Questions and Answers from the FIT Early Identification of CP training on June 17, 2020

1) *The Prechtl General Movements Assessment (GMA) – Who can take the training? Where is the training offered? Is the training offered online?*
   a. The GMA is offered for physicians, PTs, OTs and other health professionals working in the field of infant neurology through the General Movements Trust, which is an international organization. The training is in person. A recent 3-day course that was scheduled for May 31-June 2 in Columbus, Ohio was canceled. The cost of that course was $950.00. Scheduling training in the US is on hold.

2) *The Hammersmith Infant Neurological Examination (HINE) - Who can take the training? Where is the training offered? Is the training offered online?*
   a. The HINE is offered for physicians, PTs, OTs and other health professionals working in the field of infant neurology. In New Mexico, the HINE training is overseen by the Cerebral Palsy Foundation in Columbus, Ohio. Several HINE trainings have occurred in our state. The trainings were in person. Currently, NM is adhering to social distancing guidelines and a training was recently piloted to see if it can be offered while still adhering to the guidelines. More information should be available soon.
   b. The HINE training is offered at no cost to participants, though the sponsoring agency is required to pay for the trainer's travel and meals and have adequate space to provide the training lab.

3) *With the limited number of PT's and OT's, assistants would be a great source to be used when the*
   therapists cannot be there for these assessments. Something to consider.
   a. NM licensure requirements for assistants limit the assistants' scope of practice. Under the license, they are not able to complete assessments. Assistants are highly trained and able to communicate concerns with the therapists for further evaluation.

4) *Who can diagnosis Cerebral Palsy? Does it need to be a neurologist? If you have an infant who is high risk, would you recommend a referral to ECEP or a neurologist?*
   a. The diagnosis of CP is a medical diagnosis and is made by a medical doctor. Often that is a neurologist though it can be made by pediatrician or family medicine physician.
   b. Options for diagnosis in NM can include :
      i. UNM CP Clinic at Carrie Tingley Hospital
      ii. Presbyterian Chronic Care Clinic
      iii. Children's Medical Services outreach clinic - https://www.nmhealth.org/about/phd/fhb/cms/
      iv. ECEP clinic
      v. Pediatric Neurology
   c. UNM CP clinic is able to fast-track a request for a HINE (we think)

d. ECEP is one option for referral. If you are requesting a developmental assessment that includes concern for motor disorder and risk for CP, indicate that on the referral and ECEP could fast track the HINE before a full evaluation can be scheduled. *Indicate this on the referral*

5) *The largest challenge is when we suspect CP, then what? Doctors almost always "want to wait and see".*
   a. Using a standardized assessment like the HINE that when scored, indicates clear risk, could be shared with the child's PCP. Sharing your assessment results with the child's parent and the PCP is recommended.
   b. Become familiar with the articles that indicate that the "wait and see" attitude is detrimental to children, and possibly to families, might help you. Of course, use tact and never tell a provider that they are harming anyone but, sharing new information might help. "here, Dr. ****, are some articles/information that discuss why acting sooner rather than later can help children and families." Naturally, you would need to be mindful about collaborating and working with the provider and family (not embarrassing the provider). Not supporting intervention at an early age may simply be due to lack of information/education.

6) *Thank you for advising FIT providers and letting families know that they can still get therapy if their pediatrician wants to wait. What could be the reason for the referral for therapy when a parent does a self-referral?*
   a. Providers on the FIT team can request to add an OT or PT evaluation to the IFSP based on motor concerns and red flags (refer to the decision tree).
   b. If families prefer, they can request a referral from their child's primary care provider for pediatric PT or OT and the infant could be seen in an outpatient therapy clinic. The reason would be concern with delayed and/or disordered motor ability.

7) *If a child has an existing diagnosis that shows some of these same signs and symptoms, should this child still be evaluated for CP?*
   a. That depends – a neurological condition that is progressive is not cerebral palsy even though the child may have similar symptoms. A child who sustains a traumatic brain injury or contracts encephalitis may have the same signs and symptoms and should be evaluated for CP.
   b. Evaluating for a neurodevelopmental delay might also describe the condition that will cover a variety of diagnoses.

8) *Hip dislocation*
   a. The risk of developing hip dislocation in children with cerebral palsy has been estimated to be within 15% - 20% and occurs in children with spasticity. Non-operative treatment may include appropriate positioning and the use of orthoses. Operative procedures may include adductor-psoas tenotomy, varus osteotomy of the proximal femur, or pelvic reconstruction.

b. A systematic review of non-operative treatment included botulinum neurotoxin A; botulinum neurotoxin A and bracing; complementary and alternative medicine; intrathecal baclofen; obturator nerve block; positioning; and selective dorsal rhizotomy. There was significant variability in treatment dosages, participant characteristics, and duration of follow-up among the studies. Overall, the level of evidence was low. No intervention in this review demonstrated a large treatment effect on hip displacement.

   Miller S D, Juricic M, Hesketh K, et al. Prevention of hip displacement in children with cerebral palsy: a systematic review. Dev Med Child Neurol . 2017 Nov;59(11):1130-1138. doi: 10.1111/dmcn.13480.

9) *I've seen kids with severe CP benefit functionally from botox, but it appears that with the retirement of one of our leading neurologists, there may not be access to this resource in New Mexico at this time. Is the task force aware of other or emerging avenues for this type of treatment?*
   a. Botulinum toxin (BoNT) studies have found it to be effective for reducing spasticity and impacting motor function when used in conjunction with gait training, hand function, casting, orthotics, OT, PT, and electrical stimulation (Novak, et al, 2020).
   b. Within the UNMH system, Dr. Denise Taylor is treating children with Botox. The pediatric rehabilitation number is 505 272-4511.

10) *When is it developmentally appropriate to show hand/side dominance? At what age?*
   a. It has long been believed that handedness did not develop until 3-4 years of age (Gesell & Ames, 1947). This concept is outdated based on current research (Fagard 2013). When infants start grasping objects around 5-6 months of age, handedness is not strong. Infants grasp using their whole hand and easily shift from one hand to the other. Bilateral coordination using the hands together for a task occurs around 10 months of age. Babies at a year of age can show a hand preference especially if the task requires precision. When we are observing handedness in babies under 2 years, we are looking at whether one hand is strongly preferred and the other is used minimally or not at all. We observe the quality of the motor action and whether the baby can complete bimanual tasks that require two hands.

11) *What is the age limit for a MRI without sedation?*
   a. This depends. Babies need to be still and not moving when performing the MRI.
   b. Some providers will attempt to feed a baby, swaddle them, and hope that they will sleep through the MRI, which typically only works with a young infant
   c. Some providers are comfortable with MRIs that use sedation. Asking about the risks as well as what sedative is used can help guide your decision.
   d. An important aspect of using an MRI to confirm a diagnosis of CP is that some babies' MRIs look normal but their clinical appearance is atypical. Remember, CP requires a clinical diagnosis.

12) *My challenge is getting a good look at a child on Zoom now that we can't see families face to face. I've been using a baby doll to show parents what I need to see. Any suggestions?*
    a. Using a doll is a good strategy. Also, you might ask the parent to stop the face to face interaction with them and film the child moving for 2-3 minutes including the child playing with a toy as this might give you additional information about handedness/preference. This will allow you to observe active movement. Based on your observations and on the parent's report, talk through next steps. If doing a movement assessment, you can send the parents a copy of the AIMS via email before the visit and let them know the positions/actions that you hope they can film.
    b. Based on your knowledge of what the child is doing, you can use a doll and/or talk the parent through the activity. Have the parent participate in solving the problem of ways to include the child based on the child and parent's preferences.
    c. Because there is a "record" function on Zoom, you can also send families short clips of how to move their baby into positions by recording you using a doll. Not optimal but could be helpful!
    d. A great resource is Positioning For Play. It is downloadable and you can send parents an attachment of a position in advance that you will be discussing for an upcoming Zoom session.

Presenter Contact Information:

Sandy Heimerl sheimerl@salud.unm.edu
Gerri Duran gduran@salud.unm.edu
Karen Lucero karen.lucero@inspirationsabq.com