



High Risk Infants: Caring for Our Most Vulnerable Population

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Children'sSM
Healthcare of Atlanta
Dedicated to All Better

Objectives

- **Examine** conditions associated with prematurity and other medical conditions seen in infants
- **Create** familiarity with the complex discharge needs of high-risk infants
- **Appreciate** the collaborative method a medical team uses to address the needs of at risk families
- **Identify** the medical team's role in assessing and reporting medical neglect



Infants With Chronic Medical Conditions

- Those with chronic physical and developmental conditions requiring health services beyond other infants
- Families experience higher emotional, physical, economic and social demands
- Caregiver capacity challenges (ie: developmental delays, mental illness, TBI's) increase challenges navigating the complex healthcare system
- Added requirements can result in failure to receive needed medications and adequate medical care



A Perfect Storm...

A highly complex, medically fragile infant born into an overwhelmed family system with limited resources, minimal supports, and diminished community service...



The Medically Fragile Infant



The Medically Fragile Infant

- High overall admission rate
- Long term chronic medical conditions that are present at birth or develop in the neonatal period
- Highly vulnerable population
- Requires highly advanced and complicated care



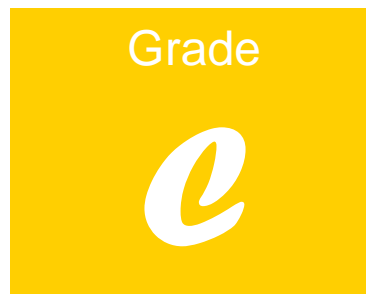
A Few Thoughts on Prenatal Care

- High-risk for undetected complications and prematurity
- Lack of plan to address medical problems
- Rule out detectable substance abuse
- Decreased level of parental engagement/bonding
- Indicator of probability of multiple social barriers
- Allows for hidden teen pregnancy

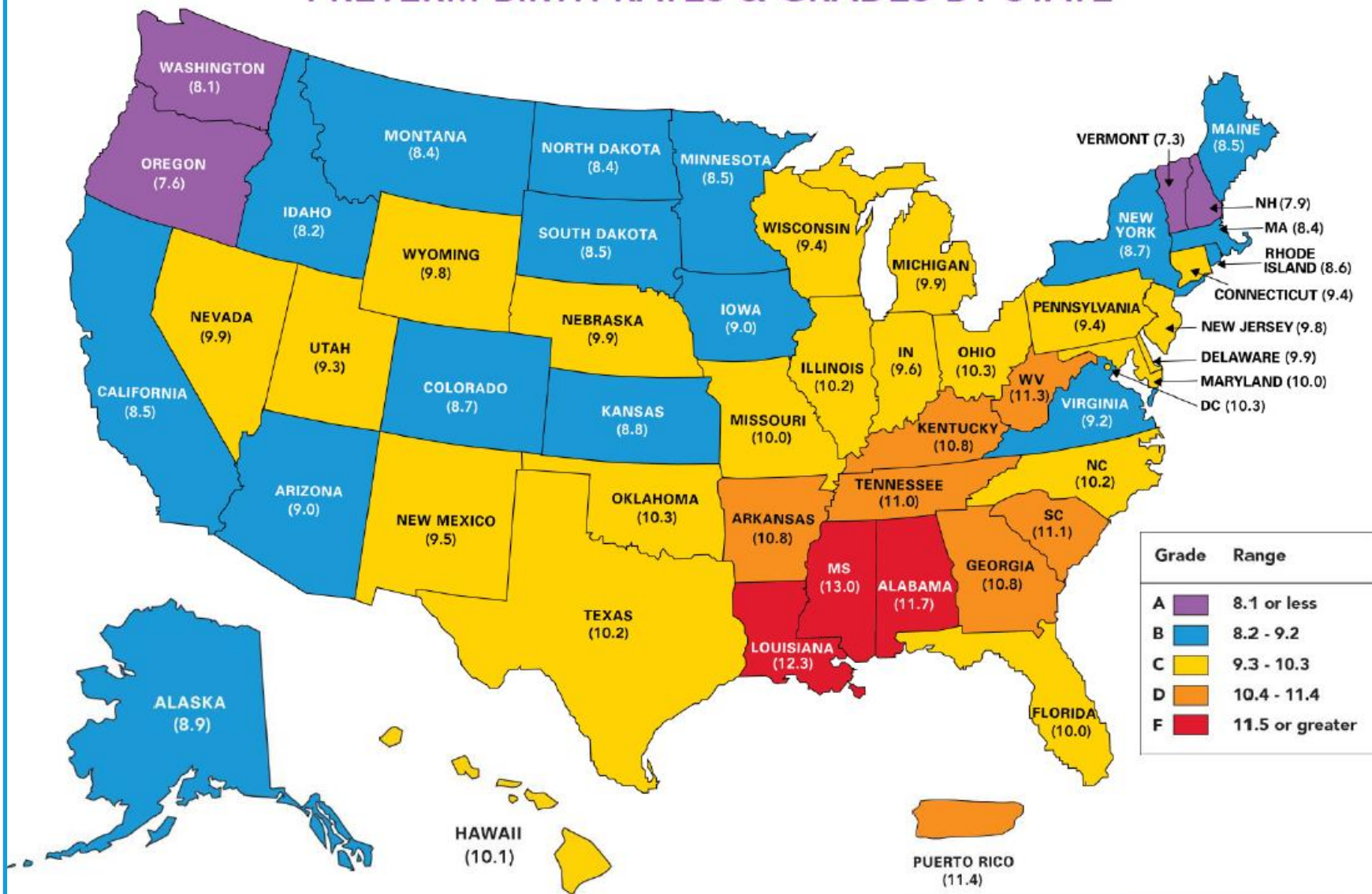


Prematurity

- The March of Dimes reports **9.6%** of births in the US are preterm – **grade C**
- Preterm birth occurs before 37weeks gestation
 - 34-36wks – 71.2% (late preterm)
 - 32-33wks – 13%
 - 28-31wks – 10%
 - <28wks – 6% (extremely preterm birth)

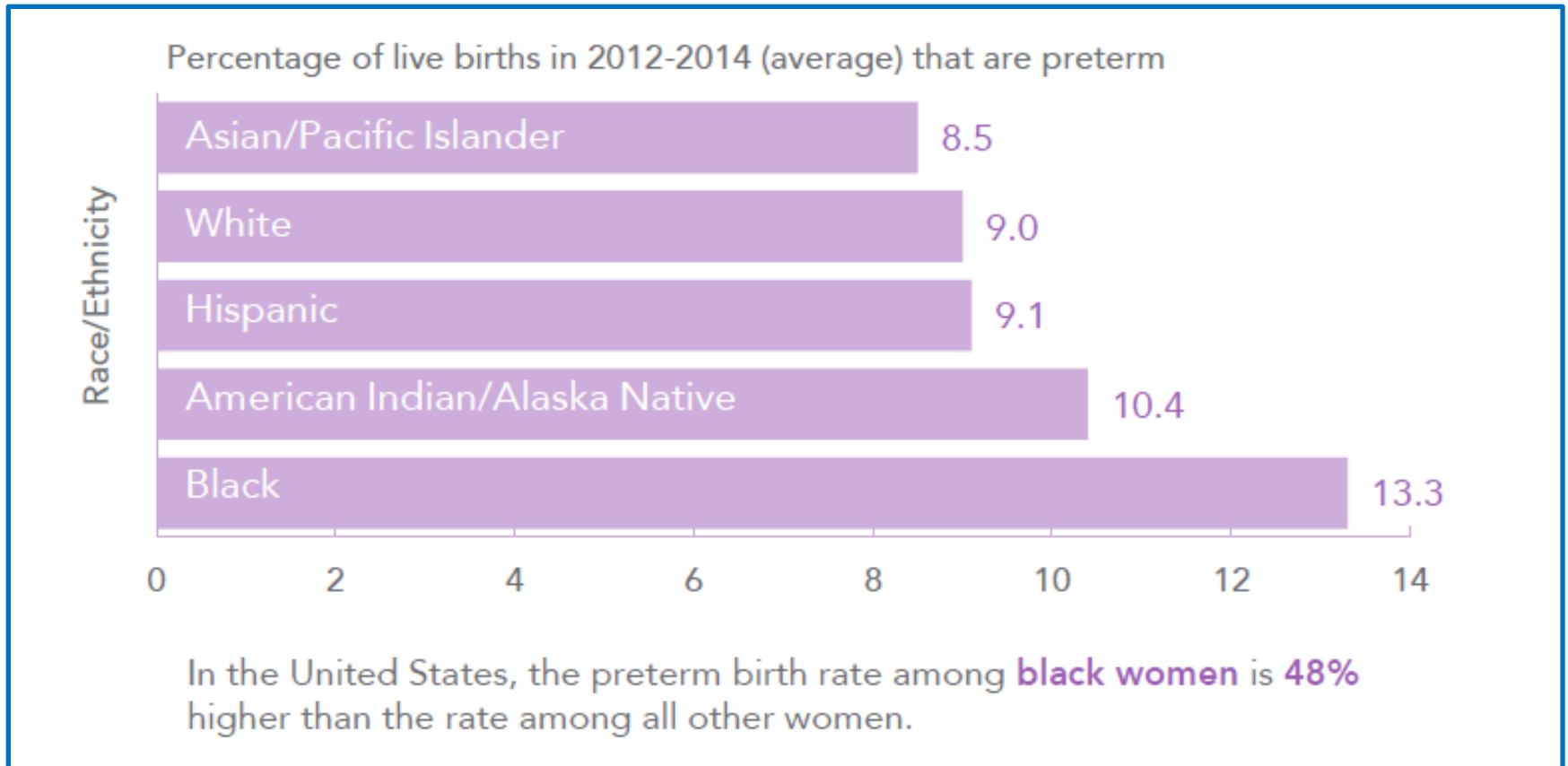


PRETERM BIRTH RATES & GRADES BY STATE



<https://www.marchofdimes.org/materials/premature-birth-report-card-united-states.pdf>

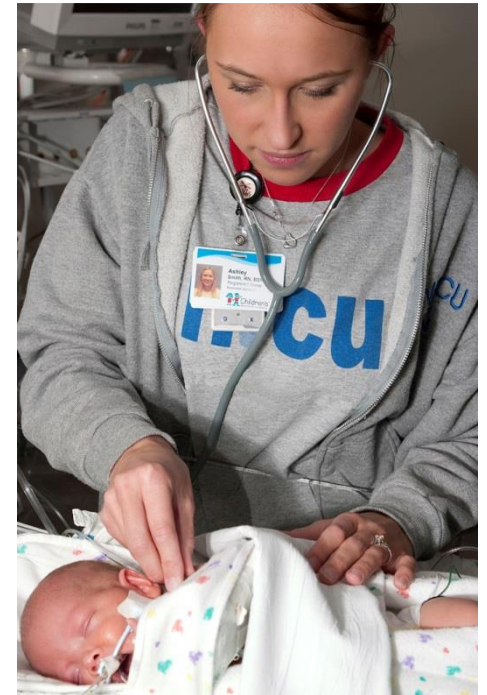
Race & Ethnicity in the United States



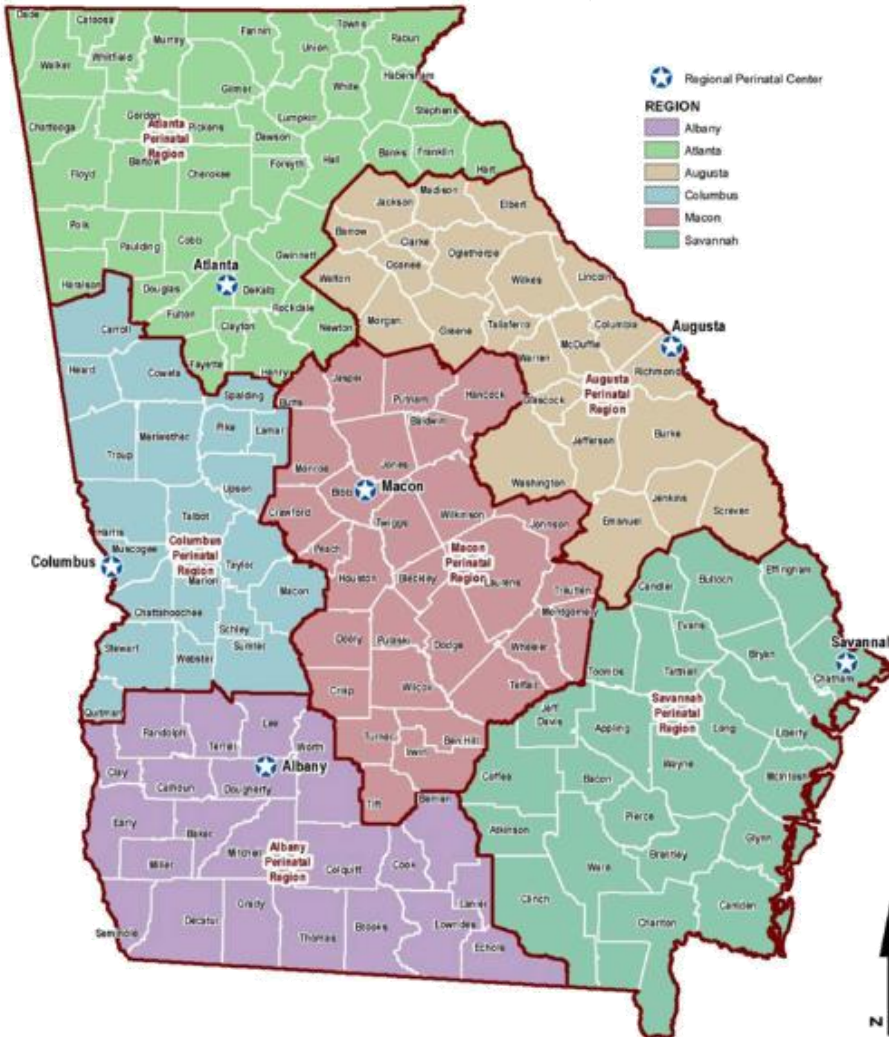
<https://www.marchofdimes.org/materials/premature-birth-report-card-united-states.pdf>

Prematurity

- Infants born before about 32 weeks of gestation face the highest risk
- Preterm birth contributes to one third of all infant deaths
- Preterm birth accounts for 1:5 children with cognitive disability, 1:3 children with vision impairment and almost half of children with cerebral palsy



Regional Perinatal Centers



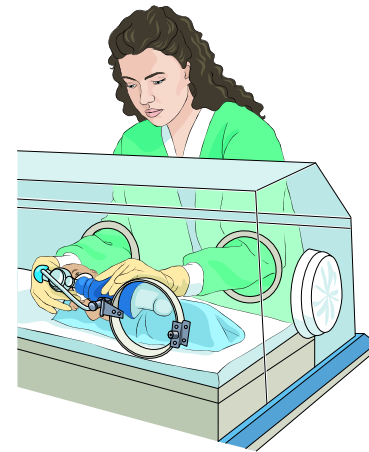
- Babies from all over Georgia are referred to Atlanta for surgical care including heart surgery and ECMO



Medical Conditions Associated with Prematurity

Preemies

- All organs may not be fully developed at birth
- When organs are not fully formed they are very susceptible to injury
- The organs most commonly impacted by preterm birth are:
 - The gut (stomach, intestines, colon)
 - The lungs
 - The brain



The Gut

- **Necrotizing Enterocolitis (NEC)**
 - Infection in the intestine wall causing parts of the intestine to die
 - When the whole gut dies the baby cannot survive
 - Can lead to Intestinal Perforation or Short Gut syndrome
 - Surgery may be necessary to remove damaged intestine
 - Baby may not have enough intestine to absorb nutrition using his digestive system
 - May need to receive nutrition through specialized, high calorie nutrition that runs directly into a vein (TPN)



The Gut

- **Gastroesophageal Reflux Disease (GERD)**
 - Acidic stomach fluids wash back into the esophagus (severe heartburn)
 - Fluids may go to the lungs causing pneumonia
 - GERD may require feedings by a tube inserted through the nose to the stomach, or directly into the stomach
 - Feeds are delivered by a feeding pump
 - A procedure called a fundoplication (muscles at the top of the stomach are tightened) can ameliorate GERD
- **Dysphagia**
 - An inability to swallow liquids safely causing some to go into the lungs



Tummy Babies



NG-Tube



The Lungs and Airway

- **Respiratory Distress Syndrome (RDS)**
 - Breathing problem due to insufficient surfactant in the baby's lungs
 - Causes excessive stiffness of the lungs, chronic lung disease or severe airway issues which may result in a tracheostomy
- **Tracheostomy**
 - Surgical opening in the trachea, below the larynx (voice box) to allow air to enter the lungs
 - Bypass a narrowing in the area below the larynx
 - May be accompanied by a ventilator to manage oxygen supply



Airway Babies



The Head

- **Intraventricular Hemorrhage (IVH)**
 - Bleeding in the brain
 - Grades 1 and 2 are usually minor
 - Grades 3 and 4 observed for developmental delay
- **Hydrocephalus**
 - Excessive accumulation of fluid in the brain
 - “Water on the brain”- cerebrospinal fluid (CSF) - fluid surrounding the brain and spinal cord
 - Excessive CSF results widening of the ventricles
 - May creates harmful pressure on tissues of the brain
 - Shunt placement for fluid drain - often a life long need



The Head

- **Anoxic Brain Injury**

- A lack of oxygen to the brain for any number of reasons

- **Cerebral Palsy**

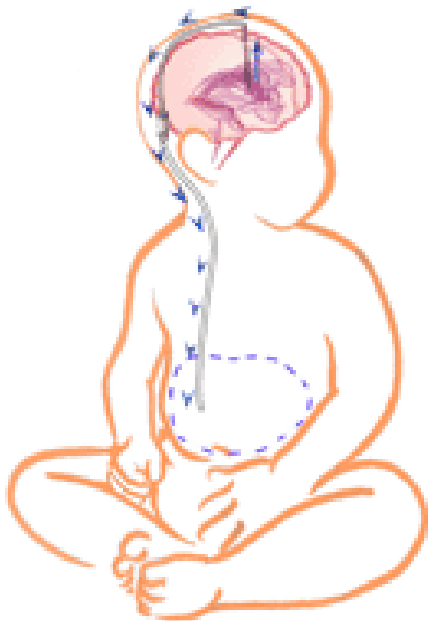
- Caused by abnormal development or damage to the parts of the brain that control movement, balance, and posture
 - Problems occur during pregnancy but may occur during childbirth, or shortly after birth

- **Non Accidental Trauma/Shaken Baby Syndrome**

- Caused by physical abuse

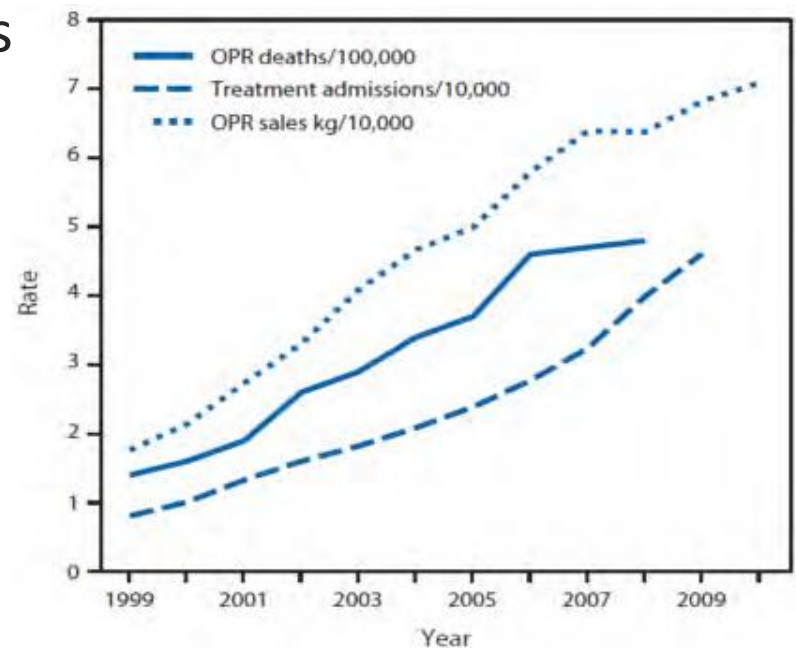


Neurological Injury



Neonatal Abstinence Syndrome (NAS)

- Withdrawal symptoms opioid drugs use in pregnancy
- Incidence has doubled in a 4 years
- Rx for opioids have increased 4-fold over the last decade
- 40-80% of heroin and methadone exposed newborns develop NAS
- ~5% of those exposed to opioid pain relievers develop NAS
- 440,000 infants are exposed to illicit drugs and alcohol per year



Centers for Disease Control and Prevention

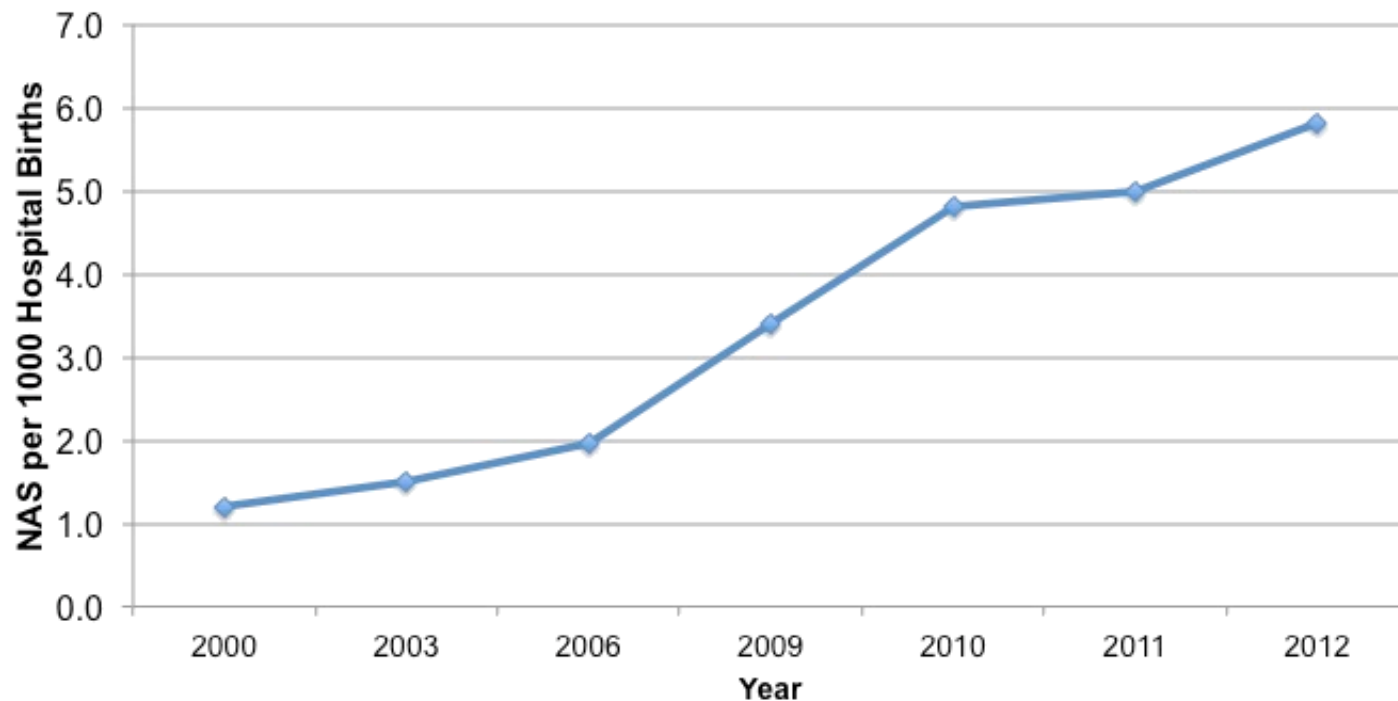


Symptoms of NAS

- Infants withdraw in much the same way as adults
- No psychological addiction, only physiological
- Intestinal symptoms
 - Poor feeding/vomiting/loose stools
 - Dehydration and poor weight gain
- Neurologic symptoms
 - Tremors/hypertonia
 - Irritability/decreased sleep
 - Seizures, Dilated pupils
- Tools (Finnegan score) determine the degree of withdrawal and treatment needed
- May need to stay in the hospital for several weeks weaning from their medications



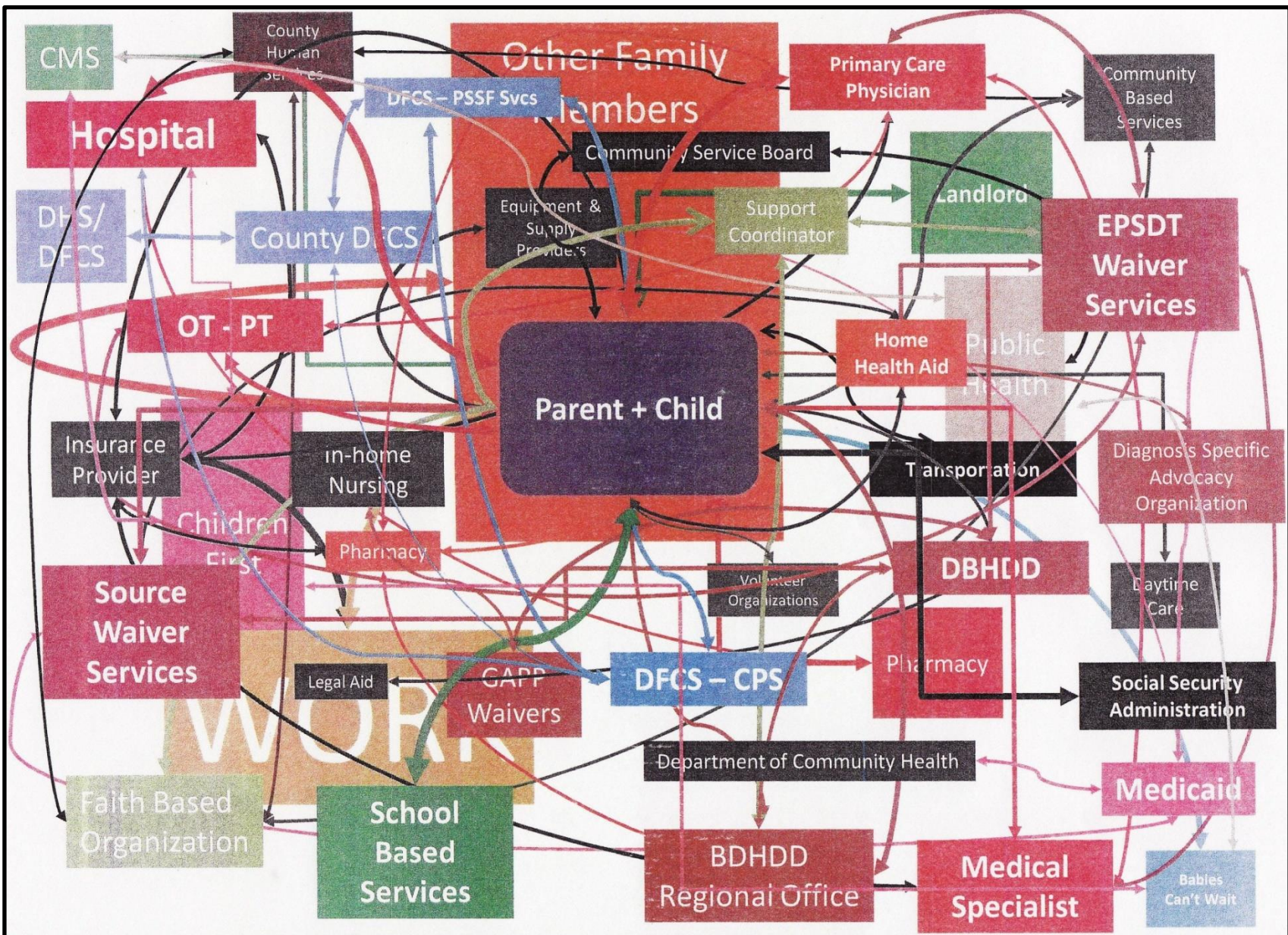
Incidence of NAS in the US, 2000-2012



Patrick SW, et. al. Neonatal Abstinence Syndrome and Associated Healthcare Expenditures – United States, 2000-2009. *JAMA*. 2012 May 9;307(18):1934-40.

Patrick SW, Davis MM, Lehman CU, Cooper WO. Increasing incidence and geographic distribution of neonatal abstinence syndrome: United States 2009 to 2012. *J Perinatol*. Apr 30 2015.





A do-it-yourself guide to services for children & youth with special health care needs or developmental disabilities

The Complex Discharge

- **Parenteral Nutrition (Total Parenteral Nutrition/TPN)**
 - Protein/fats/sugars/salts given by surgically placed catheter when complete feedings not tolerated
- **NG or Gavage Feedings**
 - Tube placed through the nose or mouth into the stomach when the baby is unable to suck and swallow
- **G/GJ Tube Feedings**
 - Tube inserted into the stomach or through the stomach into the part of the small intestine (jejunum)
 - Formula is delivered into the stomach by a pump



The Complex Discharge

- **Apnea monitor (Smart monitor)**
 - Monitors breathing and heart rate and alarms if episode of slowed or no breathing
- **Home mechanical ventilation**
 - Necessary if the baby has a tracheostomy
- **Home oxygen via nasal cannula and pulse oximetry**
 - For lung conditions of prematurity such as bronchopulmonary dysplasia/ chronic lung disease



The Complex Discharge

- **Suctioning equipment**
- **Developmental therapies such as PT/OT/Speech**
- **Medical specialty follow-up**
 - in addition to routine primary care visits
 - often 5 or more specialists
- **Other referrals**
 - Childkind, home nursing, community support, etc.



Example: 5 month old w/short gut

- Continuous G-tube feeds
- 12 hrs - 2 daily boluses
- TPN through a central venous line 18 hours daily
- Labs biweekly
- Daily medications via central line
- Central line care using sterile technique & G-tube site cleaning
- Report to the ED with fever of 100.5 degrees
- Daily home nursing
- Order/receive supplies on time
- Communicate w/ the Intestinal Rehab Team
- Appointments with GI doctor, eye doctor, heart doctor, kidney specialist etc.



Management of Chronic Medical Conditions

- Have a structured, often nonnegotiable plan of care
- Medical plan of care keeps patient in stable medical condition - allows highest function
- Even when followed, it is likely that the child will need to be admitted to the hospital
- Caregivers participate in the structure of medical plan of care, are provided teaching, written materials, guidance, and constant support from the Medical Team for successful maintenance of the medical plan in the home



Addressing the Needs



Surviving Healthcare

SHOW UP

This is not always easy

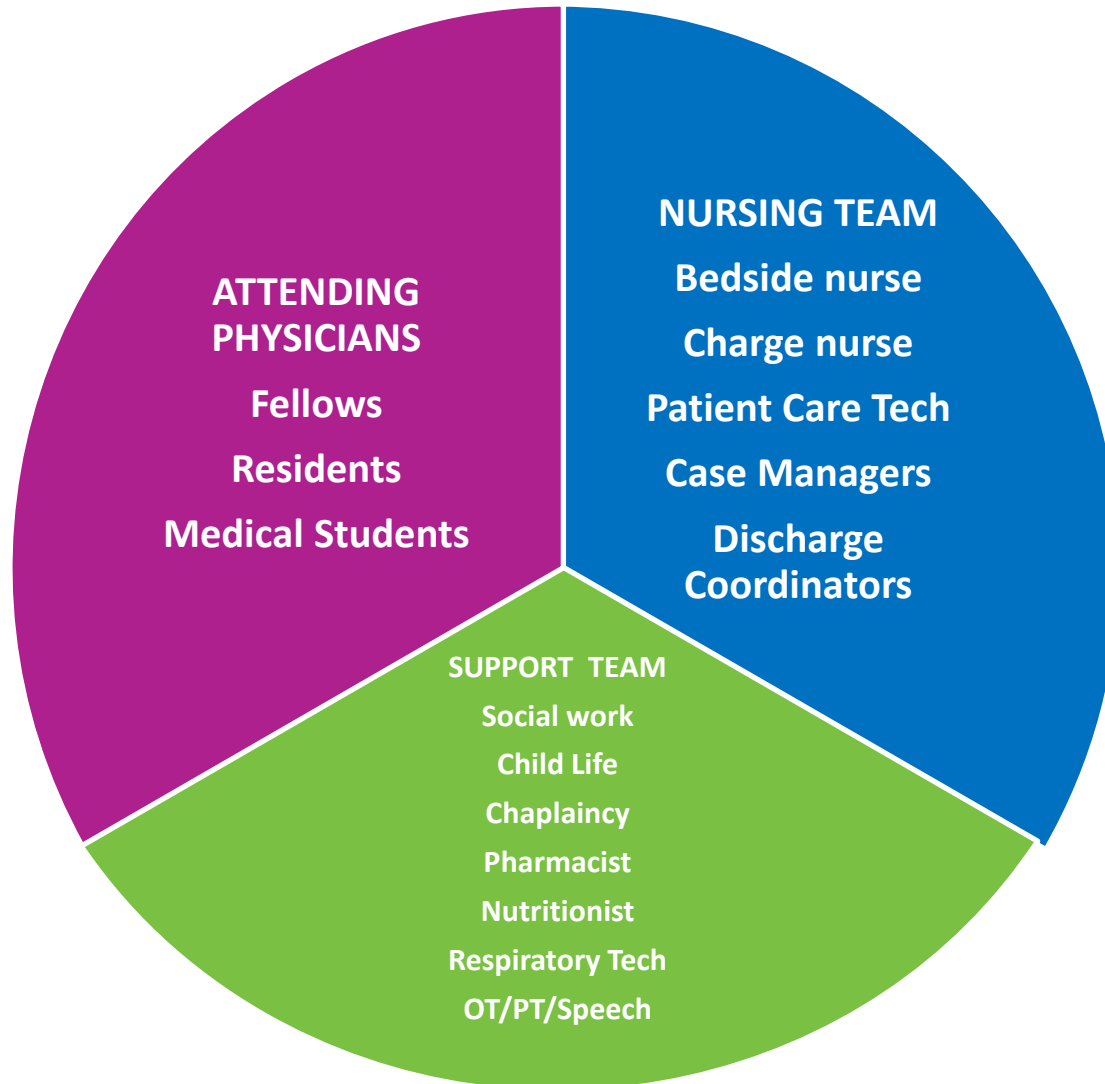
Know and participate in the **PLAN**

COMMUNICATE

Frustrations, disagreements, barriers, fears, and expectations



Medical Team Members



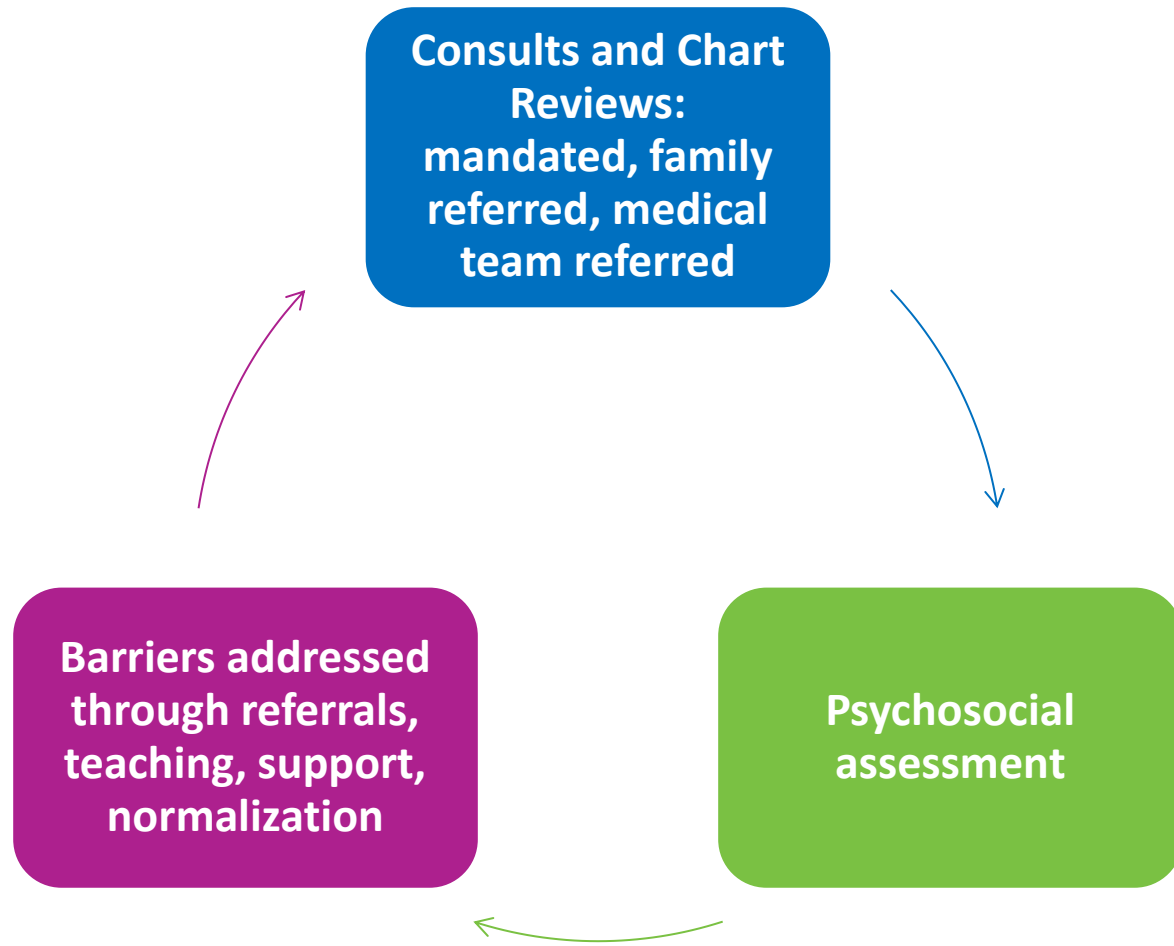
Medical Team/Family Collaboration

- Daily, family-centered rounds for inpatients
- Bedside teaching of caregivers for inpatients, and continued teaching in outpatient clinics
- Parent rooming-in prior to discharge
- Care conferences for discussion of condition, discharge expectations, and caregiver concerns
- Education materials: Handouts, videos, booklets, teaching sheets, discharge instructions, etc.
- Assessment of psychosocial barriers impacting care

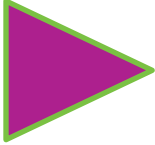
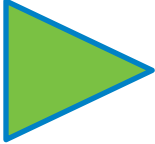
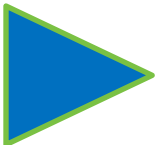


Planning for a Successful Transition

Finding and Addressing Barriers



Barriers Defined by AAP

	Barrier
	Lack of communication
	Lack of access to care
	Lack of trust in healthcare professions
	Lack of Parent health literacy
	Impairment of caregivers
	Poverty/economic hardship
	Misunderstanding of different cultures
	Child's attitude/behavior
	Family culture/beliefs
	Family chaos & disorganization



Interventions

- Access services to facilitate translation
- Strengths perspective/family system support
- Address misconceptions, anxieties, distrust
- Educate the family about need for care
- Involve the family to develop a medical plan
- Develop written contracts with families outlining care
- Enlist community resources
- Arrange for direct observation of family's caregiving
- Arrange for extended care to assist patient/family
- Referral to Early Intervention
- Referrals for financial, housing, childcare resources



Diminishing Resources

- Medically fragile day care
- Child Kind home-based services
- Changes to Children's First programs
- Decreases in GAPP nursing hours
- Lack of pediatric transitional and skilled care placements (residential and medical)
- Caregiver respite and support



The Social Worker is an advocate for the family but also is the mandated reporter at Children's for all concerns of abuse or neglect. We make all reports to DFCS on behalf of the medical team, but the decision to report is a team decision.



Social Work Assessment

Acuity level	Psychosocial concern	Action
LOW	<ul style="list-style-type: none">■ Caregiver strong historian■ Caregiver knowledgeable of condition■ Caregiver participates in care■ Caregiver demonstrates capacity to advocate for their child's needs■ Good support system■ Independent with navigating complex healthcare system (inpatient/outpatient/home health, etc)	<ul style="list-style-type: none">■ Psychosocial assessment■ Collaboration with Medical Team■ Alignment with appropriate referrals■ Additional support as indicated by the caregiver



Social Work Assessment

Acuity level	Psychosocial concern	Action
MEDIUM	<ul style="list-style-type: none">▪ Current or prior barriers to care▪ Communication difficulties▪ Current or prior DFCS involvement▪ Addition of new technology or equipment▪ Limited social support▪ Needs additional support w/ navigating healthcare system (inpatient/outpatient/home health, etc.)▪ Unaddressed mental illness, substance abuse, parent with significant developmental delays, or parental educational level▪ Questionable maternal attachment	<ul style="list-style-type: none">▪ Psychosocial assessment▪ Collaboration with Medical Team▪ Identify and address any barriers to care▪ Alignment with appropriate referrals▪ Establish ongoing relationship with caregiver▪ Assistance with navigating the expectations of healthcare



Social Work Assessment

Acuity level	Psychosocial concern	Action
HIGH	<ul style="list-style-type: none">▪ Poor maternal attachment▪ Poor caregiver coping▪ Untreated, unaddressed MI, SA, CD, TBI▪ Poor or no participation in care▪ Not able to utilize community services, no resources▪ Lacks external support system▪ Basic needs supersede patient needs▪ Cannot advocate for patient needs▪ Can not or will not demonstrate knowledge of care▪ History of social complexities interfere with ability to focus on the patient need	<ul style="list-style-type: none">▪ Psychosocial assessment▪ Identify and address any barriers to care▪ Advocate for needs with Medical Team▪ Alignment with appropriate referrals▪ Establish ongoing relationship with caregiver▪ Ensure caregiver understanding/participation▪ Care conferences▪ Care coordination

Medical Neglect - American Academy of Pediatrics (AAP) Definition

Per the American Academy of Pediatrics, there are 5 factors necessary for the diagnosis of medical neglect

Per AAP	Example
A child is harmed or is at risk of harm because of lack of health care	Premature infant with swallowing disorder at risk for failure-to-thrive and/or aspiration pneumonia
The recommended health care offers significant net benefit to the child	NG tube recommended by MD Speech therapy recommended Appropriate daily caloric intake aids overall growth and development
The anticipated benefit is significantly greater than its morbidity, so that the reasonable caregivers would choose treatment over non-treatment	Children with NG tubes can catch up with weight gain, receive proper nutrition, and demonstrate positive overall growth and development
It can be demonstrated that access to health care is available and not used	Caregiver receives supplies & teaching Caregiver continues to feed by mouth Patient does not gain weight
The caregiver demonstrates an understanding of the medical advice given	Mother agrees to NG tube placement Demonstrates competency Documented teaching by Nurse Educator



CHOA Definition of Neglect

- When a parent or caretaker inadvertently or deliberately fails to provide the proper care or attention essential to a child's medical or developmental needs.
- The absence or omission of essential services to the degree that such deprivation harms or threatens to harm the physical or emotional health of a child or disabled person.



Practical Definition

- Lack of access to caregivers
- Inability/refusal for essential care
- Caregiver needs supersede needs of the patient
- Lack of communication w/medical team
- Refusal or termination of services
- Lack of problem solving in caregiver
- Non-addressed behavioral health or substance abuse concerns



When Needs Outweigh Our Ability to Help

- Opposition to medical plan, putting the patient's life at risk
- *Unresolvable barriers* during hospitalization, raising concerns for patient safety at time of discharge
- Continued lack of follow through by caregiver despite multiple attempts to resolve
- *Caregiver's inability to sustain basic needs*
- Subjective information provided by the caregiver cannot be substantiated by facts
- Mental health or substance abuse in caregiver



A Partnership to Help Families

- Medical neglect concerns evolve over time may compromise patient's safety
- A child protection referral **may fracture a relationship between the medical team** and the caregiver
- We are mandated to report medical neglect; however, **this does not mean our relationship or our help ends** with the patient and caregiver
- DFCS involvement is needed in cases where the family is struggling to survive this unexpected, unwanted, change in their day to day life



Summary

- Technology, substance abuse, and economic stressors have contributed to an increasingly complex infant population
- Added requirements of special care result in a difficult transition to home
- Infants with chronic medical conditions have higher emotional, physical, economic and social demands and caregivers increasing the risk for neglect and abuse

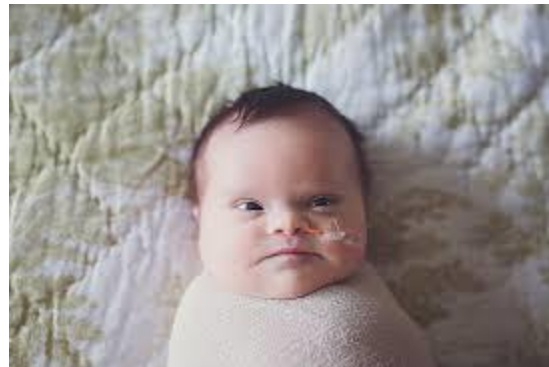


Summary

- Families w/ multiple barriers require access to multiple supports
- Resources not keeping up with the demand - How can we as a community plan for better?
- We rely on our community partners and the courts to ensure the safety and to access services to keep babies in their homes



We strive for a collaborative effort
to ensure the well-being of all
children in our care...



Questions and Comments?