

Disparities in Access to Intervention for Children with Disabilities: Who Wins? Who Loses?  
Suzann K. Campbell, PT, PhD, FAPTA  
Professor Emerita, University of Illinois at Chicago

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**OBJECTIVES: THE LEARNER WILL--**

1. Describe disparities in access to early intervention for children in the U.S.
2. Explain how test choice and standards for delay, as determined by state early intervention agency standards, affect access to intervention.
3. Define the characteristics of poverty as a health-related diagnosis.
4. Develop strategies for personal and collective action that may facilitate earlier access to services for families of children with special health care needs.

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**Statement of Interests**

- SK Campbell is Managing Partner of Infant Motor Performance Scales, LLC, the publisher of the Test of Infant Motor Performance, the Test of Infant Motor Performance Screening Items, and the Harris Infant Neuromotor Test.



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**First, Some History and Perspective**

- The **Past**: History of early intervention (EI)
- The **Present**:
  - Outcomes of very low birth weight
  - How "early" is early identification?
  - Disparities in access to services
  - Barriers to referral and access to services
- The **Future**: Solutions to problems of access

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**The Past History:  
Public Support for Early Intervention**

- In 1975 Congress passed Public Law 94-142, the Education of All Handicapped Children Act
- Reauthorization in 1986 added Part H to establish a program of EI for infants and toddlers
- With 1997 reauthorization, called Part C of IDEA

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**The Past History:  
Public Support for Early Intervention**

- In 2004, Congress recognized the importance of the brain development that occurs in the first 3 years and the need to extend reach better to under-served populations
- Currently all states participate but the program is NOT free for families and is underfunded at both state and federal levels

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The **Present**: Mortality and Morbidity Following Preterm Birth

- Although survival rates around the world vary with resources, mortality in this group in the U.S. is now only about 10%. Nevertheless surviving infants have high rates of disability, around 40%, which have not decreased significantly
  - *Rogers & Hintz Sem Perinatol 2016*

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The **Present**: Mortality and Morbidity Following Preterm Birth

- Although the overwhelming emphasis on early identification of disability is on cerebral palsy (CP), it is less prevalent than other disabling conditions in the most at-risk group of infants born extremely preterm, i.e., at less than 28 weeks gestational age (GA)
  - *Rogers & Hintz Sem Perinatol 2016*

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The **Present**: Mortality and Morbidity Following Preterm Birth

- Overall rates of CP are
  - 0.11 percent in children born at term
  - 0.7 percent in children born at 32-36 weeks gestation
  - 6.2 percent in children born at 28-31 weeks gestation
  - 14.6 percent in children born at 22-27 weeks gestation
  - *Spittle et al Clin Perinatol 2018*

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