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.
Clinical Care Pathways for Children Diagnosed with Cerebral Palsy at High Risk for Cerebral Palsy

Josh Lucero, SPT and Early CP Risk Detection and Intervention Task Force

Clinical Care Pathway for Parent/Guardian

Pre-Referral

NICU

Other Medical Provider

Parents

Evaluation

Trained Health Professional
Neuromotor Evaluation

Positive Result

Negative Result

Referral

Early Intervention (RT if Qualified)

Outpatient Clinic

UNM High Risk of CP Follow up Clinic

Cerebral Palsy Clinic

Pediatrician Follow Up

Evidence-based Interventions

Children born with Cerebral Palsy experience extra challenges in their lives with independence and mobility. The initiative to diagnose children in infancy either at high risk for cerebral palsy or confirmation of cerebral palsy means they are able to receive services earlier in the most critical time of brain development when synapses are being formed. Therefore, early diagnosis and appropriate early intervention is essential to the overall development of the child.

Clinical care pathways provide directional guidance for parents and medical providers to know a step-by-step, evidenced based roadmap the child will need to follow to optimize function and quality of life. These pathways have been developed based on evidence based publications, referral patterns in New Mexico and around the nation, and work of the Early Cerebral Palsy Risk Detection and Intervention Task Force.

References

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Clinical Care Pathway for Medical Providers

Infant Displays Detectable Risks

< 5 Months Corrected Age
- General Movements Motor Assessment + MRI of Motor Areas in Brain + History Taking for Risk Factors
- If GM Motor Assessment Not Available and MRI Not Safe/Affordable
  - HINE: < 73 - High Risk for CP
  - MRI for Abnormal Neuroanatomy
  - DAYC: AIMS + NSMDA

> 5 Months Corrected Age
- If MRI Not Safe/Affordable
  - HINE: < 73 - High Risk for CP
  - MRI Not Available

Results
- High Risk For Cerebral Palsy
  - Determine Severity & Impairments
  - Refer to early intervention and outpatient therapy
- Cerebral Palsy
  - Pediatrician Follow Up with Monitoring
- Neither

References

Note: Necessary if the infant shows any one of the following:
- The inability to sit independently at 9 months of age
- Hand function asymmetry
- The inability to take weight through plantar surface of feet
WHAT DOES EARLY INTERVENTION LOOK LIKE?

**Begins with an evaluation**
- Parent concerns are gathered
- Various evaluation tools and clinical observations utilized
- Includes a HINE or GMA if one has not been done or for reassess

**Plan of Care (Outpatient therapy) or IFSP (NM FIT) developed**
- Specific recommendations made can depend on care model
- Needs to include physical, occupational, and/or speech therapy services

**Interventions are based on evidence-based practice guidelines**
WHERE DO I GO?

UNM Information Specialists
- NM FIT and pediatric outpatient therapy providers
  phone 505-272-8549 or 800-552-8195
  cdd.unm.edu/infonet

NM FIT Program at 1-877-696-1472
  33 providers throughout the state offer licensed therapists and a wide range of support

Outpatient Pediatric Therapist (physical, occupational, speech therapist, vision, etc.)

Services from both a NM FIT agency and an outpatient therapy provider may be needed
NEW MEXICO: EARLY INTERVENTION (PART C) IDENTIFYING “HIGH RISK”

- The current state of practice in the US for birth-to-three early intervention programs are that 10 states use the GMA and 18 use the HINE – and few states use either tool routinely (Pediatric PT Journal July 2019 article)
NETWORKING OF VARIOUS STAKEHOLDERS

- Parents
- Consumers
- Physicians
- Therapists
- Nurse Educators
WHERE DO YOU FIT IN THIS MATRIX?
EDUCATION AND TRAINING

• Understanding of the Practice Guideline
• Identification / Screening / Referral
• Assessment to identify high risk
• Evidence based targeted intervention
RESOURCES: PEOPLE

- **CP Task Force and Steering committee**
  - Members volunteering time & energy, to create a system of care

- PTs, OTs in Early Intervention and Private Practice

- Physicians, neonatologist, social worker, nurse, neurologist, parent, SLP, LEND trainees / graduate students

- **NICUs** - UNM, Presbyterian, Lovelace

- UNM CP clinic

- UNM Center for Development and Disability- LEND and ECEP
AWARENESS IS AN ISSUE

- Recently published national survey of pediatric PTs and OTs in the US indicated that therapists had little knowledge of evaluation tools or evidence based practices for infants at high risk for cerebral palsy. (Gmmash & Effgen 2019)
NECESSITY IS THE TRUE MOTHER….

- In lieu of state funding, how can we move forward?
- Partnering
  - Private funds for education – lesson: take a stakeholder with you!
  - Find a connection – Ashton Kutcher did not work out...but, Nathalie Maitre, MD, sure did!
- Those associated with capacity to network
  - Universities
  - Pediatricians/Specialty Providers
  - State Associations
  - Administrators
PLAN TO TAKE STEPS THIS WEEK

- What opportunities are available for MRIs for young children in your area?
- Find out about choices for therapy in your area.
- Find out about collaboration between public and private therapists, (FIT, Private Therapists, Hospital out-patient departments)

- Meet with the radiologists to whom you frequently refer. Discuss alternatives.

Set up a community meeting to discuss referral processes and follow-up in your community
MEET WITH YOUR LEGISLATOR

Find the Representative in your district at NMLegis.gov

Call or E-mail to discuss the need

Ask them to cosponsor a bill by the CP Task Force to Fund the mission to educate professionals and the public on early identification and intervention