# **Disclosures**

• **Dr. Hussey-Gardner** receives funding from the Baltimore City Infants & Toddlers Program (BITP) to support Maryland's PRIDE. In addition, she received funding from the Maryland State Department of Education (MSDE) to develop web-based learning modules related to prematurity. Finally, she received honorariums for presentations related to prematurity that she provided to local jurisdictions in Maryland. Dr. Hussey-Gardner is the Chair of Maryland's SICC.

• None of the author presenters have disclosures to make.

### **Prematurity and Low Birth Weight**

Understanding the Need & Implementing Early Intervention: A Local, State & National Perspective

University of Maryland School of Medicine Brenda Hussey-Gardner, Ph.D., M.P.H. Baltimore City Infants & Toddlers Program Gloria Valentine, M.S. Maryland State Department of Education Pamela Miller, Ed.D. Center for IDEA Early Childhood Data Systems Donna Spiker, Ph.D.













### **Outcomes**

To understand prematurity, associated developmental delays and the benefits of intervening early.

To become familiar with one model of collaboration between a NICU and a local Part C program, along with the impact of this model on program outcomes.

To consider the implications of serving this population at the State level.

To become aware of the draft potential DEC Position Statement on LBW.

Brenda Hussey-Gardner, Ph.D., M.P.H. Associate Professor of Pediatrics University of Maryland School of Medicine

### LOW BIRTH WEIGHT, PREMATURITY & **EARLY INTERVENTION: OVERVIEW**





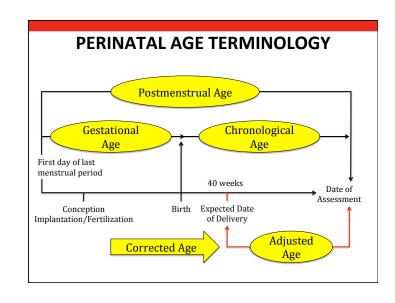


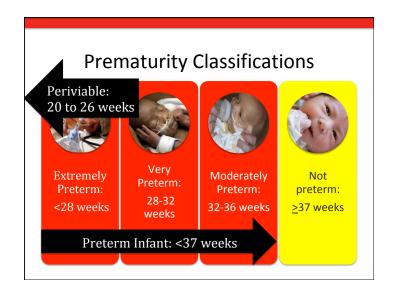


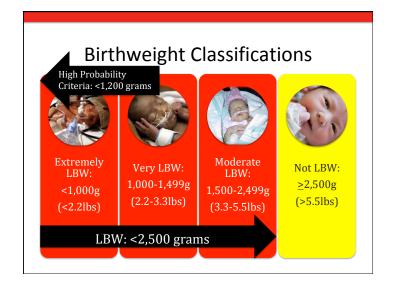




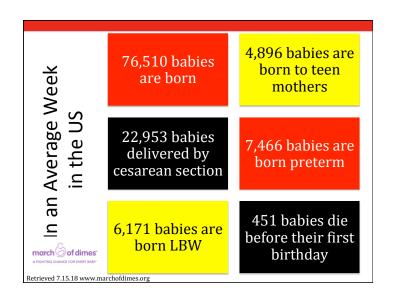


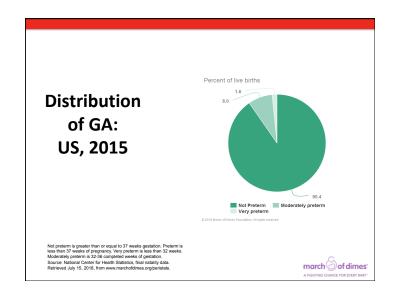


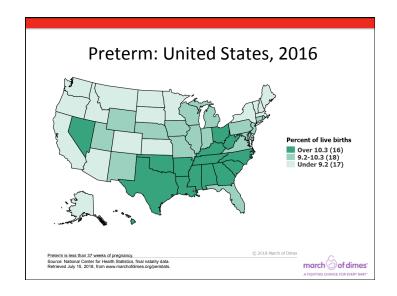


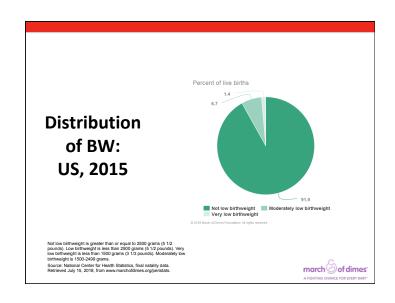


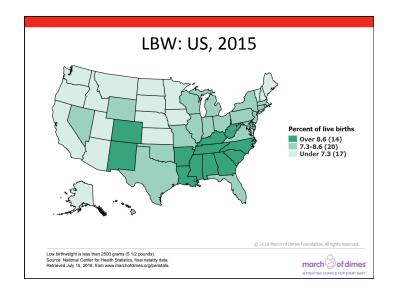


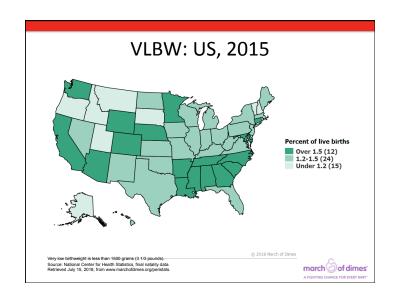


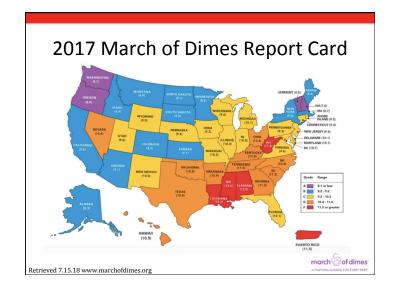


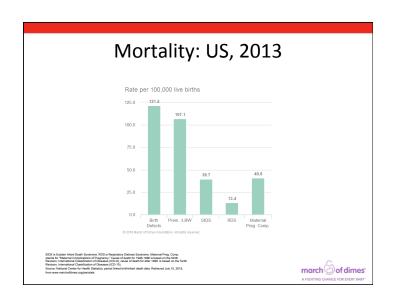




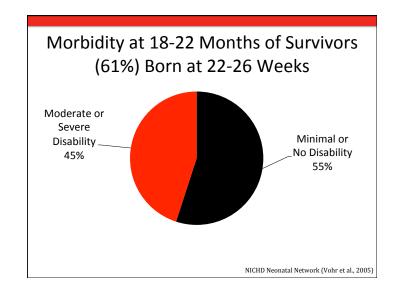


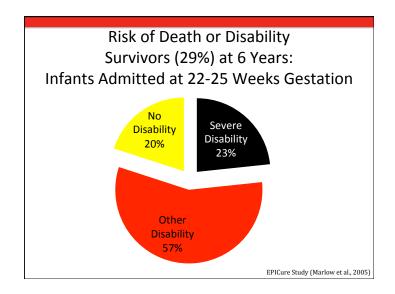












### Delays Associated with Prematurity & LBW

- Expressive and receptive language (Barre, Morgan, Doyle, & Anderson, 2011)
- Cognition and later school achievement (e.g. reading and math, grade retention, placement in special education) (Hack, Klein, & Taylor, 1995; Klebanov, Brooks-Gunn, & McCormick, 1994)
- Executive functioning (Zelazo, Blair, & Willoughby, 2016)
- Social-emotional development (Mathewson, et al., 2017; Msall & Park, 2008; Institute of Medicine, 2007; Bhutta, et al., 2002; National Research Council and Institute of Medicine, 2000)
- Motor development (Vohr et al., 2005)
- Vision & hearing impairments (Vohr et al., 2005)

### **Promising Review of Outcome**

- Premature birth incidence & survival rates increasing due to advances in obstetric & neonatal intensive care
- Those born at limits of viability at high-risk of adverse neurocognitive function
- Data from earlier generation cohorts, born in substantially different eras, cannot be relied on to predict outcome today
- Review, by birth cohort year, shows a changing developmental trajectory in which today's extremely preterm survivor likely to have fewer severe medical complications, better neurological outcomes & fewer adverse cognitive effects

(Baron & Rey-Casserly, 2010)

# Evidence of Benefits of EI: Infant Health and Development Program (IHDP)

### First Multi-Site RCT

- Effect of early childhood development and family support services with pediatric follow-up
- · Preterm & LBW infants

### Intervention

- Year 1: weekly home visits
- Years 2 & 3: monthly home visits, full-time center-based educational program & family support

### Outcomes at 36 Months

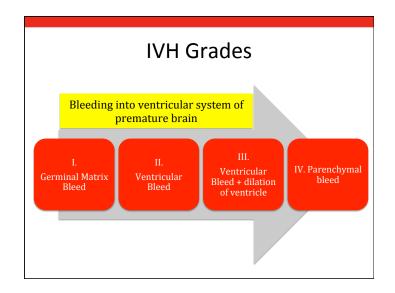
- · Significantly higher IQ scores
- Significantly lower behavior problems
- · Significant increase in maternally reported minor morbidity
- No evidence of increase in serious health problems

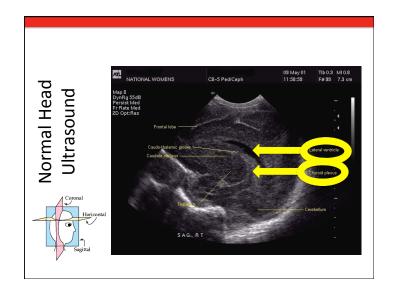
(Gross, Spiker, & Haynes, 1997; Mallik & Spiker, 2016)

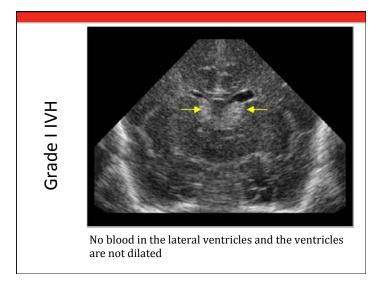


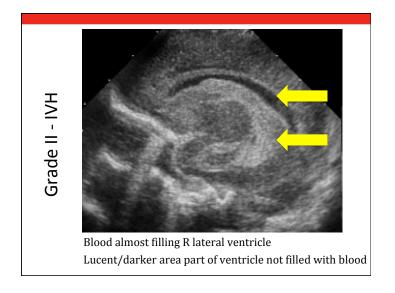
Medical Conditions Associated with Prematurity

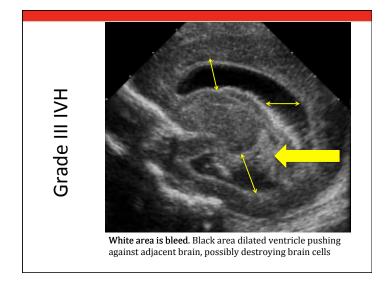
Intraventricular Hemorrhage **IVH** 

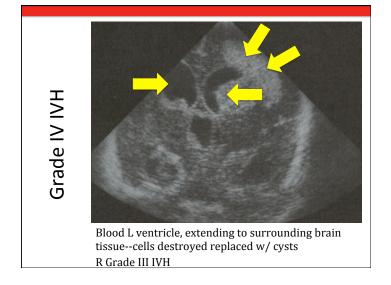






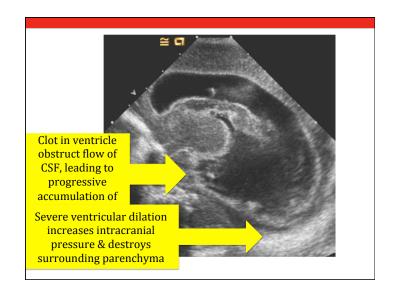


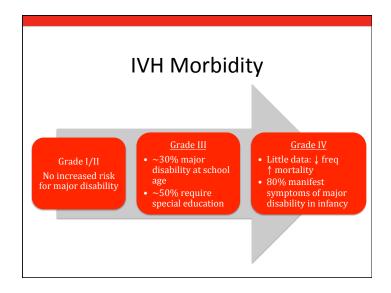




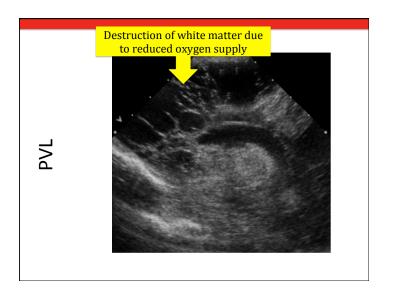
Post Hemorrhagic Hydrocephalus

PHH





Periventricular Leukomalacia **PVL** 



### **Chronic Lung Disease**

(Also known as BPD: Bronchopulmonary Dysplasia)

### **CLD**

**Necrotizing Enterocolitis** 

## **NEC**

### CLD

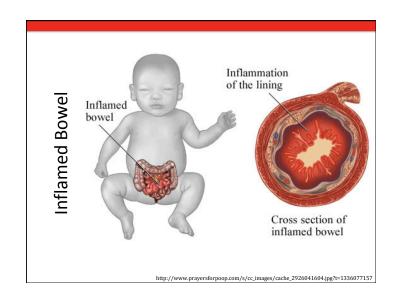
- Need for oxygen on DOL #28
- Need for oxygen at 36 weeks PCA



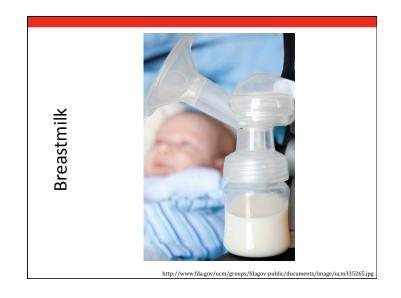


Normal lung x-ray

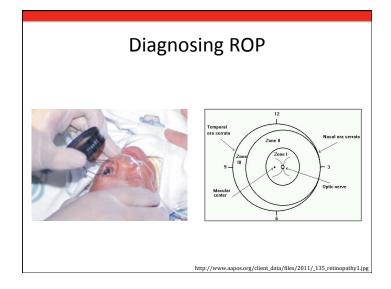
X-ray depicting CLD

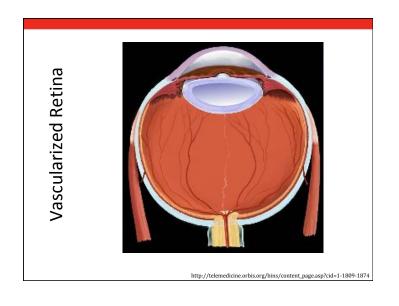


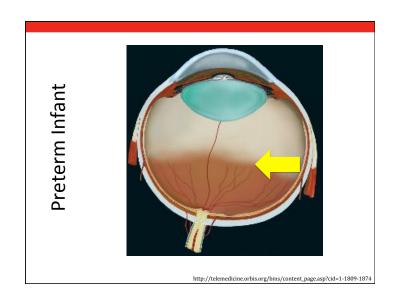


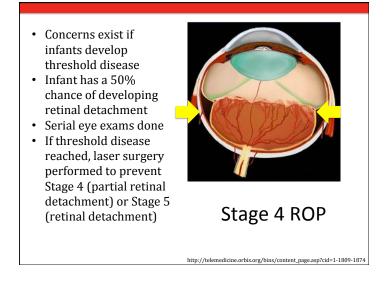


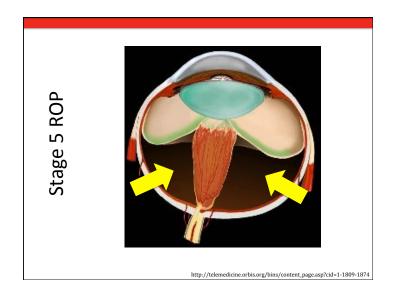
Retinopathy of Prematurity **ROP** 











# Outcomes Strabismus Crossed Eyes Amblyopia Lazy eye Myopia Nearsightedness Thinning of the retina Retinal tears Glaucoma Can result in hardening of eyeball & loss of vision Visual field loss Reduction in contrast sensitivity Nystagmus Involuntary movement side to side

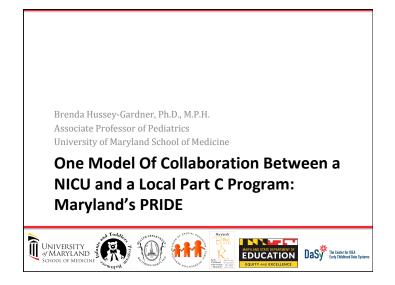
Hypoxic Ischemic Encepalopathy

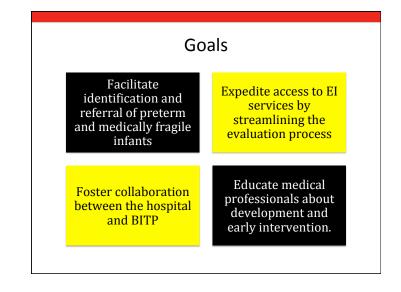
HIE

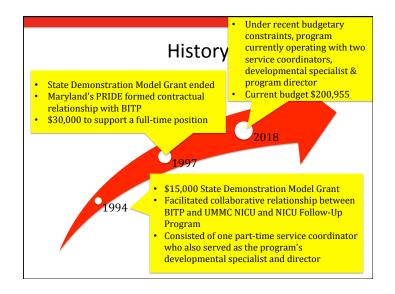
### HIE: Diagnosis

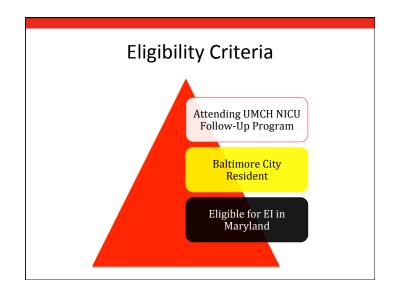
- Profound metabolic acidosis
- Apgar 0-3 for > 5 minutes
- Neonatal neurologic manifestations (seizures, coma, hypotonia)
- Multi system organ dysfunction (CV, GI, renal)

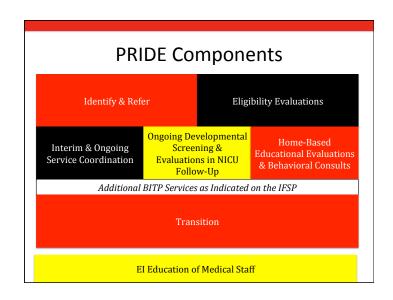




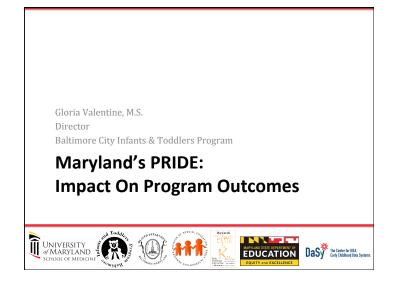


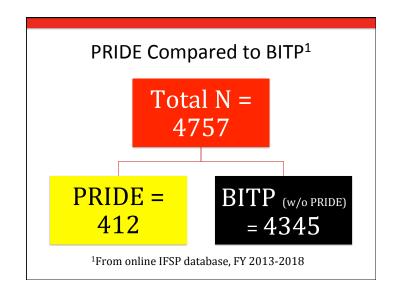


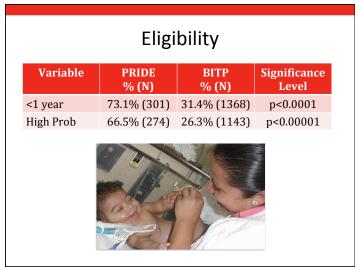


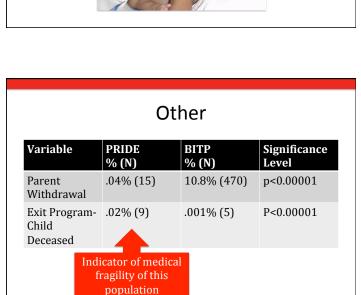












### Eligibility Age at Referral **PRIDE** Significance **BITP** (Mean) Level (Mean) Overall 8.39 mos 17.28 mos p<0.0001 High Prob 4.82 mos 9.93 mos P<0.0001 25% Delay 18.27 mos 20.67 mos P<0.0037 P<0.0002 Atypical Dev 8.44 mos 14.93 mos

### Service Coordination an Important Key

Service coordinators in the NICU develop a relationship with families

Allows interventions and supports as soon as needs arise

Equips families to provide care for their child and have the resources they need to participate in their own desired family outcomes

### Pediatric faculty Professional Pediatric residents presentations at Neonatology fellows University of NICU nurses **Collaborative Benefit:** Marvland School of Medical and genetic Medicine **Public Awareness** counselors University of Maryland Family NICU Presentations Mercy NICU · University of Maryland Mercy Pediatric Grand • Johns Hopkins Rounds · St. Agnes • Sinai

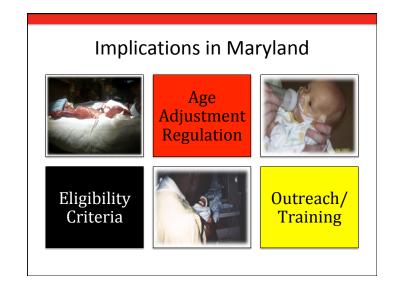
### **Funding & Sustainability**

Utilize developmental evaluations conducted as part of routine care in UM NICU or NICU Follow-Up Program

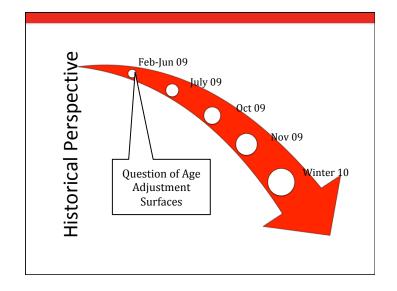
MA billing for reimbursement offers a way to provide additional support & sustainable funding through unpredictable funding environments

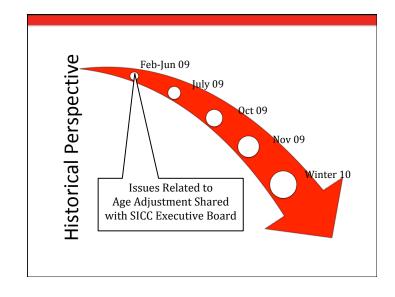
Collaborative partnership offers "in-kind" supports that help sustain the program

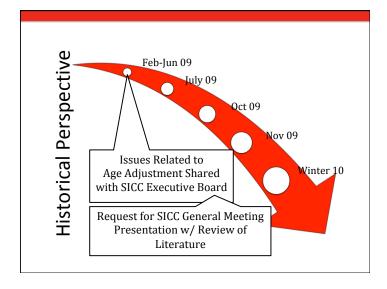


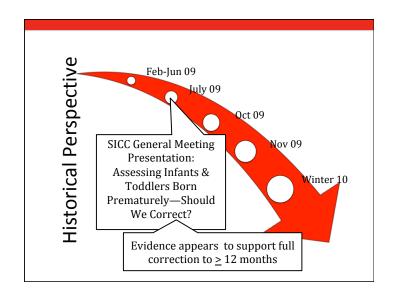


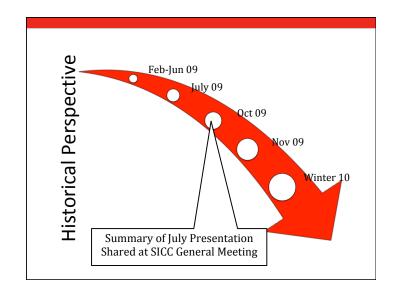


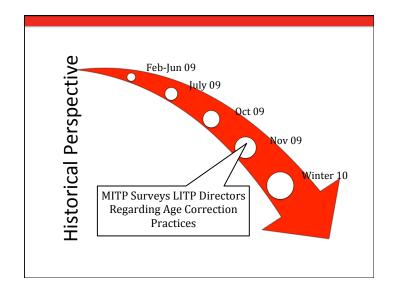


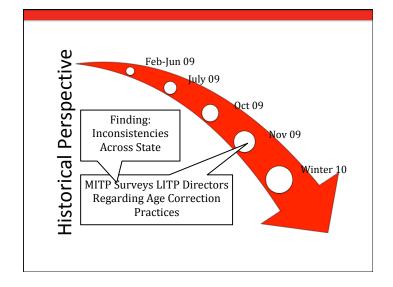


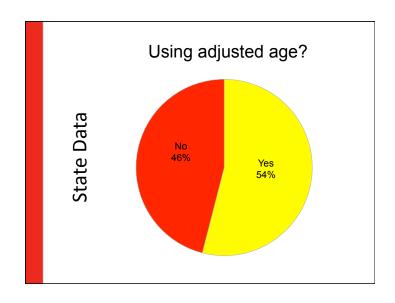


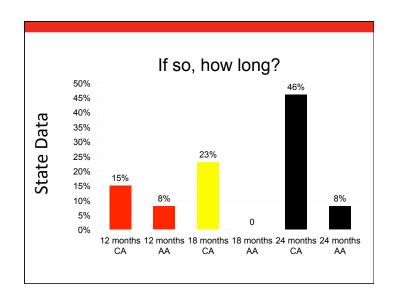


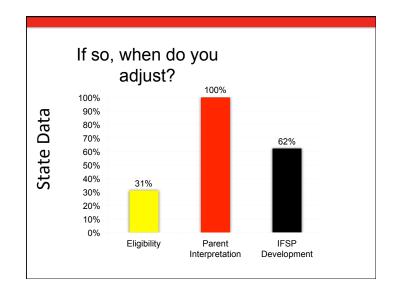


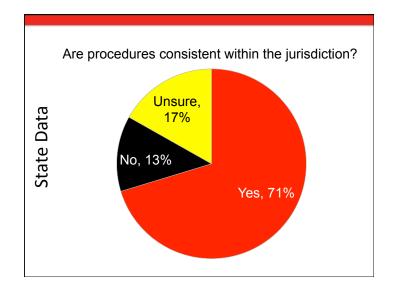


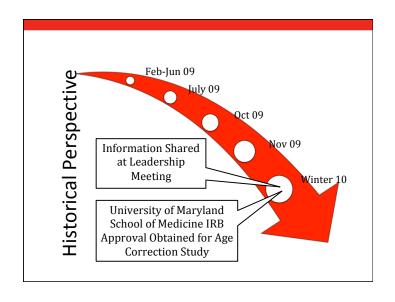


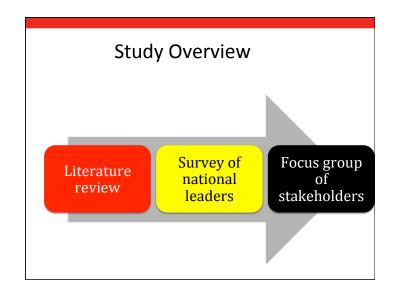


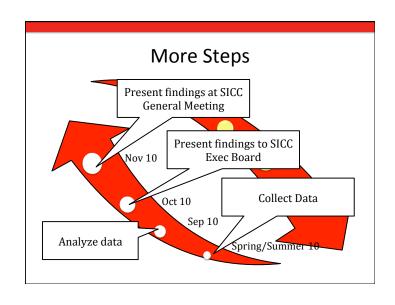


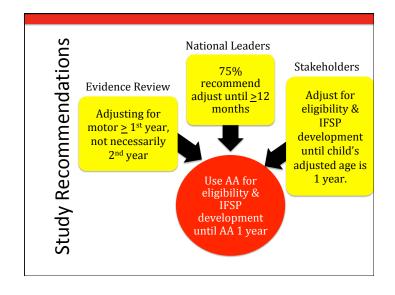












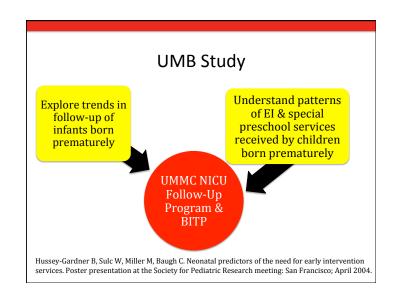
### **Public Comment**

- 16 of 25 public comments mentioned adjusting for prematurity
  - 15 recommended using adjusted age:
    - Families, including parents, grandparents, etc. (7)
    - Citizens (4)
    - Hospital Representatives (1)
    - Private Agency (1)
    - Service Coordinator for an LITP (1)
    - SICC (1)
  - 1 Public Agency simply requested consistency in State

**Eligibility Criteria** 

# Adjusted Age for Prematurity COMAR 13A.13.01.03B(2) and (12)(a)

- (2) "Adjusted Age" means, for children born before 37 weeks gestation, the number of weeks born prematurely subtracted from the infant's chronological age. An infant's adjusted age is used until the infant's adjust age is twelve months.
- (12) "Developmental Delay" means the presence of:
  - (a) A 25 percent delay, using a child's <u>adjusted</u> or chronological age, and as measured and verified by appropriate diagnostic instruments and procedures, in one or more of the following developmental areas:
    - (i) Cognitive development,
    - (ii) Physical development, including vision and hearing,
    - (iii) Communication development,
    - (iv) Social or emotional development, or
    - (v) Adaptive development;



### Method

- Retrospective reviews UMMC NICU Follow-up Clinic's & BITP databases
  - All infants born in 1997, 1998, 1999
  - Baltimore City residents
  - Gestational age < 37 weeks
  - Referred to UMMC NICU Follow-up Clinic
- 154 followed until age 3 years

### **Diagnoses Correlated with Specific Services**

	Any	PT	ОТ	SI	SLP
CLD	.254**	.182**	.194**	.186**	.162**
РНН	.002	.061	.124*	.129*	079
Hypothyroidism	.152*	.045	.054	.083	.156*
IVH III-IV	.245**	.239**	.230**	.101	.144*
SNEC	.151*	.144*	.180**	.116	.178**
PVL	.085	.089	.183**	.192**	.105
ROP	.259**	.238**	.234**	.166**	.157**
Seizures	.088	.122*	.061	038	053
Tone Abnormal	.087*	.132*	.105	.041	.081

\*Significant at the .05 level. \*\* Significant at the .01 level.

### Diagnoses Predicting Services, Above & Beyond Birthweight (<1200g)

	Any	PT	ОТ	SI	SLP
CLD	X		X		
PHH				X	
IVH III-IV	X	X	X		
SNEC			X		X
PVL			X	X	
ROP		X	X		
Seizures		X			
Tone Abnormal	X	Х			

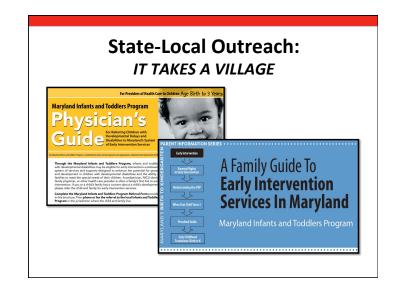
X denotes multiple regression significant at p < .05.

### Conclusions

MITP inclusion of high probability conditions as eligibility criteria is supported by results of this study

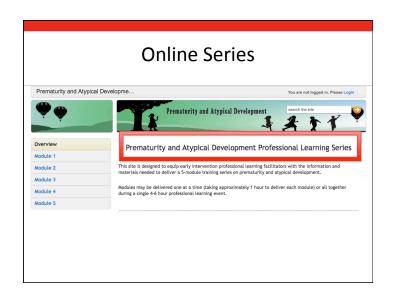
CLD & SNEC was added to existing eligibility criteria

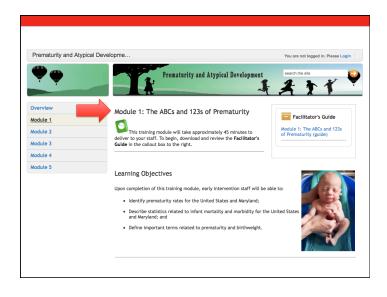
### **OUTREACH EFFORTS**

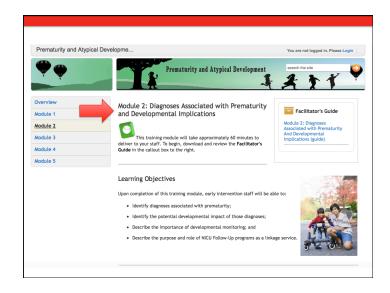


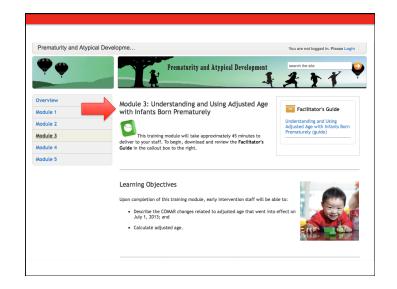
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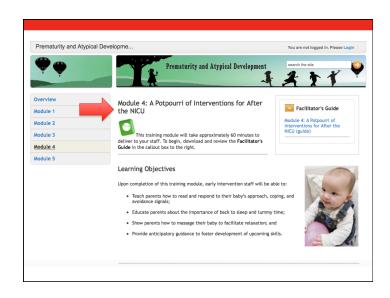
TRAINING & WEB-BASED TUTORIALS



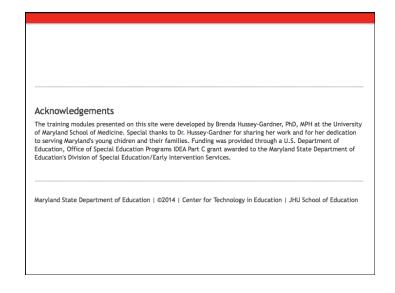














Brenda Hussey-Gardner, Ph.D., M.P.H. Associate Professor of Pediatrics University of Maryland School of Medicine

### **LESSONS LEARNED**











A Video Montage

### PERSPECTIVES OF STAKEHOLDERS

### **Lessons Learned**

Don't wait until delays are present

Establish statewide high probability conditions related to prematurity

Implement statewide age correction policy

Determine strategies to identify and refer in the NICU

Importance of collaboration between NICU and NICU Follow-Up and early intervention program

Value of on-site service coordination

Essential to educate medical staff, fellows, residents, nurses and other medical team members

Donna Spiker, Ph.D.

Center for IDEA Early Childhood Data Systems

### **Draft Potential DEC Position Statement on Low Birthweight**















### Purpose of the potential statement....

- \* This is a product of DEC in draft form.
- \* It is about the identification and eligibility for Part C early intervention (EI) services of children born low birth weight (LBW) and/or preterm in the United States.





### **Development process**

- \* DEC position statement workgroup made up of DEC members who are mainly researchers and EI TA providers who began work to develop the statement by reviewing literature on:
  - LBW development and health and
  - effects of early intervention on LBW.
- ★ Workgroup followed DEC guidelines: <a href="https://www.decdocs.org/position-statement-guidelines">https://www.decdocs.org/position-statement-guidelines</a>



### **Development process (cont)**

- Draft potential statement put out for DEC member and partner review.
- \* Workgroup is revising draft statement.
- Draft potential statement is now pending review and approval by DEC Executive Board.





### Workgroup members included.....

- \* Patricia Blascoe, Chair
- \* Serra Acar
- \* Kristi Atkins
- \* Evelyn Foard Shaw
- \* Jane D. Smith
- \* Donna Spiker
- ★ Jane Squires



### **LBW terminology**

- ★ LBW = < 2500 grams or 5.5 pounds (about 10% of population)</p>
  - very low birth weight (VLBW) = <1500 grams</p>
  - extremely low birth weight (ELBW) = < 1000 grams
- Preterm birth is defined as <37 weeks gestation of a 40-week pregnancy</p>
  - moderate to late preterm = 32 to <37 gestational weeks
  - very preterm = 28 to <32 gestational weeks</p>
  - extremely preterm =< 28 weeks</p>





### What did literature say about LBW?

- \* Able to keep smaller and smaller and earlier gestation infants alive.
- \* Many LBW spend 2-6 weeks in NICU.
- \* Parents experience stress and uncertainty and need support during the transition home.





# What did literature say about LBW? (cont)

- \* Medical and health conditions in first year of life and can continue to later ages.
- \* Many show early difficulties with:
  - motor development including oral-motor difficulties
  - language acquisition, processing, and communication
  - engagement (e.g., exploration, initiative),
  - emotional regulation (e.g., persistence, frustration, competence),
  - social-emotional competence (e.g., joint attention, imitation/play, empathy, prosocial behaviors)



# What is known about LBW in Part C eligibility definitions?

- \* The criteria used to define LBW as a condition for eligibility varies greatly from state to state.
- Only a few states include prematurity as a diagnosed condition to be considered for automatic EI eligibility.



# What is known about LBW in Part C eligibility definitions? (cont)

- For most states, LBW infants need to have a significant medical condition or demonstrate observable developmental delays before being eligible for Part C early intervention services.
  - In assessing El eligibility, the use of corrected age (i.e., age the child would be if they had been born on their due date) may overestimate their abilities.





### Conclusions about LBW eligibility

- \* There is abundant evidence that this is a population at high risk for poor outcomes and the origins of their poor outcomes begin prenatally and in infancy.
- \* The costs of the poor health, learning, behaviors, school achievement, and long-term life outcomes of LBW and/or preterm are substantial.
- \* These data support identifying and providing El services early on to reduce the long-term costs and poor outcomes.



# DEC product in draft form recommends that.....

- LBW and/or preterm should be considered an established condition to automatically make an infant eligible to receive EI services.
- \* There is no need to wait to provide El services until full blown delays and functional deficits are present.





# DEC product in draft form recommends that.....

- Across the range of LBW, there is strong research evidence to support the contention that all LBW infants born ≤1500 grams are high risk for delays, and this weight should be the definition for the national standard for automatic EI eligibility.
  - In addition, children born < 37 weeks should be considered for El services.



### Other considerations....

- In the DEC product in draft form, the workgroup recognized that expanding eligibility may create challenges for many states.
- \* But the DEC product in draft form suggests that:
  - states review their eligibility policy and consider how their eligibility criteria align with the most current research.
- The workgroup recognized that there is a need for collaboration and data tracking across health care and EI professionals to facilitate referrals, track children's outcomes over time, and research interventions.



# DEC product in draft form recommends that.....

- ★ Some states may want to expand their eligibility criterion to include the full range of LBW (≤2500 grams) because the full range of LBW clearly confers risk status as well.
  - Especially for LBW children from low income families and who have cognitive and/or behavioral concerns that can manifest later at school-age.
- \* States can also use informed clinical opinion to determine eligibility for many LBW infants.



### Questions and more information.....

- \* If you want more information or have questions about the potential position statement, please contact:
  - Peggy Kemp, DEC Executive Director peggy@dec-sped.org





### For more information about DaSy....

- Visit the DaSy website at: http://dasycenter.org/
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### **Thank You**

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### **SMALL GROUP DISCUSSIONS**











