151245. https://doi.org/10.1016/j.semperi.2020.151245

Information Overload at Discharge

Table 2
Necessary information for PCPs about NICU graduate

Category	Specifics
Prescribed medications	• Explanation of the "indication" for each medication and the problem it is treating • Whether the dose is calculated per kg of weight or is a standard dose • What to do if the infant misses a dose or vomits a dose • Where and when to refill the medication • Whether the medication needs to be adjusted for weight gain and, if so, how often
Feeding	• Indications for special formula • Mixing instructions for 2, 3, and 4 ounces of formula • Name of alternate formula (eg, Neocate/Elecare, Neosure/Enfacare, Alimentum/Nutramigen) to prevent substitution error • Local source for special formulas (pharmacy, grocery store) • How long special formula should be continued and what formula to transition to
Subspecialty clinic referrals	• Which clinic is for which problem? • What will be done at first visit (if repeat laboratory tests, can PCP order and send results to subspecialists)? • Which clinic to reschedule immediately if missed (eg, ophthalmology clinic for active ROP)

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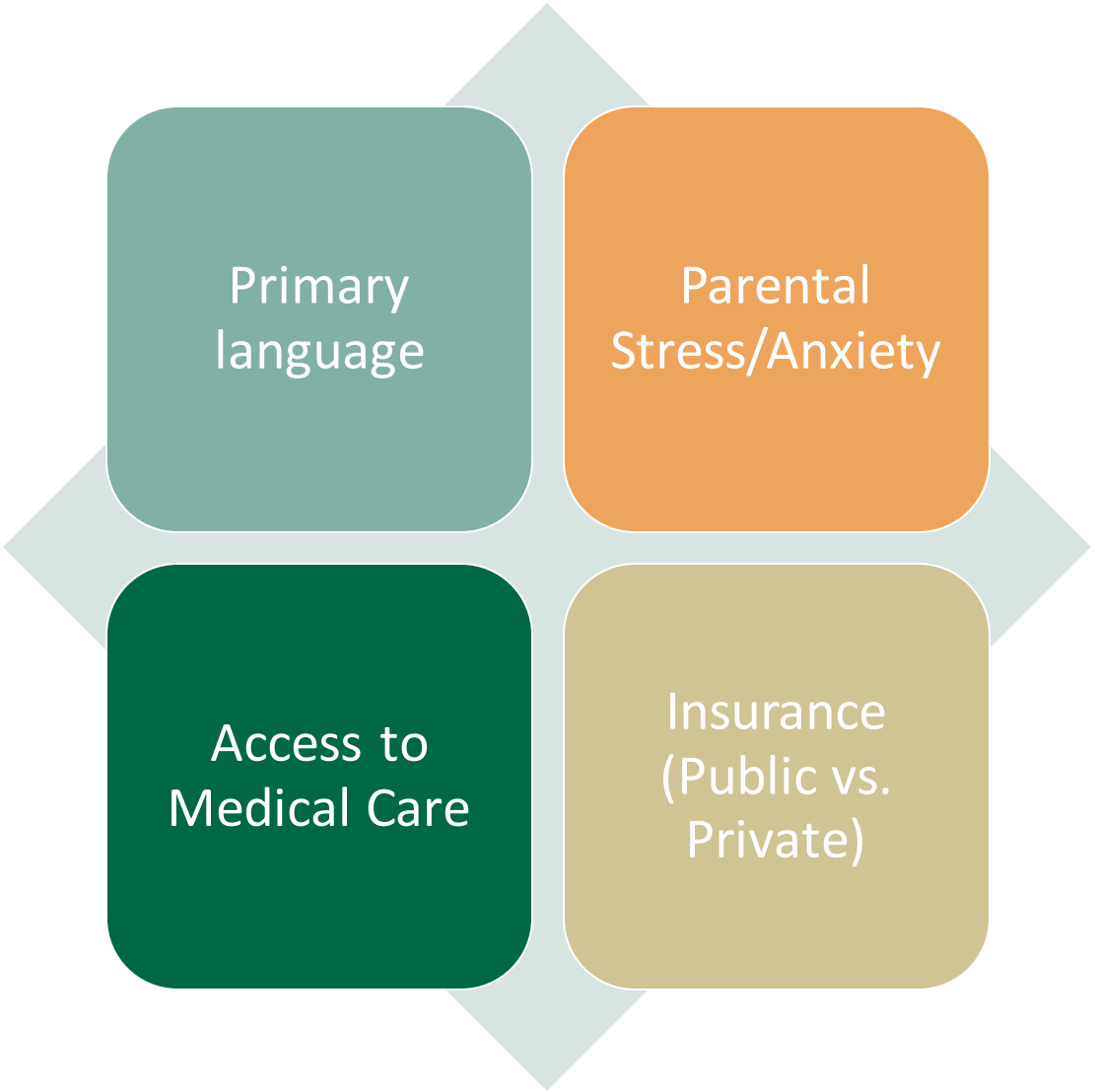
Barriers


Primary language
Parental Stress/Anxiety
Access to Medical Care
Insurance (Public vs. Private)

Discharge Summary Elements

- Infant's name in the hospital (and after discharge, if different)
- Admission indication, birthweight, head circumference, length and gestational age
- Maternal history including prenatal labs
- Discharge diagnoses
- Hospital course written by systems
- Physical exam at discharge including head circumference, length and weight percentiles
- Discharge physical exam findings (highlight any abnormal findings)
- Discharge medications and administration instructions
- Home feeding plan (breast milk fortification, formula type, recommended nipple, frequency and volume)
- Newborn hearing screen results and any follow up screening needed
- Newborn screening dates and abnormal results
- Car seat challenge results
- Immunizations administered and immunizations recommended that were not given
- Pending lab or test results that need follow up
- Prognosis (if guarded)
- If indicated, medical equipment needs
- Any known pertinent social, family, or medical history
- Community service referrals made or recommended and any counseling opportunities available to the family
- Any tasks to be completed (follow-up appointments or tests not yet scheduled)
- Interpreter or communication needs
- Any referrals to resources for specific diagnoses
- Community resources (counseling, mental health, substance dependency, visiting nurses, financial resources, etc.)

NICU Follow-Up Call Elements

A NICU representative should call the family **within 3 days** after discharge.

(The NICU representative could be a nurse, patient navigator, discharge coordinator, PA or NP, social worker, or other person as designated by unit criteria)

During the follow-up call, the NICU representative will assess the family's understanding of:

- Discharge conditions and instructions
- Feedings and how to mix the feeding
- Medications and medication instructions
- Follow-up appointment dates/times and reason for appointment, referrals

The NICU representative will also inquire regarding:

- General well-being of infant and family, including family mental health
- Any anticipated or unanticipated issues/challenges
- Referrals/appointments that have not been made and assess barriers

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Family Engagement in Transfer to Home

- Families have different needs, priorities, and expectations when choosing a PCP for their infant
- The patient-specific care plan should be developed with input from the family and agreement and support from the caregivers
- Ensure family understanding of the discharge summary and care plan by discussing information in the family's primary language
- Provide families with the knowledge and skills to advocate for their baby's care
- Following up with the family after discharge centers their needs and experiences

"Despite already being established with a pediatrician for my older son, it felt like starting over from ground zero after discharge from the NICU. The people who knew my baby were no longer involved. At times, we felt very alone."

Alexa, mother of micro preemie twins

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