Virginia Commonwealth University

Supporting Development of Infant's Born Preterm: Do our policies match the needs?

Stacey Dusing, PT, PhD

Assistant Professor, Physical Therapy Director, Motor Development Laboratory

Core Faculty, Virginia Leadership Education in Neurodevelopment Disability (Va-LEND)

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Objectives

- Review risk factors associated with development in infants born preterm
- Discuss the role and challenges of early detection of disabilities
- Provide an overview of science behind rehabilitation interventions
- Consider the strengths and challenges of early intervention policy for infants born preterm
- Compare early intervention policy and rehabilitation science

No conflicts of interest!







Infant Born Preterm Terminology

- Full Term Birth: 37-42 weeks of gestation
- Preterm birth: <37 completed weeks of gestation
- Late preterm: 34-36 weeks of gestation
- Chronological Age: Age since birth
- Adjusted or Corrected Age: Age if the infant had been born on due date (40 weeks) (Chronological age weeks or months preterm)



Premature Birth in the United States

• Preterm birth accounts for 11.7 percent of all births in 2011



- The majority of preterm births are late preterm
 - Late preterm (34-36 weeks) 8.3%
 - Preterm (<34 weeks) 3.4%</p>



Births: Final Data for 2011. Division of Vital Statistics www.cdc.gov/nchs/births

Racial disparity



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Rate of survival continues to improve



Survival is not the only goal!

- Developmental outcomes relate to:
 - Quality of life
 - Academic success
 - Family stress







Lifecourse changes here!





Neurodevelopmental outcomes: <27 weeks at 30 months

Cognitive Disability

Language Disability



Serenius 2013 JAMA 309(17)

Preterm <27 weeks at 30 months

Motor

Any disability



Serenius 2013 JAMA 309(17)

Lower gestational age increases risk!

- For each week of lower gestation the scores decreased
 - Cognitive 2.5 points
 - Language 3.6 points
 - Motor 2.5 points
- Boys language scores were 5 points lower than girls on average

• Does not address school age issues!!

Serenius 2013 JAMA 309(17)

Cognitive Outcomes – into school age

- Meta-Analysis of Neurobehavioral Outcomes: (Aarnoudse-Moens 2009)
 - Infants < 33 weeks of gestation and/or <1500 grams
 - 7.2-11.4 (0.48-0.76 SD) points behind peers in academic achievement scores at 11 years old.
 - Problems with: academic achievement, inattention, behavior problems, and poor executive function



Motor Outcomes: GA & Weight Matter

- Cerebral Palsy:
 - Rate increases with each week lower gestation
 - 4-12% birth weight <1000g</p>
 - 6-20% born <27 weeks</p>
 - 21-23% born <25 weeks</p>



- 6 times more likely to have CP if born 34-36 weeks compared to term infants
- Developmental Coordination Disorder/ Minor Neurological Dysfunction:
 - 9% of infants born < 1000 g and 28 weeks had DCD
 - 2% of full term cohort

Allen 2008, Goyen 2009, Himmelmann 2005



Intraventricular hemorrhage

- Cohort of 2414 infants born 23-28 weeks of gestation, assessed at 2-3 years
- 33.9% had Intraventricular Hemorrhage (IVH)
- Moderate to severe neurosensory impairment was present in
 - 43% with isolated Grade III-IV IVH
 - 22% with isolated Grade I-II IVH
 - 12% with no IVH

Bolisetty 2014



White Matter Injury (WMI) at term age

- Very Preterm (≤32 weeks) with WMI are at increased risk of intellectual, language, and executive function delay
- Moderate to severe WMI: 3.3-5.6 times more likely to have delays at 4-6 years old
- Mild WMI: 1.7-3.0 times more likely to have delays at 4-6 years old

Woodward 2012

Impact of Preterm Birth on Families



Impact of preterm birth on families

- Mothers of infants born preterm.....
 - have lower physical and psychological health at 2 months post discharge than mothers of full term infants
 - report problem obtaining medical care including visits with specialist in development
 - express fear about their infant's development and a willingness to do what was needed to meet the infants needs

Garel 2004 and 2006, Philip-Paula 2013



Mothers continue to struggle 12 months post discharge

- Maternal Fatigue, feelings of guilt about preterm birth, anxiety over developmental concerns, post-traumatic stress
- Maternal impression that the baby needed help to learn everything, feeding was a struggle for many, some have behavioral concerns about the infant
- 25% of the infants had a re-hospitalization. Some parents reported the re-hospitalization was even more stressful than the initial one as mothers were more attached to the infant

Garel et al 2006



Quality of Life Preschool - Systematic review

- WHO definition of HRQoL: a state of complete physical, mental, and social wellbeing and not merely the absence of a disease
- Infants born PT had lower
 - Physical functioning
 - Social functioning
 - Emotional functioning (in some studies)
- Differences in HRQoL present at school age as well.

Zwicker and Harris 2008



Quality of life – adolescents born preterm

- Self reported PedQL was lower (78 vs 83) in the preterm vs full term infants at 9-10 years old.
 - much higher HRQoL than children in most other chronic condition groups.
- Parents continue to report lower HRQoL in adolescents but children do not when using self report measures as teenagers



Can we reduce the rate of disability and impact the infant's and family's Lifecourse?

Early detection

Developmental support







Challenges in Early Detection – Definition

What is delay / disability?

- Infancy
- Preschoolers
- School aged

What warrants intervention?

- Severe activity limitations
- Mild or moderate activity
 limitations
- Impact on society vs. family
- Quality of life
- Developmental delays

Do we intervene for at- risk infants before delay/disability?



Challenges in Early Detection: assessment tools

Standardized tests



What domains? What age?

Brain Imagining/MRI



 Impairments of Body Function and Structure



Orton 2008, Morgan 1996



Advances in early detection – Lack of variability longitudinally

Generalized Movement Assessment

Lack of Early Postural Complexity





Dusing 2014 in press

Hadders-Alga 2004

Challenges for Early Detection – Who follows up

- There is NO standard system for assessing high risk children!
 - NICU follow up clinics which are not mandatory
 - Pediatricians who should "screen" development based on AAP guidelines
 - <u>Individuals with Disabilities Education Improvement Act</u> (IDEIA) of 2004 (Public Law 108-446) Reauthorized in 2011 with revisions



NICU Follow-up clinics



- Interdisciplinary clinics with expertise with preterm infants
- Review of medical reports of all subspecialist infant was referred to post NICU and follows up on infant specific issues
- Medical and developmental impressions combined to make recommendations for care and provide guidance to parents
- May only see the infant every 3-12 months



Individuals with Disabilities Education Improvement Act (IDEIA)

Birth – 3 year olds



Part C Early Intervention for Infants and Toddlers Infant Toddler Connection 3-21 year olds (in Virginia 2-21)



Part B Special Education



Early Intervention Eligibility – varies by state

- Defined by each state based on federal guidelines
- In Virginia:
 - Child functions at least 25% below chronological or adjusted age in 1 or more area of development
 - Child manifests atypical development or behavior
 - Child is diagnosed with physical or mental condition with high probability of resulting in delay
 - Infants born \leq 28 GA, PVL or hospital stay >28 days

Early Intervention Entrance: Lots of Steps and Barriers

Lots of steps

- Referral or self referral
- Intake
- Eligibility Determination
- Team assessment / Infant Family Service Plan (IFSP)
- Initiation of services

Only 50% of infants referred completed the eligibility determination and assessment

Barriers

- Required multiple phone contacts
- Parents not understanding the process or reassurance for MD
- Suspicious of system and providers

Jimenez 2012



Many eligible children are not enrolled in El

- All states have eligible children (based on delays) are not enrolled in El
- Early Childhood Longitudinal Survey Birth Cohort (Rosenberg 2013)
 - Varies by state with largest issues in states which require less delay to qualify
 - States with stricter criteria tend to capture a higher % of eligible kids
- If a child is not eligible (<u>http://www.ideainfanttoddler.org/pdf/2011_State_Challenges.pdf</u>)
 - 72% of states refer to another agency, but do not follow the child.
 - 14% enroll the child in a tracking program

Rate of EI utilization in infant born preterm

- El service utilization by infants born very preterm age 2 years
 - Only 28% of those with mild disability
 - Only 51% of those with moderate or severe disability
- Those with the highest social risk received the least services



Early Detection and Parents

- Infants born preterm are at high risk are not systematically assessed in the United states!
- Don't parents know the risk and seek care?

Caregiver Developmental Concern at NICU Discharge, infants born < 30 weeks

- 61% of mothers were concerned about their infants development
- Concerns were <u>not</u> related to:
 - Maternal factors: education level, reading books on baby, SES, maternal anxiety, coping, or stress
 - Infant Factors: medical risk scores, gestational age, Cerebral injury, Infant behavior, neurological exam or feeding quality
- Only maternal depression and fewer siblings were associated maternal developmental concern

Pineda, **2013**



Intent to Access Developmental Services at NICU Discharge, infants born < 30 weeks

- 81% reported intent to access therapy or early intervention after NICU discharge.
- Associated variables: Only higher maternal education was significantly associated with increased intent to access services.

Interventions – Who, What, When, and How much

At risk and early



When delayed



Daily, weekly, monthly

Parents, educators, therapists



Debates in Rehabilitation Interventions: Is our goal to...

> Reduce Disability

> > -risk factors

-intervention prior

to delay

Participate in Society

-once delayed access service

-focus on a participation

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Intervention to Reduce Disability



Use it Or Loose it!

Plasticity in greatest in infancy

Theory and Neuroscience (Thelen 1994, Ulrich 2010)

- The nervous and musculo skeletal system self-organize around the stimulus placed on them
- Newborn infants shape these systems through activity from conception through adulthood
- Intense activity is widely accepted in rehabilitation of older children and adults as necessary to promote change in these systems



High Intensity Focused Rehabilitation – retrain the brain!

- Constraint Inducted Movement Therapy (CIMT)
 - 5-6 hours per day for several weeks
- Body Weight Supported Locomotor Training
 Daily practice taking lots of steps with help
- Vestibular Rehabilitation
 - Daily exposure to vestibular input

Research Based Intervention Programs

- 4 Programs used in small research studies that challenge current El practices
- Developmental programs that focus on "at-risk" infants motor development
- These programs focus on providing additional variable experiences to infants in the first months of life



Parent Delivered Movement Training

- Purpose: Evaluate the effectiveness of movement training on emergence of reaching
- Subjects: 26 infants born <33 weeks of gestation, <2500 grams and 13 full term infants
- Interventions: Randomly assigned to movement training or social training both parent delivered



Movement Training

- 20 min per day by parent, 5 day week, for 8 weeks
- Started at 2 months of adjusted age
- Educational booklet and training provided at the start of intervention



Results

- Outcome measures: contact duration and number during seated reaching measurement
- PT infants with movement training contacted the toy at younger ages and for longer duration than PT with social training
- Conclusion: Caregiver-based daily training reduced short-term motor deficits in PT infants



Therapist Delivery Posture Intervention

- 10 subjects, 5 in each group
 - Therapist provided intervention with focus on trunk using principles of neuro developmental treatment
 - Parent delivered intervention with Child Life Specialist running a group on global development
- 4-12 months old, with posture and movement dysfunction
- 10 sessions, in 15 days
- Outcomes: GMFM

Arndt 2008





Authors Conclusions

- Support for Therapist Delivered Intervention including a series of dynamic trunk activation interventions
- High Frequency Short bursts of intervention
- Generalized infant play intervention was not as effective
- CAUTION with interpretation given very small sample size

Clinical Trial of Sitting Intervention

Home Program Group

- 1 time per week for 8 weeks, at home
- Focus on family training
- Supporting function in family routine / education
- Reducing errors in movement
- Supporting postures for function without errors

Perceptual Motor Group:

- 2 times per week for 8 weeks, in clinic
- Child focus with modeling for parent
- Education to support current sitting level
- Encourage child initiated movement, errors ok.
- Touch cues



Results



- Infants in the home intervention improves slightly
- Continued to be very stationary



- Infants in the perceptual motor group learned to sit, move out of sitting, and crawl faster
- More complex movements



Treadmill training in Infants with Down Syndrome

Intervention

- 8 minutes per day for 5 days per week
- Very low speed
- From pull to stand to walking



- Walked 6 months earlier
- This higher intensity program is more beneficial than few days or shorter sessions



Supporting Play, Early Exploration, and Development Intervention (SPEEDI) for Infant

- Intervention to improve parent infant interactions and infant development. NICU to home
- Feasibility established, small pilot with infants with CNS injury planned, proposal under review for larger RCT





Outcomes we are tracking with SPEEDI

- Development of
 - Postural control and motor skills
 - Reaching for toys
 - Exploring toys
 - Parent infant interaction
 - Cognitive development
 - including problem solving
 - Feeding possible





Summary of Evidence for Early Motor Experiences

- Theoretically early motor interventions should improve functional abilities in multiple domains
- Emerging research support this theory and the use of early experiences to advance development
- Evidence supports both parent & therapist delivered intervention depending on the infants motor abilities
 - Require intense, frequent, focused activity, updated to match infants development often

Intervention to Maximize Participation:

Individuals with Disabilities Education Improvement Act (IDEIA)

Birth – 3 year olds



Part C Early Intervention for Infants and Toddlers Infant Toddler Connection 3-21 year olds (in Virginia 2-21)



Part B Special Education

Early intervention (EI) services

- Be family centered Supporting family decision-making and active participation in enhancing the child's development
- Are embedded in the natural environment for that child or a child of the same age without a disability
- Promote child development and participation in daily activities and routines
- Ultimate goal: <u>Children will be ready to enter inclusive and</u> integrated classrooms and learn alongside their peers



Early Intervention under IDEIA

- On average 4.5 hours of intervention per month is provided by El
- Most programs include some parent education and some infant interaction
- May include infant educator, physical, occupational, speech or vision therapy
- Tremendous variability in what infants receive
- <u>http://www.ideainfanttoddler.org/pdf/2011_State_Challenges.pdf</u>

Research on the effectiveness of EI (Orton J 2009)

- Cochrane review of 21 studies with Intervention started < 12 mo
- Intervention to advance motor or cognitive function in infants born preterm.
- Heterogeneous interventions
- Outcomes:
 - improved cognitive outcomes at infant age and at preschool age (not sustained at school age)
 - little effect on motor outcome at infant or school age, and there was none at preschool age.



Does Early Intervention Policy Match the Needs of Infants Born Preterm and Their Families?



Comparison of policy and science

Policy for El

- States determine criteria for eligibility and may or may not include at risk infants
- No standard for longitudinal assessment which may result in under utilization
- Low frequency and intensity of intervention is not effective for motor development

Science

- May prevent delays and disability by serving at risk
- Assessments must to frequent and ongoing to catch a developing delay and assess efficacy of intervention
- High frequency and intensity is needed for neuroplasticity

Policy challenges for EI

- Cost of providing services is restricting services
 - 8 states implemented/increased family fees
 - 9 states required families to use their private insurance
 - 13 states reduced provider reimbursement
 - 8 states required prior approval for hours of service that exceed an identified amount
 - 9 states narrowed eligibility
- 13 states indicated they would run out of fund during 2011-2012 fiscal year, 11 were not sure but might.

Http://www.ideainfanttoddler.org/pdf/2011_State_Challenges.pdf



Policy Challenges for You to Ponder

- Is our goal to prevent disability or help infants and families learn to live with disability?
- Do our policies support longitudinal assessment to identify emerging delays?
- Do our policies allow for early, intense, focused intervention and should they?
- How do you serve those at the greatest risk, with limited resources?

Can we help change policy?

Michael C. Lu, M.D., M.P.H. Associate Administrator Maternal and Child Health Bureau Health Resources and Services Administration

- <u>http://mchb.hrsa.gov/blockgrant/index.html</u>
- MCHTransformation@hrsa.gov

Questions?



scdusing@vcu.edu



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