New Mexico Early Childhood Education & Care Department | Family Support and Early Intervention Division FAMILY INFANT TODDLER (FIT) PROGRAM

CENTER FOR DEVELOPMENT & DISABILITY

Early Childhood Evaluation Program – Technical Assistance & Consultation

Continuing Education series for NM FIT Providers

Presented by

Gerri A. Duran, PhD, MS, OT/L, FAOTA
Sandy Heimerl, PT, MS, DPT
Karen Lucero, PT, MS, PCS

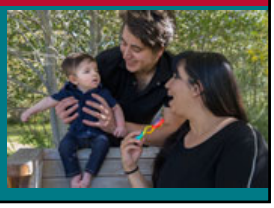
Early Childhood Evaluation Program (ECEP) Interdisciplinary Clinical Faculty and Staff

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CENTER FOR DEVELOPMENT & DISABILITY

When and Why to Refer: Maximizing Potential for Infants At Risk for Cerebral Palsy/ Childhood Onset Disability

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University of New Mexico Health Sciences Center
Department of Pediatrics - Center for Development & Disability



Introductions and Housekeeping

- Today's Team
- We want to see you!
- We want to hear you!
  - Please use the chat or jump in with comments, ideas, and questions.
  - Goal is to share experiences and knowledge.



Objectives for today



- Describe cerebral palsy and how it affects infants and young children
- List three red flags for concern for motor disorder
- If red flags identified, describe the next steps

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Why is early identification important?



- Early signs of Cerebral Palsy (CP) can be easy to miss, and too often professionals recommend a “wait and see” approach
- The average age of diagnosis of CP is around 2 years of age
- CP can be reliably diagnosed before 12 months
- High risk of CP can be identified before 6 months
- When children are not identified early, the window of neuroplasticity is missed.

What is Cerebral Palsy?

(Novak et al 2017)

“CP describes a group of developmental disorders of movement and posture, causing activity restrictions or disability that are attributed to disturbances occurring in the fetal or infant brain. The motor impairment may be accompanied by a seizure disorder or by impairment of sensation, cognition, communication and /or behavior. “

New definition is being considered

Cerebral palsy (CP) is an early-onset lifelong neurodevelopmental condition characterized by limitations in activity due to impaired development of movement and posture, manifesting as spasticity, dystonia, choreoathetosis, and/or ataxia. It results from maldevelopment attributed to dysplasia of or injury to the fetal or infant brain that is not degenerative, although the manifestations may change with age. The phenotype of CP is complex and heterogeneous, with each person experiencing an unique presentation. In addition to motor dysfunction, people with CP frequently encounter primary and secondary impairments across various areas of development and functioning, which can significantly impact their participation in daily life.

What is Cerebral Palsy (CP)



- Children with CP have trouble controlling their movement and posture and results in activity limitations
- Causes are brain injury or atypical brain development early in life
- Genetics are now also being identified as causal
- Type of CP is related to what parts of the brain were injured
- The brain injury does not get worse, though how it is manifested changes with development
- Often accompanied by other impairments

Cerebral Palsy

https://archive.cdc.gov/#/details?url=https://www.cdc.gov/ncbddd/cp/data.html

- Most common physical disability in childhood
- Lifelong condition
- Affects 1 in 345 children in US
- The incidence is higher for children born preterm or at low birth weight
- No definitive test for CP which means we must carefully observe for signs that indicate possible CP



Potential Associated Impairments

Remember, individuals with CP are all affected differently!

- Epilepsy (42%)
- Speech and Language (55%)
- Feeding / Drooling
- Intellectual Disability (45%) or Learning Difficulties
- Vision and/or Hearing
- Constipation
- Pain – e.g. spasticity, Hip displacement
- Sleep Disorders
- ASD (7.5%)

Health Issues

Sensory Impairments
- Vision – including CVI, ophthalmologic conditions
- Sensorineural hearing loss

Nutrition, Growth, GI problems, feeding
- 1/15 receive a feeding tube.

Pulmonary Problems
- Aspiration from dysphagia with oral feeding or gastroesophageal reflux

Sleep
- Sleep disordered breathing
- GERD
- Pain

Constipation

Bone Health
- Decreased bone mass – non ambulatory, fractures

Orthopedic complications
- Joint contractures, scoliosis, hip dysplasia

Epilepsy
- 35 to 60% children and adolescents

Pain
- Up to 75% - many sources & try to identify

Cerebral palsy is an umbrella term for a group of motor disorders

Types of CP

https://cpresource.org/understanding-cerebral-palsy/types-cerebral-palsy

Motor Subtypes

- **Spasticity**: Overactive muscles with velocity-dependent resistance to stretch (84% of cases)
- **Dyskinesia:** Involuntary twisted posturing (dystonia) or involuntary writhing movement (athetosis) (4-7% of cases)
- **Ataxia**: Loss of coordination, movement with a shaky or tremulous quality (4-6% of cases)
- **Hypotonia**: Generalized low tone (2% of cases). Hypotonia is not a universally agreed subtype and not used by some international registers and countries

Spastic CP - Further Categorization

- **Hemiplegia**: One side of the body involved (39% of spastic CP)
- **Diplegia**: Both legs affected. Legs affected more than the arms (38% of spastic CP)
- **Quadriplegia**: All four limbs and trunk are affected (24% of spastic CP)

Original Seated version of the Go Baby Go technology



Motor Outcomes

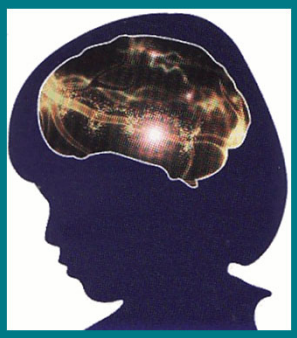


59% of children will walk

8% will walk with an assistive device

33% have limited to no walking ability

Neuroplasticity



The peak neuroplastic period when the brain is actively "sprouting and pruning in response to activity," this critical window for intervention to be most effective is often missed when diagnosis of CP is delayed.

(McIntyre et al 2011)

Neuroplasticity



Why is early identification important

- Brain development occurs most rapidly in the **first 2 years** of life
- This is when the brain is most susceptible to change
- This is when it is important to optimize neuroplastic changes and provide **targeted/specific** intervention
- Intervene early to get the best outcomes for the children

Why is early detection important?

"Cerebral palsy should be detected as soon as possible because:

1. Cerebral palsy specific early intervention using intense, motor learning task-specific approaches plus environmental enrichment optimizes natural plasticity and improves children's motor and cognitive outcomes.
2. Early, regular monitoring and treatment for the known musculoskeletal complications of cerebral palsy can prevent the onset of hip dislocation, scoliosis and contractures.
3. Parents experience more depression and stress when they are dissatisfied with the diagnostic process. Families prefer early diagnosis, followed by early intervention and parent-to-parent support."

Noritz, G. et al. Executive summary: providing a primary care medical home for children and youth with cerebral palsy. Pediatrics. 2022; 150(6):109-114

RED FLAGS before 6 months: Signs for PT/OT Consult

- Persistent fisting of the hands past 4 months
- Persistent orientation of the head to the side beyond 4 months
- Persistent head lag beyond 4 months
- Repetitive opening and closing of the mouth
- Stiffness or tightness in the legs



Boychuck, Z. et al. International expert recommendations of clinical features to prompt referral for diagnostic assessment of cerebral palsy. *Developmental Medicine & Child Neurology* 2020, 62: 89–96.

Asymmetry and Handedness







Other RED FLAGS: Appearing after 5 months of age

- Inability to sit by 9 months
- Inability to take weight through heels and forefoot
- Hand function asymmetry



Red flags- Appearing after 10 months

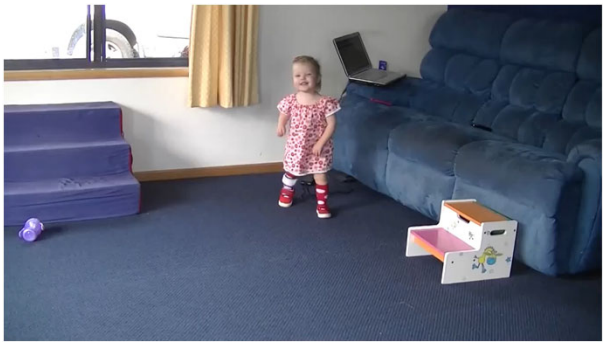


- Crawls in a lopsided manner
- Scoots around on his buttocks or hops on his knees
- Unable to stand without support
- Difficulty getting to standing position from the floor.

Examples of CP



Examples of CP



What you might hear from parents…

- Any indication that the baby is not moving
- Comments from parents or caregivers
  - "Lazy" baby
  - Observant or watchful baby
  - Babies who sleep excessively
  - How "strong" their baby is
  - He's going to be left handed like his father



Who Can Recognize Early Signs of CP

You have the important role of recognizing early signs of motor impairment

1. Watch for early signs
2. Enlist your PT and / or OT right away
3. Listen to parents*
4. Talk to parents & Share your observations

***Parental concern alone** is a valid reason to trigger formal diagnostic investigations and referral for therapy services



WHY

Get the best Outcomes for the children

Decision Tree for Early Identification of Motor Disorder
Guidelines for the Family Infant Toddler Program

Signs prompting PT or OT Evaluation before 6 months of age		Signs prompting PT or OT Evaluation after 6 months
INFANTS < 6 MONTHS WITH KNOWN RISK	**INFANTS < 6 MONTHS WITHIOUT KNOWN RISK**	**INFANTS > 6 MONTHS ALL EARLIER SIGNS AND …….**
Prematurity	Persistent orientation of head to the side beyond 4 months	Inability to sit independently by 9 months
Encephalopathy	Persistent fisting of hands beyond 4 months	Inability to take weight through flat feet when supported in standing
Stroke or Intraventricular Hemorrhage	Persistent head lag beyond 4 months	Hand function asymmetry – strong hand preference
Intrauterine Growth Retardation	Stiffness or tightness in the legs	Parental Concern
Parental Concern	Feeding issues	

What if **RED FLAGS** are identified?

- Talk to your team & include your PT, OT, and / or SLP
- Talk to parents – what are they seeing?, what are their concerns?
- Further assessment considered – Therapist completing the Hammersmith Infant Neurological Examination (HINE)
- Initiate PT and / or OT services/consult as available (don't wait for a diagnosis to start intervention!)
- Encourage parents to talk with child's PCP – consider referral to medical specialist such as neurology
- Functional Vision Assessment – referral to NMSBVI
- Consider referral to ECEP for Medical / Motor Evaluation that would include the HINE

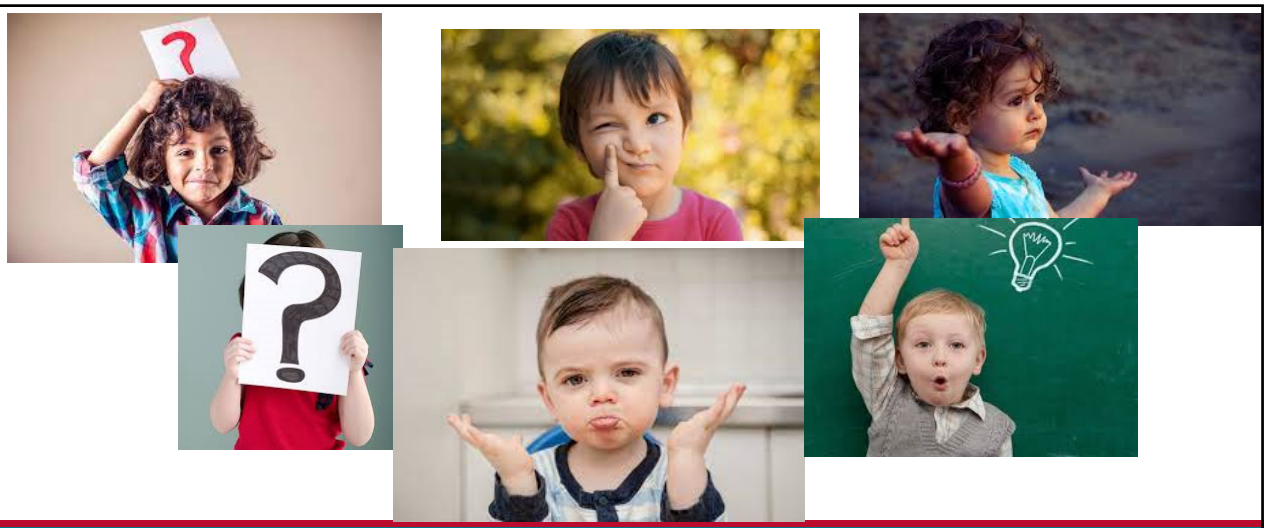
Benefits of identifying neuromotor or CP diagnosis

- Knowing high risk of CP and type of CP will **guide treatment decisions**
- Specific early intervention using **intense, motor learning task-specific approaches** plus environmental enrichment improves motor and cognitive outcomes
- Screening and monitoring for **conditions that may accompany** CP (i.e., seizures, visual impairment, hip displacement)
- **Speeds** up the process of **insurance approval** for: medication, equipment, therapy services and/or in-home care
- Allows parents to obtain **better help** their child
- Gives parents ways to **organize and strategize** around their child's specific needs.

Overview of Cerebral Palsy

https://www.youtube.com/watch?v=pm6BnzsqQbQ





Inquiries and Questions? Case Discussion

Case based discussion – what are the next steps?

Child born at 37 weeks gestation

Now is 7 months old and referred to your program

Development at 2-3 month level

Legs stiff

Uses one hand

Feeding issues

Staring spells

Case based discussion – what are the next steps?

Child born at 32 weeks gestation

Now is 3 months corrected age when referred to your program

Hands are fisted

Legs kick infrequently

Vision is questionable

Irritable often

Dislikes tummy time

Why is early identification important

- If not caught early, can have cascading effect on brain development, lead to significant motor, social, language, and cognitive deficits and the negative impact of associated impairments.

Early Intervention that includes targeted evidence based practices and developmental surveillance are key to set children up for success, determine how they learn, and support families!

Intervention examples

- Child-initiated movement
- Task specific
- Variable practice
- Environmental modification
- Parent coaching and education

Gmmash & Effgen 2019



What does this mean?

- Begin intervention as soon as suspected motor disorder
- Interventions are most successful when they are incorporated with
  - Task specific – challenging but achievable
  - Daily repeated practice of the motor task
  - Meaningful play
  - Family collaboration
  - Functional goals
  - Social elements

What does the research show to be ineffective?



Passive movement

Lack of directed movement or functional movement

Not fun - Negative emotional response

Lack of successful completion of the task

Lack of intensity – no follow through – or parent coaching

Resources for Providers and Parents

CP Foundation: https://www.cerebralpalsyfoundation.org/understanding-cerebral-palsy

United Cerebral Palsy: https://ucp.org/

Centers for Disease Control – CP: https://www.cdc.gov/cerebral-palsy/?CDC_AAref_Val=https://www.cdc.gov/ncbddd/cp/index.html

CAN Child: https://www.canchild.ca/

AACPDM: https://www.aacpdm.org/about-us

Cerebral Palsy Research Network https://cprn.org/

CP tool kit: https://cpnowfoundation.org/toolkit/

Contact information

Gerri Duran, PhD, MS, OT/L, FAOTA gerandran@comcast.net

Karen Lucero, PT, MS, PCS karen.lucero@inspirationsabq.com

Sandy Heimerl, PT, MS, DPT sheimerl@salud.unm.edu

New Mexico Early Cerebral Palsy Detection and Intervention Task Force

Early Childhood Evaluation Program / UNM Health Sciences Center / Center for Development and Disability