CENTER FOR DEVELOPMENT & DISABILITY

FIT ANNUAL MEETING
June 17, 2020

INFANTS AT RISK FOR CEREBRAL PALSY:
SUPPORTING YOUR EI TEAM'S PROVISION OF OPTIMAL CARE

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INTRODUCTIONS & POLLS

1. What is your role in FIT?

2. Are you familiar with cerebral palsy?

Why is early identification important? Consider how you can apply this information in early intervention.

Objectives

- Describe the relevance and urgency of detecting the risk of cerebral palsy in infants under 24-months of age
- Develop an understanding of the International Clinical Guideline for Cerebral Palsy (CP) and how CP or high-risk of CP can be detected early and accurately in infants
- Become familiar with the work of the New Mexico Early CP Risk Detection Task Force and how it can support FIT providers
- Discuss the possibilities and challenges of implementing the Clinical Guidelines within the FIT program

"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. "

CEREBRAL PALSY
(NOVAK ET AL 2017)

International Consensus definition of CP
(Rosenbaum et al 2004)

All infants motor abilities are evolving and changing so determining whether motor dysfunction is permanent is difficult to do when relying on non-standardized clinical assessment (subjective)

1) **Disorder of movement**
2) **Activity limitation** – varies with severity
3) **Non-progressive brain injury** may include progressive musculoskeletal changes over time
4) **Occurring early in development** - originating prenatally or early postnatally

Cerebral Palsy
(IMPACT for Cerebral Palsy, 2017)

- Most common physical disability in childhood
- Affects **1 in every 323** children in the U.S. (www.cdc.gov)
- Affects **73** New Mexico infants born each year (based on the 23,708 birth rate) https://nmhealth.org/data/view/vital/2112/
- Based on rate - **219** infants and toddlers, birth to 3 in New Mexico with Cerebral Palsy
- No Definitive Test for CP – It's clinical diagnosis
- **Typically diagnosed at age 2 years or later for milder cases**

Motor Subtypes

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

- **Spasticity**: Overactive muscles with velocity-dependent resistance to stretch (**85-91%** of cases)
- **Dyskinesia:** Involuntary twisted posturing (dystonia) or involuntary writhing movement (athetosis) (**4-7%** of cases)
- **Ataxia**: loss of co-ordination, movement with a shaky or tremulous quality (**4-6%** of cases)
- **Hypotonia**: Generalized low tone (**2%** of cases)

Further CP Categorization

Unilateral Spastic Hemiplegia: one side of the body (39%)

Bilateral Spastic: Both sides of the body
- Diplegia: both legs affected. Legs affected more than the arms (38%)
- Quadriplegia: all four limbs and trunk are affected (24%)

Potential Associated Impairments

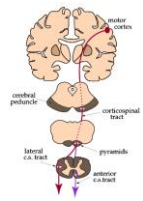
- ✓Speech and Language
- ✓Feeding / Drooling
- ✓Bladder control
- ✓Vision
- ✓Hearing
- ✓Constipation
- ✓Intellectual Disability
- ✓Learning Difficulties
- ✓Musculoskeletal problems
- ✓Pain - Hip Displacement
- ✓Epilepsy
- ✓Sleep Disorders
- ✓Behavioral issues

Examples of CP

Examples of CP

Corticospinal tract – 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

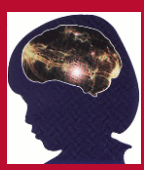


Corticospinal tract

- Rapid increase in growth and maturation from birth to 1 year, then level off between 1-2 years.
- Early motor interventions aiming to influence corticospinal tract most effective early – **Before 2 years of age**

(Braga et al 2015)

Neuroplasticity

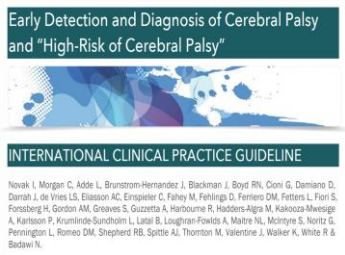


The peak neuroplastic period when the brain is actively "sprouting and pruning in response to activity" this critical window for intervention to be most effective is often missed when diagnosis of CP is delayed

(McIntyre et al 2011)

International Clinical Practice Guideline
(Novak et al 2017)

Devised by an international research network



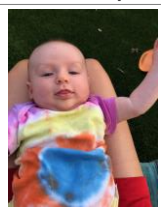
Clinical Diagnosis made as early as possible

- Infant receives diagnostic- specific early intervention
- Receives Surveillance
- Neuroplasticity is optimized
- Complications are prevented
- When available – parent can receive financial/psychological support

Diagnosis

- Diagnosis based on clinical signs, neurological symptoms and motor activity limitations
- Presence of brain lesion on neuroimaging supports diagnosis but absence of lesion doesn't preclude diagnosis
- Typically diagnosis around 24 months

Three Groups Classification



1. Premature Infants (30-40% of all cases)
2. Term infants who develop neonatal encephalopathy (formerly called HIE) shortly after birth (15-20%)
3. Term infants without risk factors (40-50%)

Recognition

Almost half of children with CP do not have identifiable risk factors and are under the care of a general or pediatric practitioner

- Normal pregnancy, labor, and delivery
- Not until the parent observed missed or delayed motor milestones – i.e. not sitting at 9 months or early hand asymmetry or lack of weight bearing is a concern often raised

86% of parents suspected their child had Cerebral Palsy before a clinical diagnosis was made

(Baird, McConachie, Scrutton 2000)

Clinical Guideline

Strong recommendation against *Wait and See* monitoring when clear diagnostic indicators exist

Risks and Benefits to the Infant

When a diagnosis is delayed……

Risks: Little-to-no focused intervention during the critical period of brain reorganization

Benefits: Diagnostic-specific early intervention and surveillance to optimize neuroplasticity and prevent complications

Benefits and Risks

What is the impact of early diagnosis of cerebral palsy on parents?

Whilst receiving the diagnosis is extremely difficult – parents prefer to know early rather than late

Risk: delayed diagnosis is harmful as parents more likely to experience depression / anger

Benefits:

- Parents participate in intervention
- Emotional support
- Potential financial support and services

Clinical Guideline

High Risk of cerebral palsy

When the diagnosis is suspected but cannot be made with certainty, the interim clinical diagnosis of “high-risk of cerebral palsy” should be given

Define “High Risk of Cerebral Palsy”

“**High Risk**” of cerebral palsy for infants 3-4 months of age - in which they do not receive the diagnosis of CP

BUT due to

- clinical factors
- neuroimaging
- findings of standardized assessments
- have a 95% probability of developing CP

Accurate Detection Now Possible

An infant’s motor impairment can now be detected very early and accurately with a combination of standardized tools.

(Einspieler & Prechtl 2005)

(Bosanquet, Copeland, Ware, & Boyd 2013)

(Herskind, Greisen, & Nielsen. 2015)

Early Accurate Diagnosis– Clinical Practice Guideline

(Novak, Morgan, Adde, et al 2017)

BEFORE 5 MOS. CORRECTED AGE

- GMA is 95-98% predictive and MRI is 80-90% predictive
- 2nd best option – HINE <57 at 3 months is 96% predictive
- All should include history taking about risk factors

AFTER 5 MOS. CORRECTED AGE

- HINE – 90% predictive, MRI and standardized motor assessment (Alberta Infant Motor Scale AIMS 86% predictive)
- 2nd best option: HINE and standardized motor assessment (DAYC 89% predictive and MAI 73% predictive)

Before 5 months corrected for prematurity

General Movement Assessment (Hadders-Algra 2007)

- 95 -98% predictive

MRI (before sedation required)

- 80 – 90% predictive
- Caution – if normal it does not preclude diagnosis of high risk for CP

Prechtl's Qualitative Assessment of General Movements (GMA)

- ✓Standardized and Scorable
- ✓A visual assessment of writhing movement patterns in infants ideally before 3 months adjusted age (before birth to 2 months)
- ✓Takes 5-10 minutes to score a video of the movements
- ✓Infants typically have fidgety movements as the brain is wiring (1-3 months)
- ✓Cramped, synchronized movement are not normal
- ✓When fidgety movements are absent and / or cramped synchronized movement present, these could indicate high risk of cerebral palsy or other motor impairment.
- ✓4 day intensive certification course

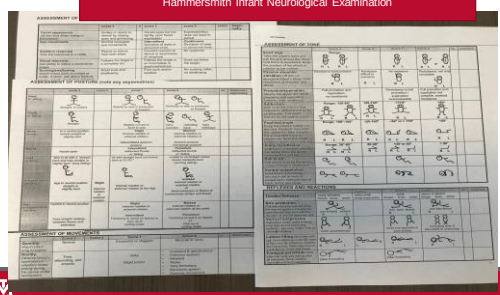
Hammersmith Infant Neurological Examination (HINE) Infants 2-24 mos. adjusted age

Assesses

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

- 26 Items
- Items scored individually with total score range from 0-78
- Scoring Form with instructions and diagrams

Hammersmith Infant Neurological Examination



Videos HINE

Approved Tools for Infant Assessment

-General Movements Assessment (GMA)

-Hammersmith Infant Neurological Examination (HINE)

NEW MEXICO DEPARTMENT OF HEALTH

DEVELOPMENTAL DISABILITIES SUPPORTS DIVISION (DDSD)

FISCAL YEAR 2020

STATE GENERAL FUND

Services for Individuals with

Developmental Disabilities,

and

FAMILY INFANT TODDLER PROGRAM /

MEDICAID EPSDT

Services for infants and toddlers (birth to three) with, or at risk of Developmental Delays and their families

SERVICE DEFINITIONS AND STANDARDS

EFFECTIVE JULY 1, 2019

Other Standardized Tools

Alberta Infant Motor Scale AIMS (FIT approved tool)
- 86% predictive of abnormal motor outcome

DAYC Developmental Assessment of Young Children
- 89% Predictive of CP

DECISION TREE
Refer for PT or OT before 6 months

Infants with Known Risk

- ❑Prematurity
- ❑Encephalopathy
- ❑Stroke or Intraventricular Hemorrhage
- ❑Intrauterine growth retardation
- ❑ Parental Concern

Infants without known Risk

- ❑Persistent orientation of head to one side beyond 4 months
- ❑Persistent fisting of hands past 4 months
- ❑Persistent head lag beyond 4 months
- ❑Feeding issues
- ❑Stiffness or tightness in legs
- ❑Parental Concern

DECISION TREE
Refer for PT or OT for INFANTS > 6 MONTHS

All signs prior to 6 mos. would prompt referral in addition these signs:

- ❑Inability to sit independently by 9 months
- ❑Inability to take weight through flat feet when supported in standing
- ❑Hand function asymmetry - strong preference of one hand over the other
- ❑Parental concern

The clinical diagnosis of cerebral palsy can and should be made as early as possible, so that:

- ❑The infant can receive diagnostic-specific early intervention and surveillance to optimize neuroplasticity and prevent complications
- ❑ The parent/s can receive psychological and financial support (when available)

Intervention Principles Gmmash & Effgen 2019

- ➢Child-initiated movement
- ➢Task specific
- ➢Variable Practice
- ➢Environmental modification
- ➢Parent coaching and education i.e. *SSOOPPRR*

NM Early CP Risk Detection and Intervention Task Force

- History of the CP Task Force
- Task Force Participants
- ***Vision***

  All infants at risk for cerebral palsy reach their full potential and realize their dreams
- ***Mission***

  New Mexico infants at risk for cerebral palsy will receive timely, specific screening and if identified at "high risk", appropriate services will be available.

TASK FORCE GOALS

- NM infants and young children at high risk for cerebral palsy receive timely and appropriate screening and referrals;
- Appropriate evidence-based early interventions and treatment services are available; and
- Infants at high risk for cerebral palsy and their families receive the support and services they need to achieve healthy and optimal development.

Education and Training

- Understanding of the Clinical Practice Guideline
- Identification / Screening / Referral
- Assessment to identify high risk
- Evidence based targeted intervention

Task Force Activities

New Mexico Occupational Therapy Association Conference August 2017; Poster presented at 2018 conference

University of New Mexico School of Medicine Pediatric Resident School May 2018

NM Association for the Education of Young Children Conference March 2018

Pediatric Physical Therapy (PT) and Occupational Therapy (OT) Continuing Education Series Lecture Nov. 2018

American Occupational Therapy Association 2019 Conference

Fact Sheet & Presentation for New Mexico Legislative Health and Human Services Committee, October 2018

New Mexico Family Infant Toddler Annual Meeting Posters June 2018; 2019

Parents Reaching Out Family Leadership Conference April 2019

Hammersmith Infant Neurological Examination Training from National Expert October 2018 and September, 2019

Infant Labs to practice assessments – July 2018, March 2019, and planned for August 2019

Webinar for PTs and OTs in Early Intervention and Private Practice for August 2, 2019

University of New Mexico School of Medicine Wylder Lecture Poster August 2018 & August 2019

Amazing Newborn Conference November 2018 and November 2019

NMAYEC Conference Presentation March 2020

Community Health Workers Presentation June 2020

House Memorial 12 – passed 2019

"RECOGNIZING THE IMPORTANCE OF THE EARLY DETECTION OF HIGH RISK FOR AND DIAGNOSIS OF CEREBRAL PALSY IN CHILDREN; REQUESTING THE EARLY CEREBRAL PALSY DETECTION AND INTERVENTION TASK FORCE TO CONTINUE DURING FISCAL YEAR 2020 ITS WORK IN IDENTIFYING BEST PRACTICES IN CEREBRAL PALSY RISK IDENTIFICATION, DIAGNOSIS AND INTERVENTIONS, AND IN CREATING A PLAN OF CARE THAT MEETS INTERNATIONAL PRACTICE STANDARDS IN, AND IDENTIFIES HEALTH COVERAGE GUIDELINES FOR, ACCESS TO APPROPRIATE AND TIMELY CEREBRAL PALSY CARE."

FIT STANDARDS and IMPLEMENTATION

- The FIT standards support the use of the HINE, AIMS, and GMA in assessment
- These tools can be included in a CME
- Or as discipline specific assessment
- If concerns found during CME, the child should be referred for discipline specific assessment immediately (assessment added to the IFSP)
- If a family has concern, the child should be referred for further motor assessment

Discussion

What are the opportunities? What are the challenges?

POTENTIAL SOLUTIONS

Telehealth

What additional information do you need?

Resources

Introducing the CP Channel http://yourcpf.org/videos-we-love/cp-channel/

AACPDM is excited to announce the release of the most recent Care Pathway, "Care Pathway for Early Detection of Cerebral Palsy". The link is located here: http://www.aacpdm.org/publications/care-pathways/early-detection

NMECPDI task force. The link is located here: http://www.cdd.unm.edu/other-disability-programs/cerebral-palsy-taskforce/index.html

SUMMARY

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Members of **New Mexico Early CP Identification & Intervention Task Force**

- High Quality Timely Evaluations
- Early and Accurate Early Detection of "High Risk" of Cerebral Palsy
- Best Available Early Intervention and Surveillance

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