Timing is Everything:
First Annual New Mexico Virtual Conference on Cerebral Palsy and Neurodevelopmental Disorders

The Referral Process: Why, To Whom, & How
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A little about us...

We Have Nothing to Disclose
What is the Concern?

- Cerebral Palsy is the most common physical disability
- 1 in 345 children in the US, Equates to approximately 76 infants born / yr. in NM
- Typically diagnosed at age 2 years or later for milder cases
- 50% of children with CP do not have identifiable risk factors and are under the care of general or pediatric practitioner
Why is early detection important?

Corticospinal tract – the principle motor system for voluntary motion of limbs

- Upper motor neurons with cell bodies in primary motor cortex and axons traveling through brainstem into spinal cord
- Spinal cord synapse with lower motor neurons – innervate skeletal muscle
Why is Early Detection Important?

- Rapid increase in growth & maturation from birth to 1 year, then levels off between 1-2 years.
- Early motor interventions aiming to influence corticospinal tract most effective early – Before 2 years of age
- Critical period missed with late identification (Braga et al. 2015)

Corticospinal Tract & Neuroplasticity
Why is Early Detection Important?

- CP intervention using intense, motor learning task-specific approaches plus environmental enrichment optimizes plasticity and improves motor and cognitive outcomes.

- Early, regular monitoring and treatment for musculoskeletal complications can prevent the onset of hip dislocation, scoliosis and contracture.

- Parents experience more depression and stress when dissatisfied with diagnostic process. Families prefer early diagnosis.

- **Wait and see** approach precludes infant from accessing supports and services and negatively impacts child and family.

Why is Delayed Identification a Problem?

- Less ability to mitigate brain injury occurs if:
  - Little-to-no intervention during the critical period of brain plasticity
  - Intervention late or with less intensity
- Specific evidence-based practices are warranted
When
Early Signs Prompting Referral for Specialist Evaluation for CP

- Persistent fisting of the hands past 4 months
- Persistent head lag beyond 4 months
- Stiffness or tightness in the legs between 6-12 months
Why is There an Advantage with Early Identification?

- If identified as “High Risk for CP” at 3 - 6 months, the infant can receive diagnostic-specific intervention to optimize neuroplasticity and reduce impairments.
- Ongoing medical monitoring and surveillance can be provided to prevent secondary problems.
- While learning their child is at high risk is extremely difficult, research has shown that parents prefer to know early rather than late.
Because neuroscience research demonstrates intensive, repetitive, task-specific, exercise should commence within the first 12 months of life to optimize neuroplasticity.
Two Risk Pathways

< 5 months

NEWBORN detectable risks

Preterm Encephalopathy Seizures Stroke IUGR

> 5 months

INFANT detectable risks

Late Milestones Hand Asymmetry
### Decision Tree for Early Identification of Motor Disorder

#### Signs Prompting Physical Therapy or Occupational Therapy Evaluation before 6 months of age

<table>
<thead>
<tr>
<th>INFANTS &lt; 6 MONTHS WITH KNOWN RISK(s)</th>
<th>INFANTS &lt; 6 MONTHS W/O KNOWN RISK</th>
<th>INFANTS &gt; 6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prematurity</td>
<td>Persistent orientation of head to one side beyond 4-months</td>
<td>Inability to sit independently by 9-months</td>
</tr>
<tr>
<td>Encephalopathy</td>
<td>Persistent fisting of hands past 4 months</td>
<td>Inability to take weight through flat feet when supported in standing</td>
</tr>
<tr>
<td>Stroke or Intraventricular Hemorrhage</td>
<td>Persistent head lag beyond 4 months</td>
<td>Hand function asymmetry - strong preference of one hand</td>
</tr>
<tr>
<td>Intrauterine Growth Restriction</td>
<td>Feeding issues</td>
<td>Parental concern</td>
</tr>
<tr>
<td><strong>Parental concern</strong></td>
<td>Stiffness/tightness in legs</td>
<td></td>
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<tr>
<td></td>
<td><strong>Parental concern</strong></td>
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How is Early Identification of Risk Possible?

- An infant’s motor impairment can now be detected very early and accurately with standardized tools.
- The General Movement Assessment (GMA)
- The Hammersmith Infant Neurological Examination (HINE) is a relatively simple and quick assessment tool for infants 3-24 months. It has high predictive ability (about 90%)
When and Who Can Administer GMA and HINE?

We have New Mexico OTs, PTs & physicians who are trained in the administration of the GMA and the HINE.

- **Prechtl General Movement Assessment (GMA)**
  - Age Range: birth - 5 months
  - Requires 3-5 minute video of baby in diaper
  - Subsequent Scoring of video
  - Can be predictive of risk for CP

- **Hammersmith Infant Neurological Examination (HINE)**
  - Age Range: (2) 3 months to 24 months
  - Takes 5-15 minutes (with practice)
  - NOT a developmental milestone evaluation
  - Can be predictive of neuromotor disorders including CP and hemiplegia
# General Movements

<table>
<thead>
<tr>
<th>Writhing Movements: Birth to approx. 8 weeks PCA</th>
<th>Fidgety Movements 3-5 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Normal</td>
<td>- Normal</td>
</tr>
<tr>
<td>- Poor Repertoire</td>
<td>- Abnormal</td>
</tr>
<tr>
<td>- Cramped Synchronized</td>
<td>- Absent</td>
</tr>
<tr>
<td>- Chaotic</td>
<td></td>
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</table>

Cramped synchronized movements  
[https://www.youtube.com/watch?v=LSa4jENxgLk](https://www.youtube.com/watch?v=LSa4jENxgLk)

Normal fidgety movements (mis-labeled in video heading)  
[https://www.youtube.com/watch?v=XrVZmG9KSxo](https://www.youtube.com/watch?v=XrVZmG9KSxo)

GMA looks at abnormal quality and quantity of movement
## GMA Compared to MRI


<table>
<thead>
<tr>
<th></th>
<th>GMA</th>
<th>MRI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity*</td>
<td>93-100%</td>
<td>60-100%</td>
</tr>
<tr>
<td>Specificity**</td>
<td>82-100%</td>
<td>89-99%</td>
</tr>
</tbody>
</table>

* **sensitivity** correctly identifies a true positive rate
** **specificity** correctly identifies a true negative rate
Hammersmith Infant Neurological Examination (HINE)  
90% predictive of CP

For Infants 2-24 months adjusted age

Assesses
- Cranial nerve function,
- Posture,
- Quality and quantity of movement,
- Muscle tone,
- Reflexes & reactions

- Standardized and scorable clinical neurological examination of infants between 2 and 24 months
- 26 Items
- Each item scored individually with (0, 1, 2, or 3) with a global score adding the scores of all individual items (range from 0-78)
- Scoring Form with instructions for performing the test and diagrams to aid in scoring
How?
Early detection after 9 months

- Inability to sit by 9 months
- Inability to take weight through heels and forefoot
- Hand function asymmetry
How? Who?
Entry into Services via Early Intervention (EI)

• Providers AND Parents can refer
  • BUT, Family Infant Toddler Early Intervention (FIT/EI) is a Voluntary Program and Parents MUST agree!

• Birth – 3 years

• Federal/State Program (paid for with tax dollars)

• FIT/EI is within the Early Childhood Care and Education Program

https://nmhealth.org/about/ddsd/pgsv/fit/
How can EI programs access therapists who can provide GMA and/or HINE?

- UNM Developmental Continuity Care Program can be added to EI agency’s IFSP and GMA and/or HINE can be provided via ZOOM
  - DCCP (505) 272-1097

- [https://hsc.unm.edu/medicine/departments/pediatrics/divisions/neonatology/dev-care.html](https://hsc.unm.edu/medicine/departments/pediatrics/divisions/neonatology/dev-care.html)

- Other EI agencies can provide same services but an MOU needs to be completed e.g. MECCA would need an MOU with Inspirations

- UNM Early Childhood Evaluation Program can provide diagnostic evaluation and/or complete the HINE. (505) 272-9846

- [http://www.cdd.unm.edu/clinics/early-childhood-evaluations.html](http://www.cdd.unm.edu/clinics/early-childhood-evaluations.html)
How can EI programs access therapists who can provide GMA and/or HINE?

- IT IS NOT OKAY to simply provide evaluations without therapeutic follow-up.
- THIS is why the CP Task Force is providing concomitant educational programs that offer information about evidence based practices (EBP)
- AND, EBP includes knowing how to speak with families about concerns in a compassionate, realistic manner
• Refer for outpatient PT or OT at community-based clinics – this will require an RX for insurances to cover

• FIT/EI services and outpatient clinic can both serve children

http://www.cdd.unm.edu/other-disability-programs/information-network/index.html
When do you ask for an MRI?

- Can use an MRI to confirm a diagnosis BUT, remember, a “clean” MRI does not r/o CP as CP is a clinical dx
- If request an MRI, provide concerns for radiologist to examine
  - E.g. Bebe walks on toes; Bebe uses right more than left
- NM does not have a pediatric neuroradiologist.
  - Consider asking how much it would cost to have MRI sent to a Children’s Hospital that has a pediatric neuroradiologist
- To Sedate or Not to Sedate?
  - Discuss all risks if you sedate under 2 years of age
When do you refer to a Neurologist?

- Many providers will not diagnosis CP and will refer to a neurologist
- If this is the case, therapies should not wait for a dx!
- Work with the bebe/family on the clinical aspects that bebe is showing!
- Regardless of dx, if a bebe has an asymmetry or a motor delay, provide therapy that is EBP
When do you refer to the UNM CP Clinic?
When you need a dx.

- Margaret Armstrong, MD, pediatrician at UNM CP Clinic
  - One of the “Founders” of the CP Task Force
  - Trained in the HINE
  - Will recommend specific therapies
  - Dr. Armstrong does dx CP – CP is one of her specialties!!

- First visit is face-to-face
- Offers comprehensive approach and multi-disciplinary
  - SW
  - Seating
  - Hip surveillance
  - Nutrition
  - Additional referrals

- Catching-up but still a wait list
How to Talk Communicate With to Parents

How the diagnosis is communicated – From Parents

• Tone positive: “Be honest, realistic, hopeful.”
• Language: Adapted to parent “Start with simple words and offer numbers if a parent wants more details”—“we shouldn't need a translator, just an interpreter if it is a different language.”
• Specific to disorder and child: “Don't be too general or use platitudes.”
• High-risk for CP: Acceptable diagnosis “We understand that the conversation will continue, and diagnosis may be revisited.”

Byrne, et al., 2019
How do we share our concerns with parents?

- We take our time
- We sit down
- We structure a conversation when parent has additional support e.g. partner, spouse, another parent
- We do not rush
- We ask for questions and we provide answers as many times as necessary

- We communicate hopeful reality
- We listen
- We allow silence
- We encourage timely interventions
- We commend them on taking the time to bring their precious child to us
- We plan for a follow-up contact and ask when they would like to re-connect
- Refer to FIT Early Intervention (birth to 3) [https://nmhealth.org/about/ddsd/pgsv/fit/](https://nmhealth.org/about/ddsd/pgsv/fit/)
Take-Aways

(Carry-outs during COVID…)

- Through careful observation, examination and listening to parents, motor delays and disorder can be identified early.
- If atypical motor development is identified – refer for intervention and to medical specialist for possible diagnosis.
- Continue to develop your capacity and network in order to support families.
There is an understanding by parents/providers that we shall use EBP

Our task force goal is to develop capacity in Health Care Providers, Therapists, and Developmental Specialists to:

- Know when to refer
- Know what evaluations are evidence-based
- Know what interventions are evidence-based
- Know how to complete evidence-based evaluations and interventions
- Build capacity throughout the state
- Network when we need consultation and collaboration
Other Resources

- Cerebral Palsy Foundation
  - [https://www.yourcpf.org/](https://www.yourcpf.org/)

- American Academy of Cerebral Palsy and Developmental Medicine (AACPDM)

- American Academy of Pediatrics – Providing a Primary Care Medical Home for Children with CP
  - [https://pediatrics.aappublications.org/content/128/5/e1321](https://pediatrics.aappublications.org/content/128/5/e1321)

- Learn the Signs Act Early – Centers for Disease Control
  - Includes developmental tracker APP
  - [https://www.cdc.gov/ncbddd/actearly/index.html](https://www.cdc.gov/ncbddd/actearly/index.html)
Questions?
Thank you.

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