Services for Child and Family Upon Discharge From NICU

Howard W. Kilbride, MD, Professor
University of Missouri-Kansas City School of Medicine
Chief, Section of Neonatal Medicine
Children's Mercy Hospitals & Clinics

Children's Mercy HOSPITALS & CLINICS
www.childrensmercy.org


161
40
33
080
4460
375


Protective Eyewear
is in here
USE IT!
11766
ACT

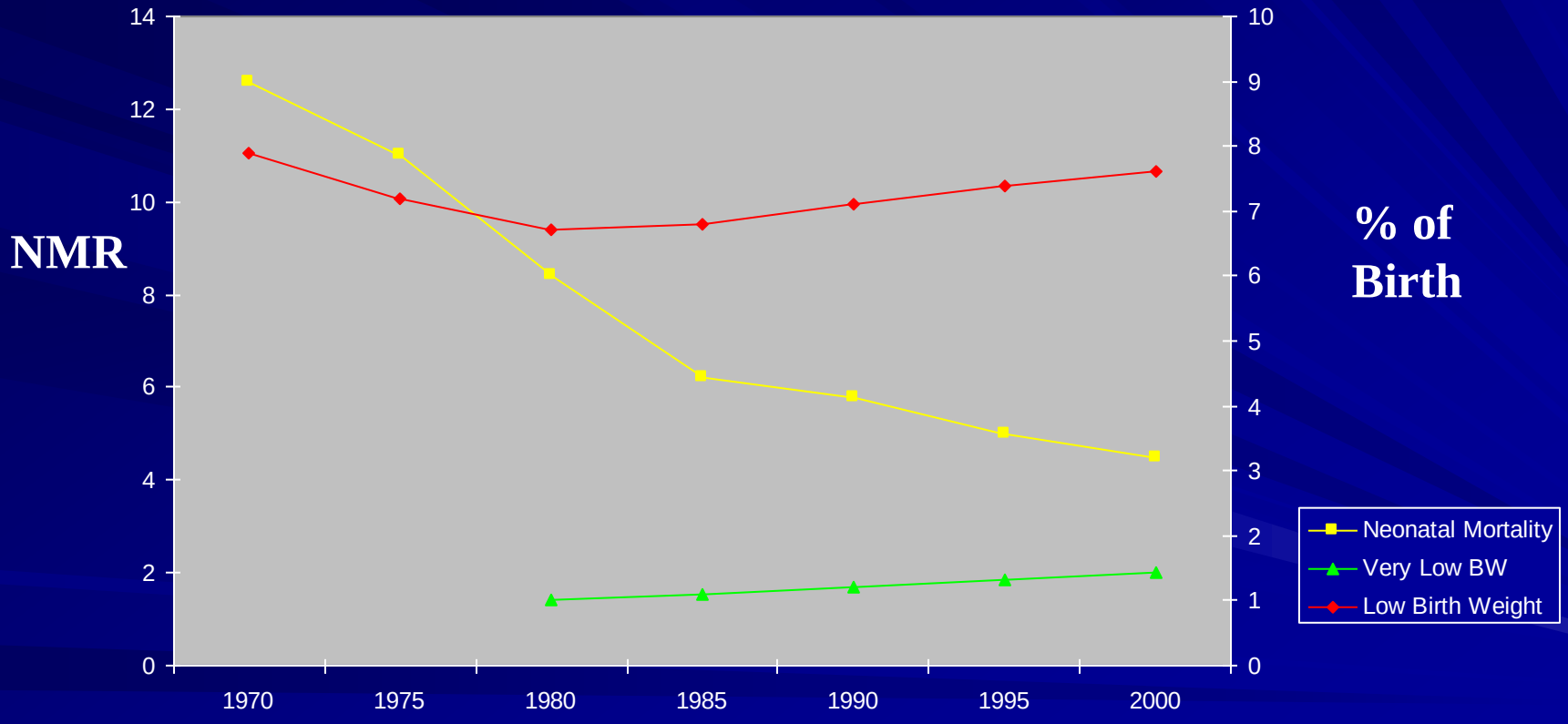
Case Example

- 33-wk GA preterm female, 1600 g BW, born after PROM
- Mother: 32 yo G4, unmarried, hx of depression, tobacco use, STDs
- Discharged at 1800 g wt on apnea monitor
- Admitted to CMH 2 weeks later with anemia, shock, and severe facial injuries

Goals of Presentation

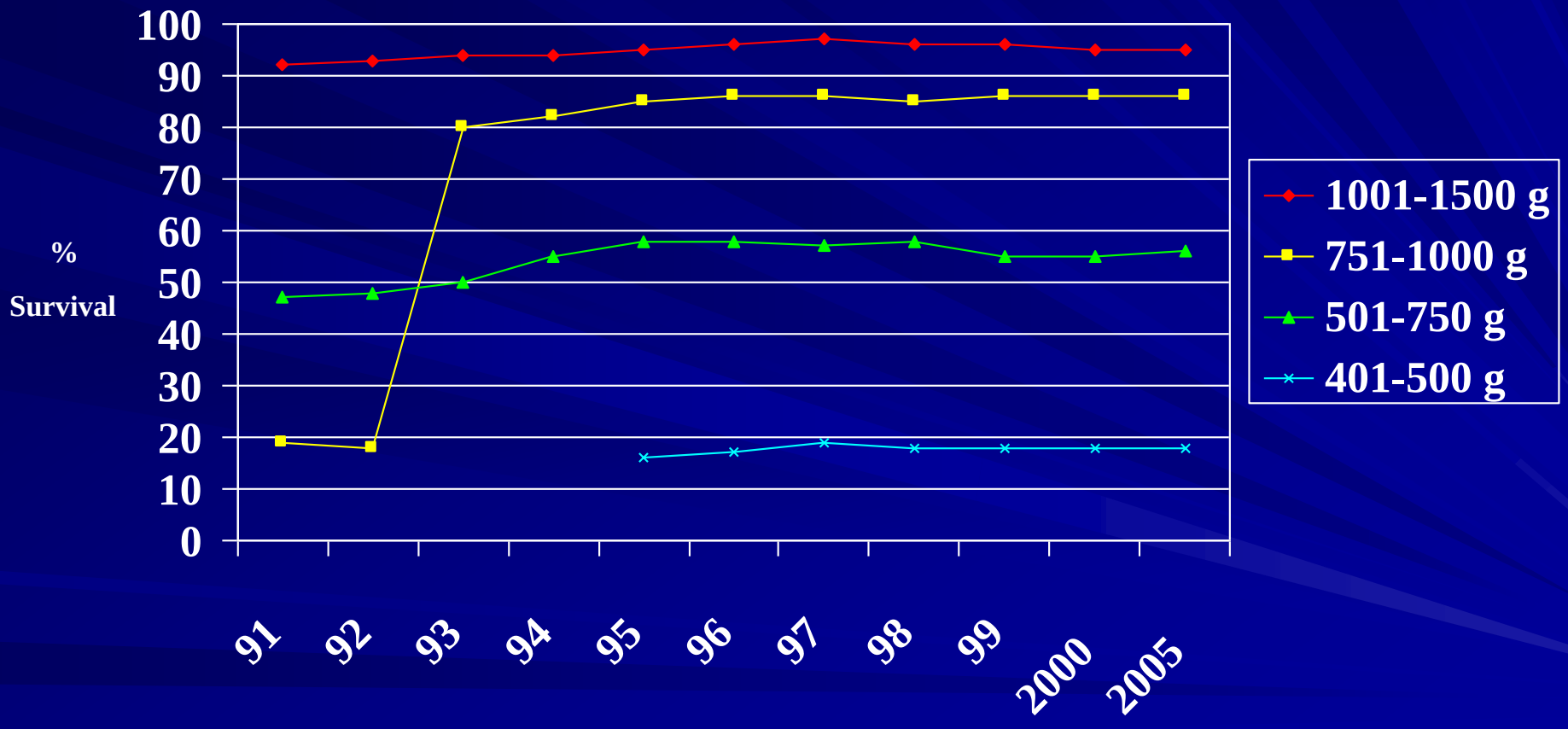
- Review epidemiology of NICU admissions/discharges
- Discuss acute and long-term medical and pyschosocial issues affecting these infants/children
- Present some specific resources needed based on current or anticipated needs
- Present a conceptual discharge program

USA Neonatal Mortality



Ref: Arias et al, *Pediatrics*, 2003

VON Birth-Weight-Specific Survival for VLBW Infants



Ref: Horbar et al. *Pediatrics* 2002;VON Annual Summaries

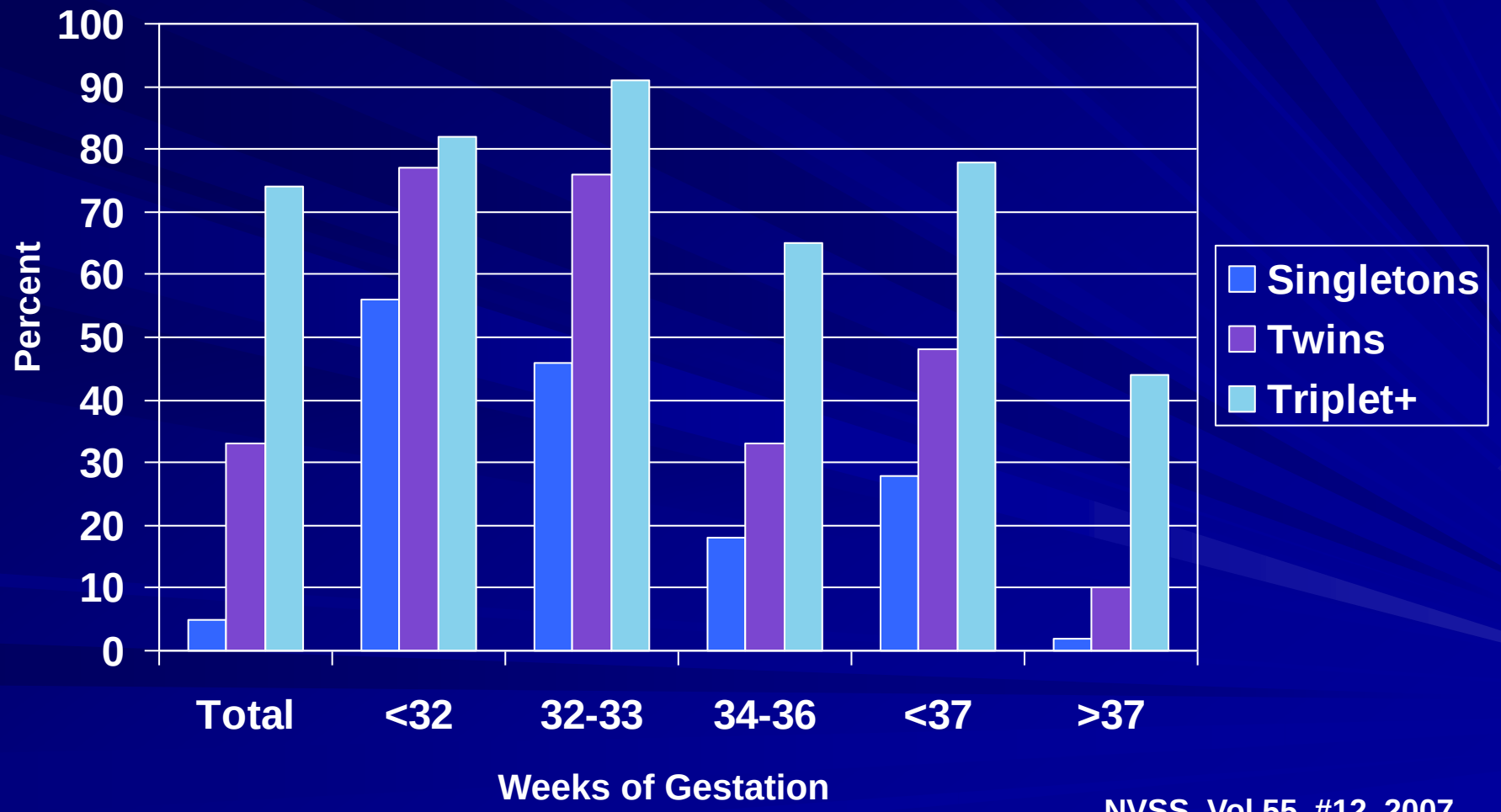
Estimated Annual Birth Statistics

3,500,000 births

- **~ 230,000 NICU admissions (6.6%)**
- **~ 60,000 VLBW infants (1.8%)**

Ref: National Vital Statistics, Vol 55, April 2007

NICU Admissions by GA (2004)



NVSS, Vol 55, #12, 2007

NICU Admission by BW

Children's Hospitals
2006 PHIS Data – CHCA
N = 22,724

<1000 g	9%
1000-1499 g	9%
1500-2499 g	25%
≥2500 g	57%

NICU Admissions >2500 g BW

Brigham and Women's Hospital 1989-1990

N=521

- 34% of NICU admits
- 79% of these > 38 wk GA
- 2% in-hospital mortality
- Diagnoses
  - respiratory distress 58.3%
  - congenital anomaly 21.2%
  - fetal distress 13.9%
  - birth trauma 5.5%

Ref: Gray, et al. *Pediatrics* 1996;97:232

Congenital Malformations

		Hospital Discharges
Congenital heart disease	**11,578**	**10,028**
pulmonary value stenosis	2538	2481
coarctation of aorta	1964	2178
transposition of GV	1642	1415
tetralogy of Fallot	1512	1376
HLHS	949	631
Central nervous system	**1669**	**1298**
spina bifida	1136	1083
Genitourinary	**27,666**	**27,101**
obstructive	13,001	12,848
GI/musculoskeletal	**6838**	**6072**
diaphragmatic hernia	1128	741
gastroschisis	1419	1377
Chromosomal abn	**5920**	**5271**
Total	**60,952**	**56,741**

Ref: Robbins, et al. Nat'l Center on Birth Defects and Developmental Disabilities, CDC MMWR, 2007;56:25

Estimated Annual Statistics

3,500,000 births

- ~ 230,000 NICU admissions
- ~ 60,000 VLBW infants
- > 60,000 congenital malformations
- ~ 185,000 DR ventilation

Ref: National Vital Statistics, Vol 55, April 2007

NICU Discharges

- Preterm infants
- Congenital malformations
- Transitional cardiopulmonary distress
  - ECMO
  - Perinatal asphyxia

Medical Complications

Infants < 1500 g BW

VON 2005

	Severe IVH	CLD	ROP	PVL	None
<1500 g	6 (2,8)	26 (13,31)	40	3 (0,4)	57 (50,68)
501-750	14	64	79	5	19
751-1000	8	14	55	4	41
1001-1250	5	19		3	63
1251-1500	2	9		1	78

Length of Hospital Stay (d)
VON 2005

		Birth weight			
Discharge Status	All	501-750	751-1000	1001-1250	1251-1500
Home	60	93	76	58	38
Died	10	19	1	1	1
All	56	79	70	55	37

VON Annual Statistics, 2005

Discharge issues for Preterm Infants

- Poor growth/nutritional deficiency
- Increased health concerns
- Chronic respiratory disease
- Apnea/SIDS
- Cognitive/motor delays
- Neurosensory disorders
- Emotional/behavioral

Nutritional Concerns for the Preterm

- Poor growth (growth retardation during NICU)
- Specific nutritional problems
  - low bone mineral content
  - iron deficiency
  - protein intake
- Oral feeding skills—? adequate intake

Nutritional Problems of Preterm Infants

- Slow growth
- Short stature
- Micronutrient deficiency
- Delayed oral skills
- GE Reflux

Resources Needed

- Special diets/lactation support
- Nutrient monitoring/ supplements
- Nasogastric feeding
- OT/PT consult
- Antireflux meds, Gastrostomy tube

General Health at 2 Years
ELBW Survivors From 1990s

	ELBW N=163	NBW N=164
Otitis media	84 (52%)	73 (45%)
LRTI*	49 (30%)	13 (8%)
Wheezing*	82 (51%)	25 (15%)
Gastroenteritis	82 (51%)	76 (47%)
Seizures*	11 (7%)	1 (0.5%)
Feeding difficulties*	32 (20%)	5 (3%)

* *P*<.05

From: Doyle, et al. *Seminars in Neonat* 2003;80:137-145
Royal Women's Hospital, Melbourne

Pulmonary Outcome for Preterm Infants

- Infants <1250 g BW, outcome at 1 year
  - ~50% wheezing
  - ~50% bronchodilator
  - ~30% inhaled steroids
  - ~50% rehospitalization
  - 10% persistent O_2 use

  Ref: Hibbs, et al. NO-CLD study. PAS 2007
- Abnormal pulmonary function persists through childhood, preterm with and without BPD

  Ref: Kilbride et al, *J Pediatr* 2003; Vrijlandt et al, *J Pediatr* 2007

Respiratory Problems After Neonatal Intensive Care

Problems

- Wheezing/asthma obstructive airways
- Lower respiratory infection
  - respiratory syncytial virus
- Pulmonary failure
  - cor pulmonale

Resources Needed

- Neonatal supplemental O_2 requirement
- Respiratory monitors
- Bronchodilators, diuretics, steroids
- Nutritional support, cardiology, pulmonology, neurodevelopmental consultants
- Tracheostomy/ventilator

Apnea:

? When to send home, when to monitor

- 68% of 24-26 wk GA infants have apnea >37 wk PMA (Donohue, *Pediatrics* 1997)
- >90% of preterms <1250 g BW continue to have apneic spells (>12 sec) by monitor at discharge (Barrington, *J Pediatr* 1996)
  - 20-fold increase in ALTE for former preterms (Samuels, et al. *J Pediatr* 1994)
  - 20% increased risk of extreme apnea to 43 wk PMA (CHIME study, *JAMA* 2001)

SIDS and Preterm Delivery

Length of gestation is independent risk factor for SIDS

GA (wk)	OR (95% CI)
28-32	2.9 (2.6-3.2)
33-35	2.1 (1.9-2.3)
36-37	1.5 (1.4-1.6)
38-39	1.1 (1.04-1.17)
40-41	Ref
42-44	1.1 (1.03-1.24)

(Halloran, Alexander. *Ann Epidemiol* 2006)

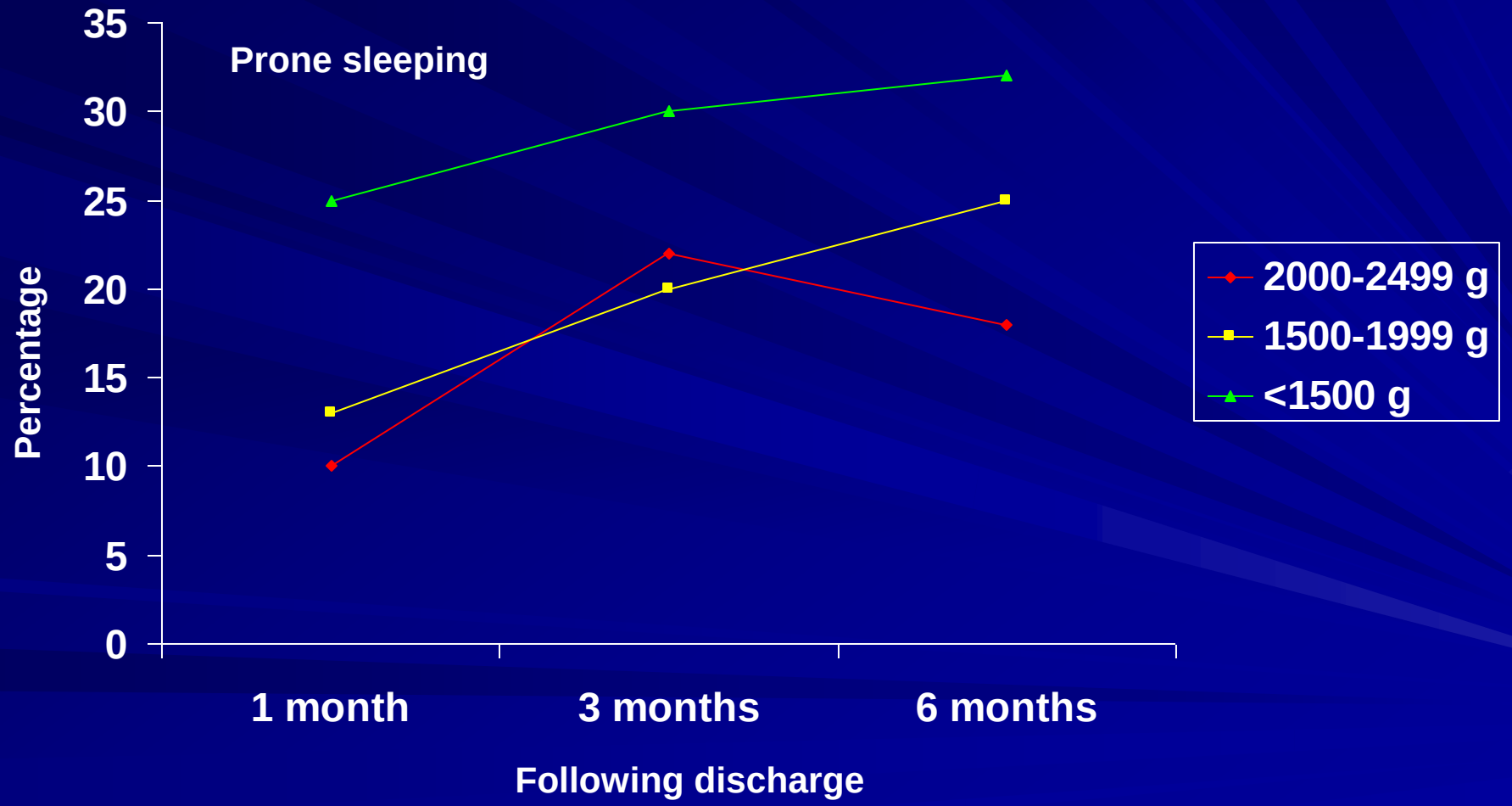
Combined Effect of Sleep Position and GA/BW

	OR for prone
Overall	14 (8.2-24)
<2500 g BW	83 (25-276)
Preterm	49 (19-128)
IUGR	39 (14-108)

(Oyen, et al. *J Pediatr* 1997)

Posthospital Discharge Sleep Position

Low Birth Weight Infants



Vernaccho, et al. *Pediatrics* 2003

Sleep Position Education at Discharge
NICU Surveys

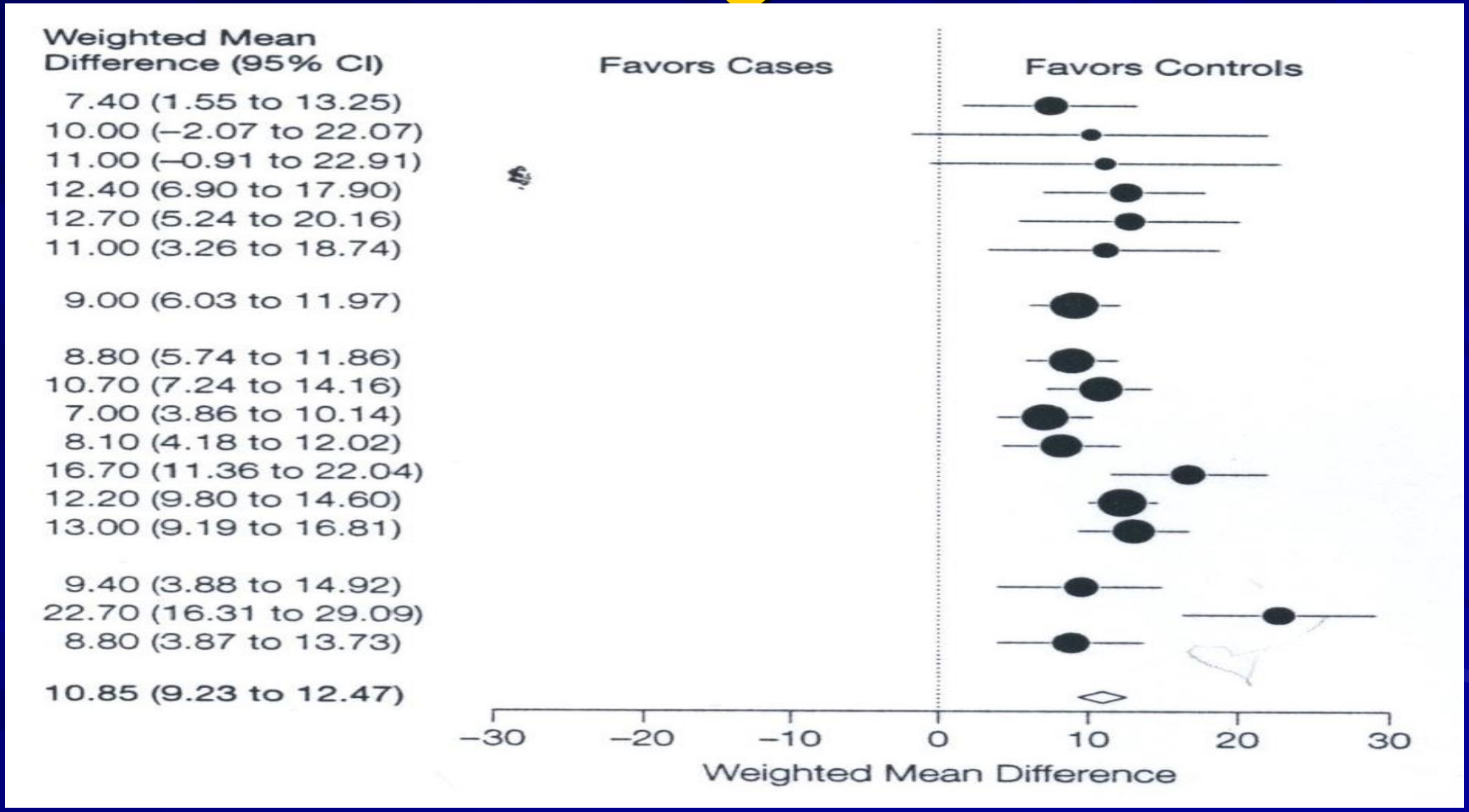
- Lack of clear policies for transitioning preterm infants to supine prior to discharge
- Insufficient parental education regarding sleep position specifically for preterm or NICU infants
- Inadequate education and training for NICU nurses regarding relationship of sleep position and environment with SIDS

REF: Great Britain (Bhat, et al. *Eur J Pediatr* 2003)
Missouri (Bullock, et al. *Am J Mat Child Nurs* 2004)
New York, NICU Nurses (Aris, et al. *Adv Neonatal Care* 2006)

Car Safety Seats for Preterm Infants

- All newborns should be transported in car safety seats (AAP 1990)
- Desaturation/bradycardia spells frequent (12% to 30%)
  - related to GA (increased 30%/wk)
- No apparent difference between car seat and car bed (Salhab, et al. *J Pediatr* 2007)
- Proper fitting remains inconsistent
  - insufficient child passenger safety (CPS) technicians
  - inadequate staff and community education
  - ↓ availability of proper car seats for <2500 g infants
  - more investigation needed

Effect of Preterm Birth on Cognition



Bhutta AT, et al. *JAMA*. 2002;288:728-737

IQ Deficit by Birth Weight

BW	IQ Deficit
≤ 1500 g	-9.4 (1.7)
1501-2000	-7.4 (1.6)
2001-2500	-3.0 (1.0)
>2500	---

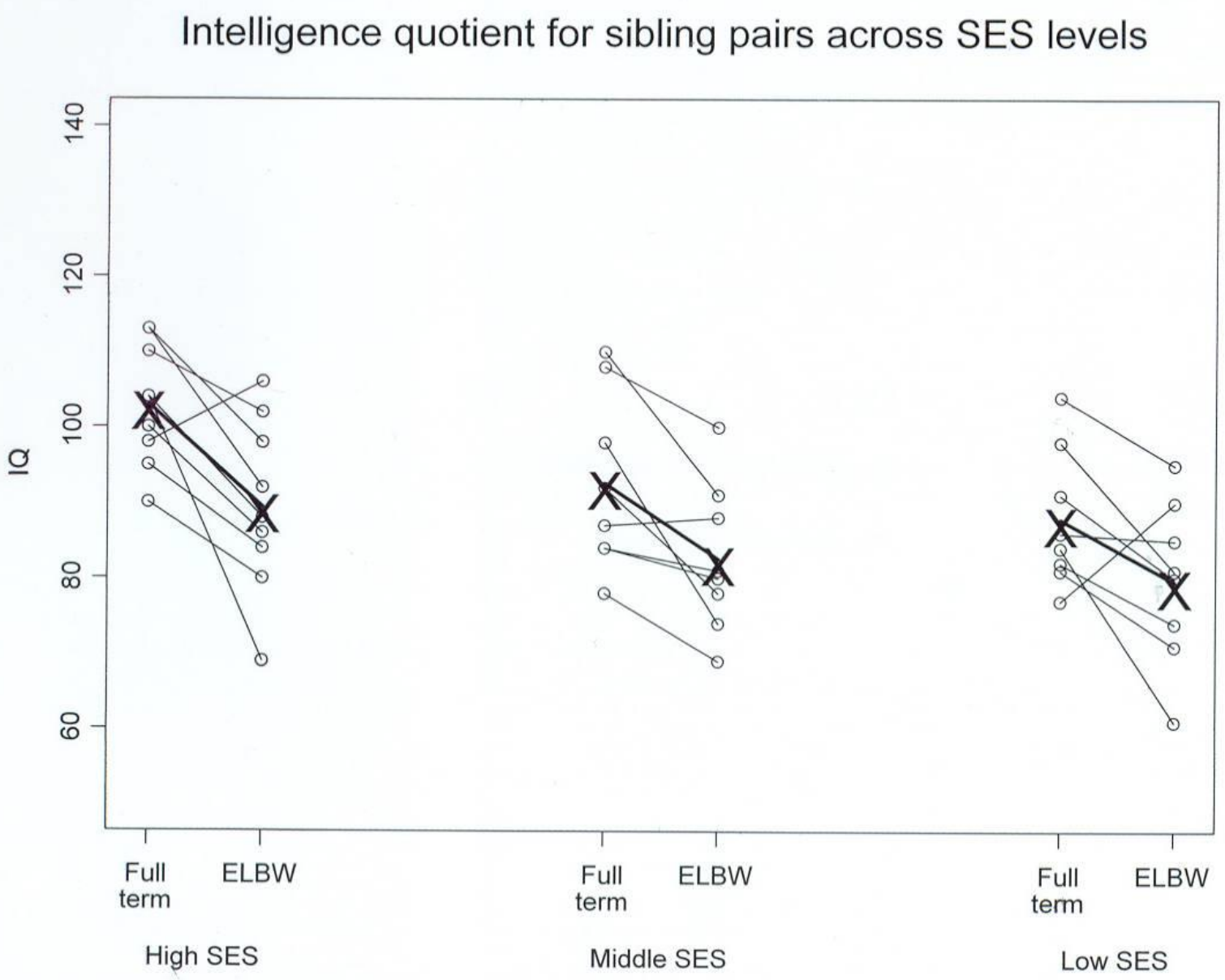
Breslau, et al. *Arch Pediatr Adolesc Med* 1994

Risk Factors for Special Education

	Odds Ratio
Male Gender	1.95
Parent education <12 yr	1.63
BW <2500 g	1.48
Apgar <8	1.44

Infants <2500 g represented 13% of nonorthopedically handicapped special education population

Ref: Andrews, et al. *Am J Prev Med* 1995;11:55



Ref: Kilbride, Thorstad, Daily. *Pediatrics* 2004;113:742-747

Neuromotor Outcome

- **NICHD Neonatal Network**
  Infants 401-1000 g BW
  18 to 22 months of age (Ref: Vohr, et al. *Pediatrics* 2004):

Cerebral Palsy	17%	(6-30)
PDI <70	26%	(8-44)

- **Epicure Study**
  Infants < 26 wk GA, 6 years of age (ref: *NEJM*, 2005):

Cerebral palsy	13%
Abnormal neuromotor	24%

6-Year Follow-up for < 26 Wks GA

Epicure Study, *NEJM* 2005

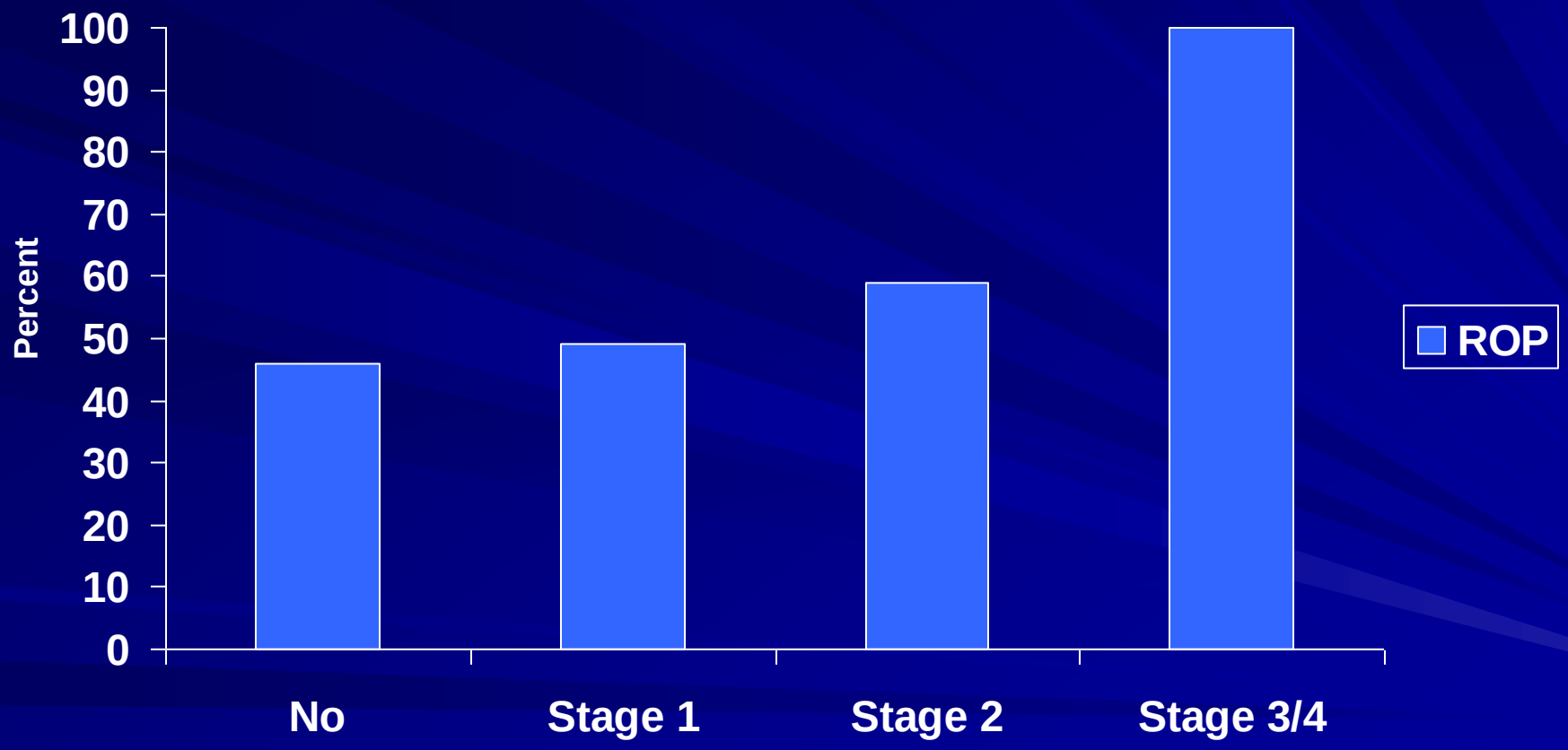
DISABILITY	≤ 23 Wk	24 Wk	25 Wk	TOTAL
NONE	12%	14%	4 %	20 %
MILD	25%	36%	35%	34%
MODERATE	38%	22%	22%	24%
SEVERE	25%	29%	18%	22%

Behavioral Effects of Prematurity

- Infants: less adaptable, less persistent, more withdrawn. Increased risk of ADHD
- Emotional/anxiety disorders
  - variable reports
- Conduct problems
  - related to neurologic risk
  - additional environmental effects
- Lower level of social competence

Ophthalmic Morbidity at 10 to 12 Years of Age for Children Born <1701 g BW

Ref: O'Connor AR, et al. *Pediatrics* 2002;109:12



Morbidity defined as below normal visual acuity, strabismus, myopic, color vision defect, or visual field defect

Audiology Follow-up

- Newborn hearing loss

  1-2/1000 LBs

- NICU patients

  20-40/1000 admissions

Year 2000 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs

Pediatrics 2000;106:798

- Establish universal newborn hearing screening program
- Target: bilateral or unilateral sensory or conductive hearing loss, >30-40 db in speech recognition frequency range (500-4000 Hz)
- Goal: early intervention (prior to 6 mo)

Infants With Delayed Onset Hearing Loss (after passing newborn screen)

Risk Factors

- Caregiver concern
- Family history
- Stigmata of syndrome known to include hearing loss or those with progressive loss (neurofibromatosis)
- Postnatal infections (meningitis)
- In utero infections (CMV)
- Head trauma
- Persistent OME
- **Neonatal complications**
  - **Hyperbilirubinemia at level requiring exchange transfusion**
  - **PPHN**
  - **ECMO**

Ref: JCIH, *Pediatrics* 2000

Functional Attributes of NICU Graduates by Gestational Age

Problem	GA weeks				*P* value
	<27	28-32	33-37	>37	
Sight	18.8	4.4	2.7	5.1	<.001
Getting around	26.5	10.0	5.9	12.9	<.001
Using hands	16.7	4.0	4.1	11.7	<.001
Taking care of self	34.7	25.8	15.6	20.8	.003
Learning	22.4	12.6	8.4	11.0	.023

(Ref: Klassen, et al. *Pediatrics* 2004;113:994)

Severe Neurological Impairment Following NICU

- Diagnoses
  - cerebral malformations
  - severe perinatal asphyxia
  - metabolic disorders
  - bacterial meningitis
  - S/P ELBW (PVL)
- Postdischarge concerns
  - feeding/GER: need for GT/fundoplication
  - seizures
  - tone/irritability/sleep
  - life expectancy
  - shortened survival related to multiple disabilities (Hutton, 1994; Strauss, 1998)
  - family support

Neurodevelopmental Risks for Term Infants Following NICU Hospitalization

- Congenital heart disease
  - 20% to 30% motor/mental delay (Robertson. *J Pediatr* 2004)
- ECMO (Kirshbom, et al. *J Thor Cardiovasc Sci 2005*)
  - abnormal neuroimaging 30% to 50%
  - functional delay 20% to 30%
- Congenital diaphragmatic hernia
  - <50% neurologically normal
  - >40% GER, feeding problems
  - 40% BPD
- CHD/ECMO
  - 50% abnormal cognitive
  - 25% abnormal neuromotor (Hamrick, *Pediatrics* 2003)
- S/P surgery

Systems of Care for Children With Special Health Care Needs (CSHCN)

Healthy People 2000 Objectives

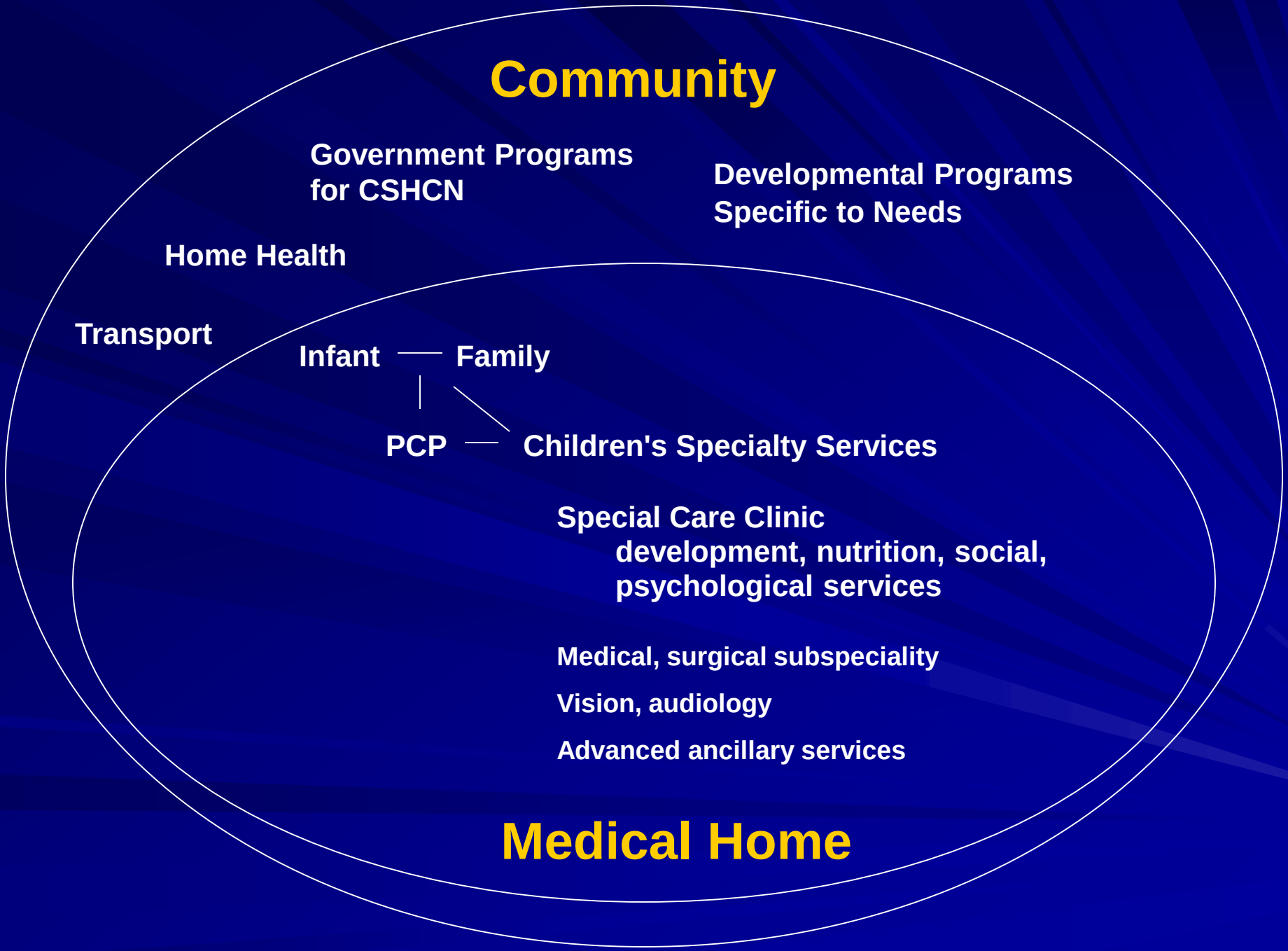
- Families and providers work as partners
- Children have access to ongoing, comprehensive health care through a *medical home*
- Children and families have adequate sources of funding
- Children are screened early and continuously for special health care needs and receive early intervention
- Community services are organized so families can use them easily
- Youth receive services to transition to adult health care, work, and independence

Ref: US Dept of Health & Human services, Healthy People 2000, Conf ed, Wash, DC

Medical Home

- **Accessible** — no financial or geographic limits
- **Family-centered** — physician knows family and has trust relationship
- **Continuity** — same providers available through childhood
- **Comprehensive** — preventative, acute, and chronic care
- **Coordinated** — POC developed, coordinated with other providers, community services; uniform database
- **Compassionate** — concern for well-being of child
- **Culturally effective** — sensitive to family's cultural beliefs

Ref: *Pediatrics*, 2002; 110:184


Community
Government Programs for CSHCN
Developmental Programs Specific to Needs
Home Health
Transport
Infant
Family
PCP
Children's Specialty Services
Special Care Clinic
development, nutrition, social, psychological services
Medical, surgical subspeciality
Vision, audiology
Advanced ancillary services
Medical Home

NICU Outcome: Importance of Parent-Infant Bond

- The infant
  - medically fragile
  - immature arousal, self-regulation
  - inattentive
  - irritable, less predictable sleep patterns
- Parents
  - separated, isolated
  - loss of control
  - grief reactions
  - "posttraumatic stress disorder"
- Developmental care (Als, et al. *JAMA* 1994)
  - professional alliance which supports parent and child
    - reduce stress
    - support parental engagement
    - improve outcome

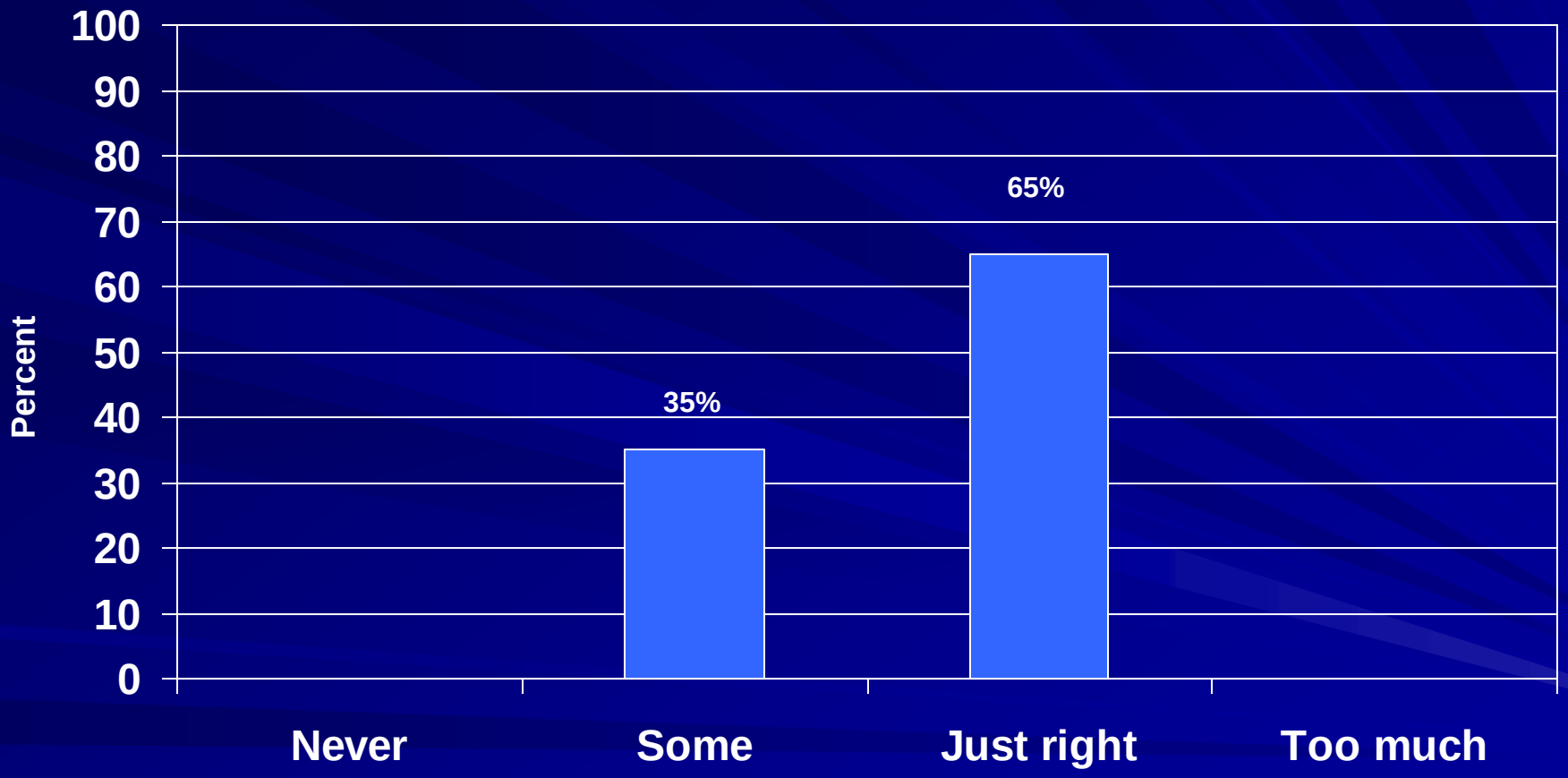
Neonatal Risk Factors	Postdischarge Environment	Functional Outcome
• Anatomical • Physiologic • Maturational	• Poverty • Maternal Health • Family Stability • Parental education • Drug use/ smoking • Maternal emotional state	• Cognitive language visual motor • Growth • Behavior • Emotional stability

Modified from McCormick, *Pediatrics* 1997

Recommendations to Enhance Transition to Home From NICU

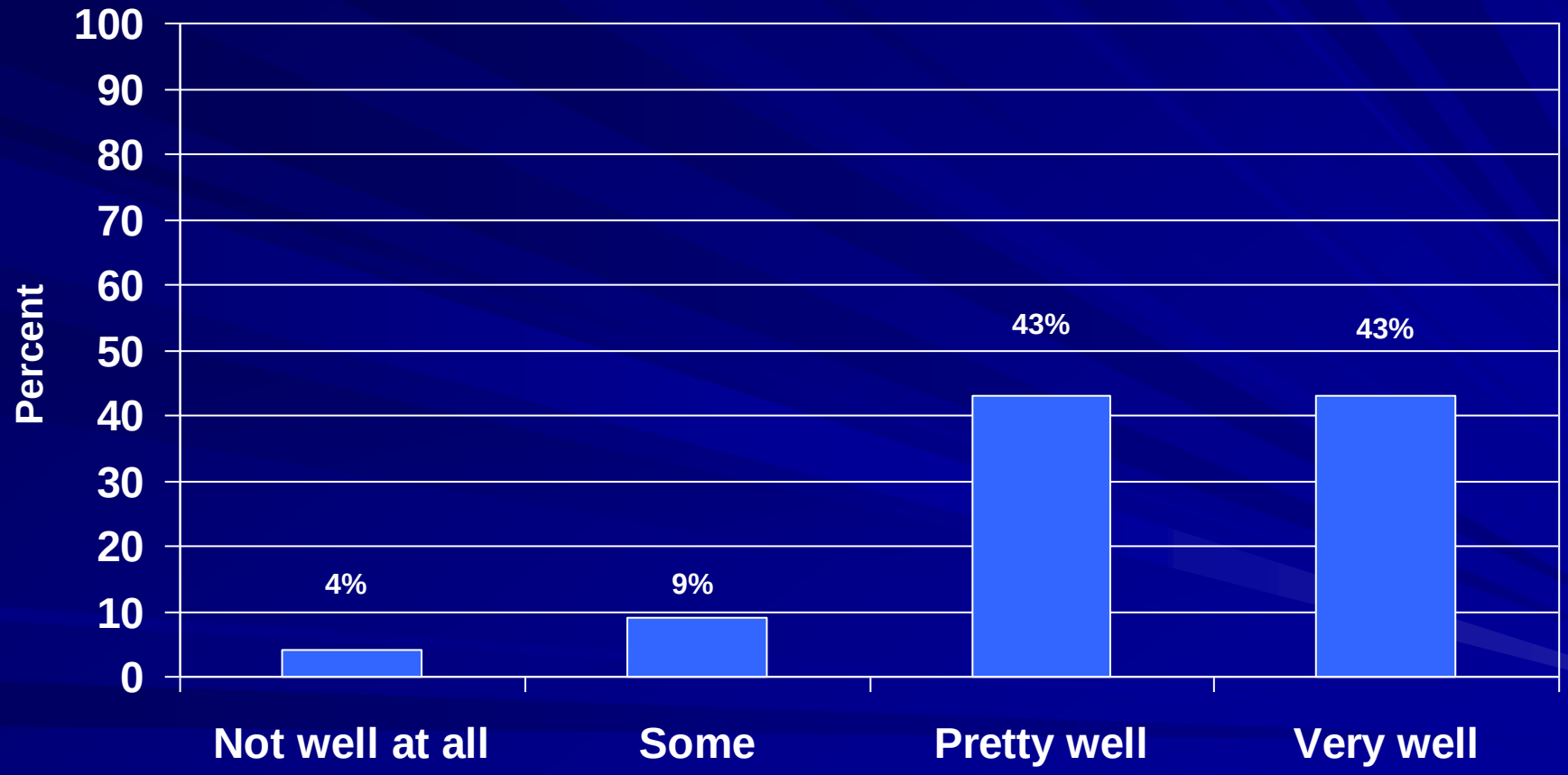
- Parent communication
  - establish criteria for discharge, known to parents
  - psychosocial assessment
  - two-way communication
    - parent-driven education
  - emergency plan with parents
  - follow-up telephone calls
- PCP communication
  - PCP visit in hospital
  - standard data tool ("hand off" tool)
- Community education
  - PCP education program
  - home health nurse training
- Follow-up
  - parents as advisors
  - parent survey

Make Decisions About Baby's Care



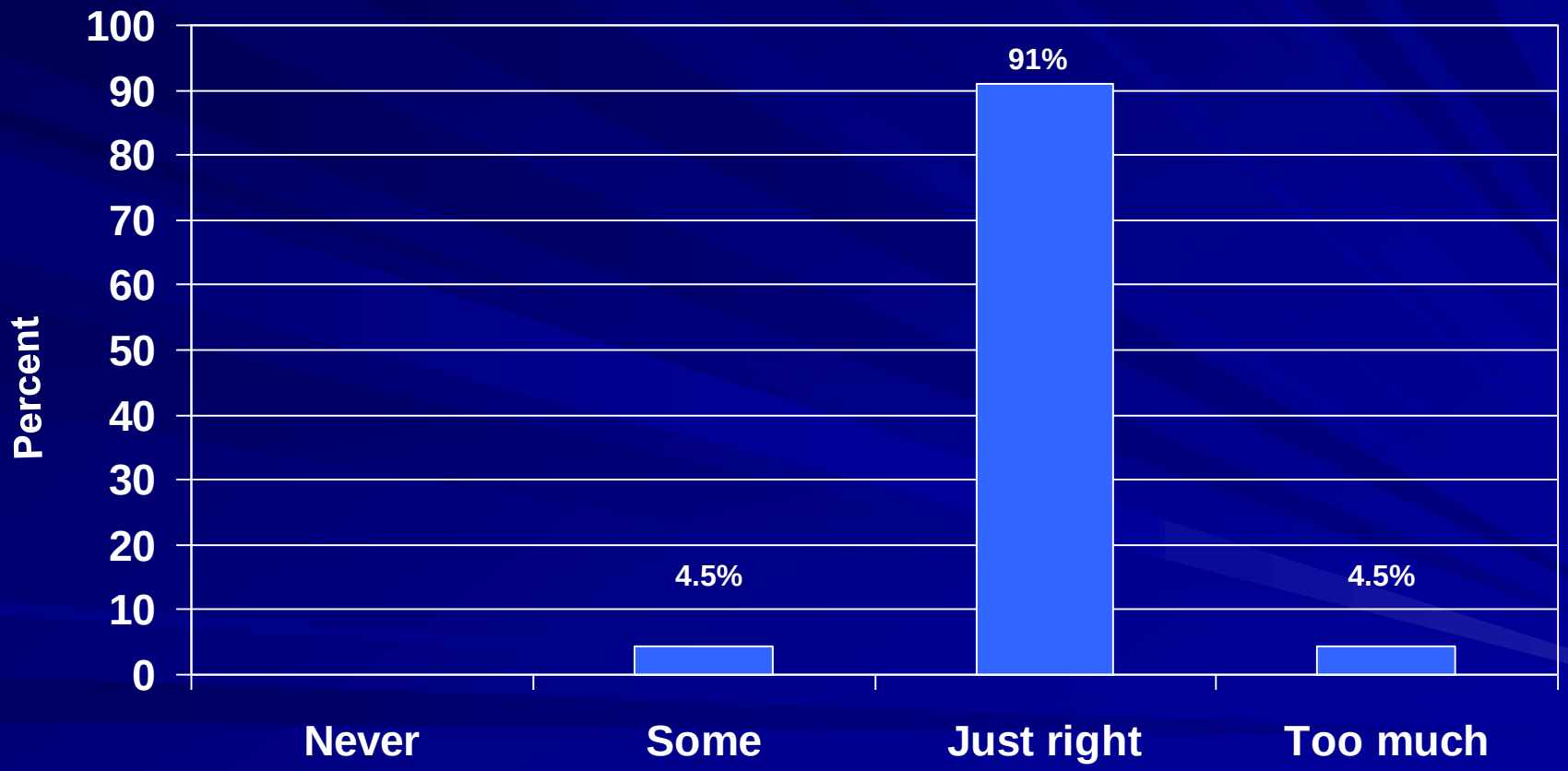
Edwards W, et al. and Vermont Oxford Network Collaborative

How Well Do You Know Your Baby?



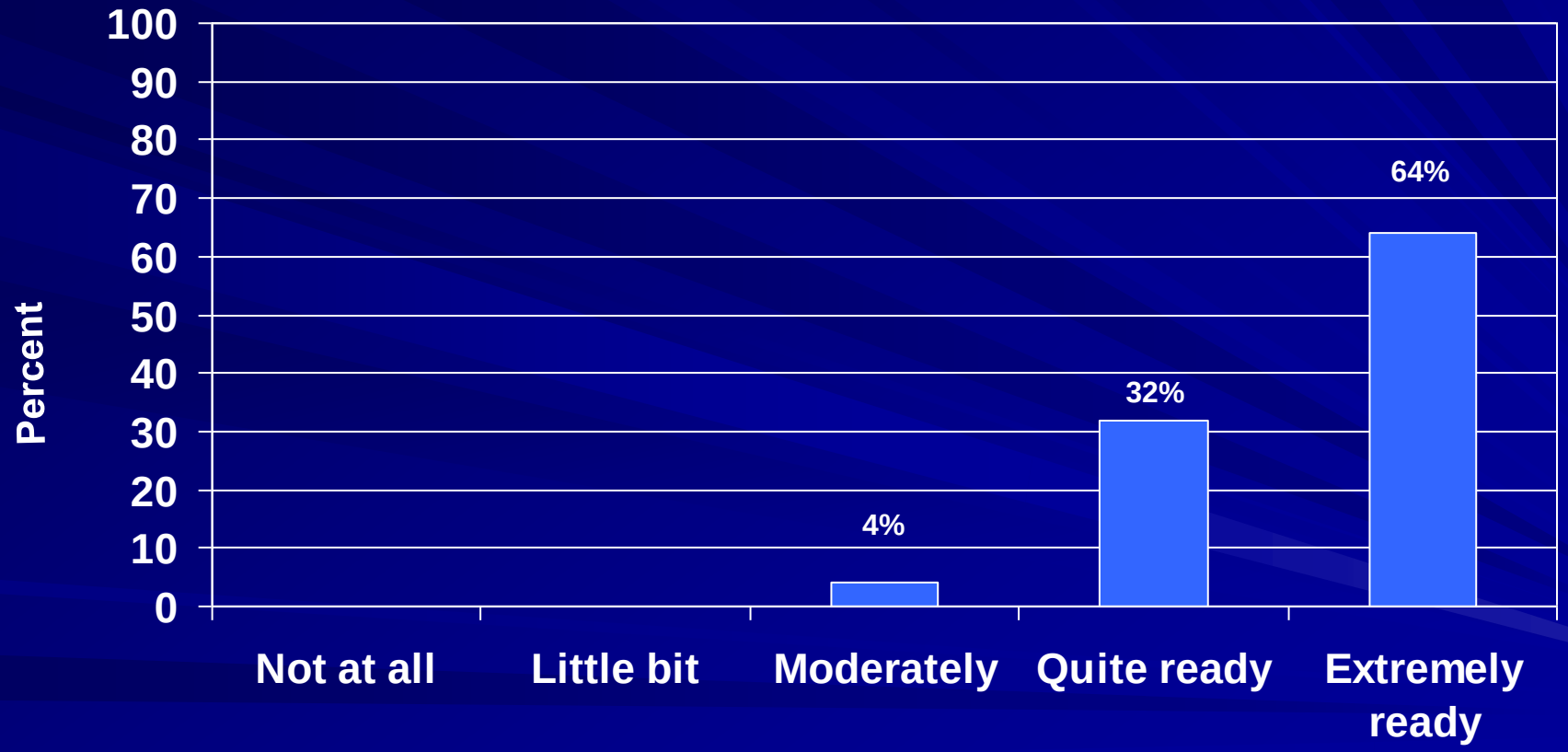
Edwards W, et al. and Vermont Oxford Network Collaborative

Participate in Baby's Care



Edwards W, et al. and Vermont Oxford Network Collaborative

Care for Baby Postdischarge



Edwards W, et al. and Vermont Oxford Network Collaborative

"A girl with a birth weight of 280 g, now 14 years old"

Letter to Ed. *NEJM* 2004;351:836-837