Developmental Outcomes and Services for Infants Born Preterm

Shaaron Brown, PT, DPT, MSPT, PCS
Department of Physical Therapy, VCU Health
Affiliate Faculty, Physical Therapy, School of Allied Health Professions
Clinical Researcher – Motor Development Lab

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Objectives

1. Understand the range of developmental outcomes seen in infants born preterm
2. List risk factors for developmental delay in infants born preterm
3. Identify the impact of preterm birth and developmental disabilities on parents and families
4. Understand the available options and purpose of community programs to support developmental services to support the preterm infant's development.

No conflicts of interest to declare.
Premature Birth in the United States

- Preterm birth accounts for 9.6 percent of all births in 2014
- The majority of preterm births are late preterm
  - Late preterm (34-36 weeks) 6.8%
  - Early Preterm (<34 weeks) 2.8%

Births: Final Data for 2014. Division of Vital Statistics
http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_12.pdf

Rate of survival continues to improve

Survival is not the only goal!
- Developmental outcomes relate to:
  - Quality of life
  - Academic success
  - Family stress
Neurodevelopmental outcome in extremely preterm infants at 2.5 years after active perinatal care in Sweden

- Over 400 infants born in each group.
- Born 2004-2007 with excellent medical care in the NICU
  - No disability within 1 SD of the control group
  - Mild between 1 and 2 SD below mean
  - Moderate between 2 and 3 SD below the mean
  - Severe disability more than 3 SD below the mean.

Serenius2013 JAMA 309(17)

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Preterm <27 weeks at 30 months

**Cognitive Disability**

- No Disability: 64.7%
- Mild: 24.1%
- Moderate: 9.4%
- Severe: 6.6%

**Language Disability**

- No Disability: 63.6%
- Mild: 22.2%
- Moderate: 9.6%
- Severe: 5.6%

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Preterm <27 weeks at 30 months

**Motor**

- No Disability: 56.5%
- Mild: 28.3%
- Moderate: 9.7%
- Severe: 5.5%

**Any disability**

- No Disability: 39.8%
- Mild: 35.3%
- Moderate: 15.3%
- Severe: 8.9%

Serenius2013 JAMA
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General Outcomes at 30 months

- For each week of lower gestation, the scores decreased
  - Cognitive: 2.5 points
  - Language: 3.5 points
  - Motor: 2.5 points
- Boys' language scores were 5 points lower than girls on average
- 7% had Cerebral Palsy
  - 2.9% walked without an aid
  - 2.9% walked with an aid
  - 1.3% were unable to walk
- 3.7% visual impairment
- 0.9% hearing impairment
- Does not address school age issues!!

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Cognitive Outcomes

- 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
- As many as 54% born under 27 weeks have cognitive impairments (Allen 2008)

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Motor Outcomes

- Cerebral Palsy:
  - Rate increased with each week lower gestation
  - 4-12% birth weight <1000g
  - 6-20% born <27 weeks
  - 31-52% born before 24 weeks
  - 6 times more likely to have CP if born 32-36 weeks compared to term infants
- Developmental Coordination Disorder/Minor Neurological Dysfunction:
  - 42% of infants born <1000g and 28 weeks had DCD
  - 8% of full term cohort

Factors Associated With Developmental Concern and Intent to Access Therapy Following Discharge From the NICU

- **Purpose:** To evaluate the relationship between maternal factors, medical factors, and infant behavior and intent to access services following NICU discharge.

- 84 were retained in the study
- Infants born 30 weeks of gestation or less
- No genetic conditions
- Recruited to a larger study at 3 days of age
- All infants had therapy in NICU and were referred to Early Intervention if born at less than 28 weeks of gestation

Pineda, 2013

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Results – Caregiver Concern

- 61% of mothers were concerned about their infants development
- Only maternal depression, fewer siblings, reading books about pregnancy/baby recently, maternal education were associated with maternal developmental concern.

- **NOT:**
  - Maternal factors: marital status, SES, maternal anxiety, coping, and stress or previous premature birth.
  - Infant factors: Critical Risk Index for Babies (CRIB) score, gestational age, Cerebral injury on CUS or MRI, Infant behavior on the NNNS (NICU Network Neurobehavioral Scale) and Dobowitz neurological exam. (DNE), Feeding quality on NOMAS.

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Results – Developmental Services

- 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.
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 infant’s needs

Garel2004 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
- PT infants 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.

How can we reduce the rate of disability?

- Early detection of disabilities
- Developmental support

Why is early detection and intervention important?

- Use it
- Or
- Loose it!

Plasticity is greatest in infancy
Early Detection - Challenges

What is disability?
• Infancy
• Preschoolers
• School aged

What warrants intervention?
• Severe disability
• Mild or moderate disability
• Impact on society vs. family
• Quality of life

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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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There is NO standard system for assessing high risk infants in US

- NICU follow up clinics are not mandatory but are recommended by the AAP
- Individuals with Disabilities Education Improvement Act (IDEIA)
- Early Intervention and Special Education
- Pediatricians should "screen" development based on AAP guidelines
- Neurology consults
AAP and NIH Insights on NICU Follow-up

- 1996 - The role of the primary care pediatrician in the management of high-risk newborn infants
- 2004 - Follow-up Care of High-Risk Infants
- 2006 - Quality-of-care indicators for the neurodevelopmental follow-up of very low birth weight children: results of an expert panel process

Who should be followed in an interdisciplinary NICU follow-up clinic? – at a minimum

- Very Low Birth Weight (≤1500 grams) and Extremely low birth weight (≤ 1000 grams)
- ≤ 28 weeks gestation
- Neurological Injury: Grade 3 or 4 IVH or PVL, seizures, microcephaly
- Chronic Lung Disease
- Term infants with Hypoxic ischemic encephalopathy
- or severe hyperbilirubinemia requiring exchange transfusion

Why 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
- Customizes developmental assessment and support based on risk factors
- Medical and developmental impressions combined to make recommendations for care and provide guidance to parents
NICU Follow-up, Early intervention, Therapy
To Which to refer?

- These are not duplicative, the systems compliment each other
- NICU Follow-up: Blends medical and developmental assessment to determine the need for care. Refers infants to early intervention or outpatient therapy for ongoing intervention.
- Early Intervention: Focus is on developmental and family needs to support participation
- Outpatient therapy: More intense discipline specific intervention

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 must:

- 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: Children will be ready to enter inclusive and integrated classrooms and learn alongside their peers
Entrance into Early Intervention

- Referral or self-referral
- Intake
- Eligibility Determination
- Team assessment for program planning
- Writing of the Infant Family Service Plan (IFSP)
- Review of IFSP with family
- Initiation of services

Early Intervention Service Provision

- On average 4.5 hours of intervention per month is provided by EI
- 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

Many children are not enrolled in EI

- All states have eligible children (based on delays) not enrolled in EI
- Early Childhood Longitudinal Survey – Birth Cohort
  - Enrollment rate varies by state with the largest number of eligible children not enrolled in states which require less delay to be eligible
  - VA: more than 50% of infants are eligible at 9 months, but less than 2% get services
  - If a child is not eligible only 14% of state enroll the child in a tracking program to reassess the child at a later date

Rosenberg 2013

Rate of EI utilization

- EI 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

**Infants, Toddlers & Families Served in Virginia**

- A total of 15,676 infants, toddlers and families received Part C early intervention services in the one-year period from July 1, 2011 to June 30, 2012
- ~52 percent increase from FY 2007 to FY 2012
- 1.03% of infants under 12 months of age are enrolled in EI in 2011, up from 0.6 in 2006

**Services Provided in VA (FY 2014)**

<table>
<thead>
<tr>
<th>Type of Early Intervention Service</th>
<th>Estimated # of Children With Initial IFSP Listing That Service in FY2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive Technology</td>
<td>13</td>
</tr>
<tr>
<td>Audiology</td>
<td>7</td>
</tr>
<tr>
<td>Counseling</td>
<td>4</td>
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<tr>
<td>Communicative Support Services</td>
<td>1,145</td>
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<tr>
<td>Health Services</td>
<td>3</td>
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<td>Nursing Services</td>
<td>2</td>
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<tr>
<td>Nutrition Services</td>
<td>5</td>
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<tr>
<td>Occupational Therapy</td>
<td>2,132</td>
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<td>Physical Therapy</td>
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<td>Psychological Services</td>
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<tr>
<td>Service Coordination</td>
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<tr>
<td>Sign Language and Cued Language Services</td>
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<tr>
<td>Speech-Language Pathology Services</td>
<td>41</td>
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<tr>
<td>Vision Services</td>
<td>10</td>
</tr>
<tr>
<td>Other Entitled EI Services</td>
<td>39</td>
</tr>
</tbody>
</table>
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**National policy challenges for EI**

- Cost of providing services is restricting services
  - 2 states implemented/increased family fees
  - 3 states required families to use their private insurance or be placed on a fee schedule
  - 1 state reduced provider reimbursement
  - 2 states required prior approval for hours of service that exceed an identified amount
  - 1 state narrowed eligibility
- 42% of states indicated had there funding frozen or decreased


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**Transition from NICU to EI – preliminary**

- 45% of infant referred to EI at the time of NICU discharge were never enrolled
- 50% of those who were enrolled in EI had been home for more than 4 months before starting any services
- Many barriers on the agency side and parental side

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**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

Challenges of Early Intervention Research

- Purpose of Early Intervention under IDEIA is to change environment and parent interactions, but it rarely measures if the intervention changed parent child interactions (Benzies, 2013)
- Interventions start late in the first year if at all, limiting impact on plasticity
- Many infants who would benefit from Early Intervention are never enrolled because they don't have delays, only risk factors

Theory and Neuroscience (Thelen, 1994, Ulrich, 2010)

- The nervous and musculoskeletal 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
- Does the same not apply to infants?

Research Based Intervention Programs

- 3 Programs used in small research studies that challenge current EI 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
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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

Heathcock 2009

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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

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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 neurodevelopmental 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

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

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- Child focus with modeling for parent
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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

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 infant's motor abilities
- Require intense and frequent activity, updated to match infant's development
Comparison of policy and science

**Policy for EI**
- States determine criteria for eligibility and may or may not include at-risk infants
- No standard for ongoing assessment which may result in underutilization
- Low frequency and intensity of intervention is not effective for motor development

**Science**
- May prevent delays and disability by serving at-risk
- Assessments must be frequent and ongoing to catch a developing delay
- High frequency and intensity is needed for neuroplasticity

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**Take home message**
- Infants born preterm are at high risk of developmental disabilities
- Families are impacted by preterm birth well into the first decade of a child’s life
- Rehabilitation may improve participation in society and possibly developmental outcomes if provided at the “right” time, dose, intensity
- Lots more research is needed!

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**Questions?**
References


• Department, POLICY 4037 (CSB) 91-2 Early Intervention Services for Infants and Toddlers with Disabilities and Their Families, 2009, Department of Behavioral Health and Developmental Services.

