Early Identification and Intervention for Infants at Risk for Cerebral Palsy

Introduction: Early identification of the infant at risk for cerebral palsy (CP) is critical for that infant's access to essential intervention services. This can happen when all involved in that baby's care understand their roles and the responsibilities that go along with that role. This is a concise summary of both specific to your interaction with the infant. Links are embedded for additional information about resources and references

Families	
Roles	**Responsibilities**
1. Caregiver 2. Advocate	1. Understand the importance of early identification of CP in getting access to care. 2. Attend follow up and Early Intervention (EI) visits. 3. Share your goals and concerns. 4. Be open to input from the team (i.e., – Neonatal Intensive Care Unit (NICU), High Risk Infant Follow-up (HRIF). 5. Participate in informed decision-making about recommended referrals and therapy plans, including where there may be a duplication of services. 6. Families are not required to have a referral or diagnosis to start physical therapy (PT), occupational therapy (OT), Speech Therapy (ST) in California. Some insurance plans, Medi-Cal, and California Children's Services (CCS) require a physician referral to allow some or full financial coverage for the services Reference (Ref): AB 1000 2013 Available at: https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=201320140AB1000 Will my insurance pay? Available at: https://www.movecalifornia.org/will-my-insurance-pay

Hospital: NICU Team/Therapist	
Roles	**Responsibilities**
1. Provide appropriate medical and therapeutic evaluation and intervention in the NICU per CCS NICU Special Care Center Standards. 2. Recommend appropriate medical and therapeutic intervention during and after NICU discharge per CCS NICU Special Care Center Standards, Part 2, Chapter 3.25.	1. Initiate developmental support and therapy conversations with parents throughout the NICU course. Discuss High Risk of CP labels that may be provided in the future. 2. Educate families on their eligibility for, and importance of, neurology follow-up, HRIF clinic, Regional Center/Early Start services, and/or outpatient PT/OT/ST services. 3. Identify who needs referrals and the team member who will make those referrals to neurology, HRIF clinic, Regional Center/Early Start services, and/or outpatient PT/OT/ST services. Ref: CCS NICU Special Care Center (SCC) Standards https://www.dhcs.ca.gov/services/ccs/Documents/CCS-Standards-Regional-NICU.pdf 4. Know the CCS referral criteria for the general and medical therapy program (e.g., – Hypoxic Ischemic Encephalopathy (HIE), spasticity, etc.); proceed with referral; assist with family completion of the CCS application. 5. Understand the responsibility to act in the child's best interest and make referrals as appropriate even if the family declines to complete an application for CCS services.

Pediatrician/Primary Care Physician/Nurse Practitioner	
Roles	**Responsibilities**
1. Provide direct medical care of the infant at risk for or with cerebral palsy 2. If not a board-certified pediatrician with expertise in the care of infants with special health needs, refer such infants to one	1. Know the signs and symptoms for the early detection of CP Ref: Early Intervention for Children Aged 0 to 2 Years With or at High Risk of Cerebral Palsy: International Clinical Practice Guideline Based on Systematic Reviews | Guidelines | JAMA Pediatrics | JAMA Network 2. Perform a comprehensive history and physical examination, including a neurologic assessment; know how to do or refer for standardized tests of development and motor assessment Ref: https://cerebralpalsy.org.au/wp-content/uploads/2018/05/180139-CP-Recommendations-post-diagnosis_professionals.pdf 3. Be familiar with eligibility criteria for CCS General Program, CCS Medical Therapy Program (MTP), and Regional Center (RC) to determine when, where, and how to refer and what to include in the referrals for each program 4. Coordinate appropriate referrals and ongoing care; support family engagement

High Risk Infant (HRIF) Follow-up: https://www.dhcs.ca.gov/services/ccs/Documents/ccsnl051016.pdf	
Roles	**Responsibilities**
1. Mandated requirement of CCS approved NICUs to identify children who might develop CCS eligible conditions after discharge from a CCS approved NICU. 2. CCS Program standards require that each CCS approved NICU ensures the follow-up of discharged high risk infants and that each NICU shall either have an organized program or a written agreement for provision of these services by another CCS approved NICU.	1. Familiarity with eligibility criteria for CCS General Program, CCS Medical Therapy Program (MTP), and Regional Center (RC) to determine when, where, and how to refer to: a. RC for Early Intervention. b. CCS for CP specific interventions and services 2. Ongoing education of the family on development i.e., anticipatory guidance. 3. Complete portions of the early detection assessment to share with CCS on referral i.e., Neurological exam- Hammersmith Infant Neurological Exam (HINE), Motor exams- General Movement Assessment (GMA). Ref: https://cerebralpalsy.org.au/wp-content/uploads/2018/05/180139-CP-Recommendations-post-diagnosis_professionals.pdf 4. Coordinating care with the child's pediatrician to request medically necessary services identified by the HRIF team (e.g., Magnetic Resonance Imaging (MRI) or neurology evaluation and with the CCS program to ensure application to the CCS general program if applicable.

Regional Center (RC): Intake coordinator, therapists, and others https://www.dds.ca.gov/rc/	
Roles	**Responsibilities**
Each Regional Center is a private, non-profit case management agency under contract with the California Department of Developmental Services (DDS) that contracts with service providers (vendors) to provide direct services to individuals with developmental disabilities in California regardless of citizenship and legal status. Developmental Disabilities include intellectual disability, CP, epilepsy, autism, and other disabilities closely related to intellectual disability. RC provides Early Intervention services to 0-3 year-old children identified with at least a 25% delay in any 1 area of the 5 developmental domains: 1. Cognitive 2. Physical - gross/fine motor domains 3. Communication - (expressive/receptive 4. Social/emotional 5. Self-help/Adaptive Ref: Codes Display Text (ca.gov)	1. It may be possible to complete the intake in the NICU with signed parental consent 2. Coordinate with the NICU discharge team to streamline RC and CCS referral (if needed). 3. During RC eligibility determination, a multidisciplinary team identifies children with CP or high risk for CP to ensure that appropriate referrals are made. 4. For RC eligible child - Provide a service coordinator who can provide ongoing education to the parents on the potential for delays emerging over time & educate regarding the availability of Family Resource Center Support 5. Refer to CCS General Program and MTP and let CCS determine if eligible for both. (Assist the family with the application to CCS so all parts are completed.) 6. Provide therapy services that do not duplicate the medical therapy services provided by the Medical Therapy Unit (MTU) 7. Communicate with the infant's pediatrician/primary care provider about the coordination of care and referrals

California Children's Services (CCS): General Program: https://www.dhcs.ca.gov/services/ccs/Pages/ProgramOverview.aspx	
Roles	**Responsibilities**
1. Mandated program to provide medically necessary services for program eligible services for kids with CP. Ref: California Code of Regulations (CCR) Title 22/Division 2/Subdivision 7 California Children's Services) Ref: https://govt.westlaw.com/calregs 2. Mandated program to authorize and track HRIF services for those meeting NL criteria. Ref: Numbered Letter (NL) 05-1016 https://www.dhcs.ca.gov/services/ccs/Documents/ccsnl051016.pdf	1. Case find infants potentially eligible for CCS with the diagnosis of CP. 2. Assess for CCS General Program and MTP medical eligibility. 3. Authorize services to CCS paneled providers and CCS approved facilities e.g., Special Care Centers (SCC) to ensure care by board certified specialists in centers that meet CCS quality standards and to allow the providers to bill Medi-Cal (reimbursed 33% above Medi-Cal rates). 4. Track ongoing eligibility for services (via annual case reviews) and refer or authorize as needed. 5. Interact with families about CCS program benefits and resources for non-program benefits. 6. Coordinate care/service non-duplication/interagency reimbursement policies with Medi-Cal Managed Care. Ref: NL 02-0301 https://www.dhcs.ca.gov/services/ccs/Documents/CCSNL02-0301.pdf 7. Once eligible for CCS MTP, conduct medical therapy conferences with the pediatrician and coordinate care/information exchange with the primary care pediatrician and other subspecialists. 8. Refer to the Regional Center if not already connected; maintain nurse case manager and therapy representatives to each of the 7 RCs in Los Angeles County.

CCS: Medical Therapy Program https://www.dhcs.ca.gov/services/ccs/Pages/MTP.aspx	
Roles	**Responsibilities**
Mandated program to provide medically necessary OT and PT. Ref: CCR Title 22/Division 2/Subdivision 7 Chapter 3 Article 2 41517.5: https://govt.westlaw.com/calregs/Document/I3755FBE35B6111EC9451000D3A7C4BC3?viewType=FullText&originationContext=documenttoc&transitionType=CategoryPageItem&contextData=(sc.Default) Ref: CA Health & Safety Code Section 123872) https://law.justia.com/codes/california/2021/code-hsc/division-106/part-2/chapter-3/article-5/section-123872/	1. Oversee medically necessary therapy services related to the MTP eligible condition (e.g., CP). An interdisciplinary team of physician, OT, PT, nurse, social worker, and patient meet once or more per year during the Medical Therapy Conference. Early identification assessment of motor and neurological systems. 2. Provide medically necessary OT and PT including related recommendations (e.g., durable medical equipment, orthotics/prosthetics, assistive technology, home programs, home/community assessment) at the MTU. 3. Employ patient-centered collaborative practice, shared decision-making, and episodic care models to empower parents and ensure consistent parent participation during critical periods (e.g., infancy). 4. Provides "medical" vs. "educational" therapy. Coordinates with school-based therapists and educators to prevent duplicating services and consults about DME, orthotics, and therapy goals. Ref: NL 11-1600 https://www.dhcs.ca.gov/services/ccs/Documents/CCS-NL-11-1600.pdf 6. Collaborate with regional centers to coordinate care without duplicating services. Ref: NL 11-1600 https://www.dhcs.ca.gov/services/ccs/Documents/CCS-NL-11-1600.pdf 7. Participate in Individualized Education Program (IEP)/Individualized Family Service Plan (IFSP) meetings. 8. Participate in SCC appointments when needed.

Outpatient Pediatric Therapists	
Roles	**Responsibilities**
1. Direct care: Provide evaluation and short-term intervention for rapid start of therapy or an episode of care. 2. Direct care: Provide therapeutic services for children who may not be CCS eligible; communicate with service coordinators, families, and other therapists	1. Conduct evaluations and therapy services (e.g., after referral from a medical doctor. 2. Refer to EI/CCS as needed. 3. Contract with EI providers (e.g., RCs) to provide services for eligible children. 4. Participate in assessment of neurological status (HINE) and refer to CCS with notes on high-risk areas. 5. Participate in the Early Start Vendor Forum (a virtual meeting hosted by East Los Angeles Regional Center Early Start where service providers discuss policy (e.g., eligibility criteria) and other relevant topics. This platform can remind/educate service providers to look for early signs of CP and contact Service Coordinators to assist with CCS referral, etc.

Family Resource Center Network & Other Family Advocacy Groups https://communityinvestmentforfamilies.org/familysource-centers	
Roles	**Responsibilities**
Parent-to-parent support via a network of 45 Family Resource Centers (FRCs) for families of children birth – 3 years of age and beyond. The funding is part of the Early Start Program through the California Department of Developmental Services and is required through Part C of the Individuals with Disabilities Education Act (IDEA). Ref: https://www.dds.ca.gov/services/early-start/	1. Facilitate parent education workshops to assist families with identifying the early signs of CP and encourage follow-up with HRIF Clinic/CCS/Well-Child Exams. 2. Support the families navigating the early at risk or diagnostic period for CP and the many systems a child may need to access (medical, CCS, Early Start). Offer emotional support, information, community navigation (i.e., educational system) and training to families and individuals with or at risk of developmental and intellectual disabilities. 3. Support professionals to engage and understand families by providing opportunities for collaboration through community outreach and distribution of educational materials.

Medi-Cal Managed Care Plans	
Roles	**Responsibilities**
1. State and federal program mandated to authorize and pay for medically necessary services for eligible beneficiaries 2. Required to refer potentially eligible beneficiaries to CCS. Ref: Medi-Cal All Plan Letter 18-011 All Plan Letter 18-011	1. Examples: Blue Shield Promises (LA Care) and Molina (Health Net). 2. Refer potentially eligible beneficiaries to CCS (i.e., NICU, HRIF). 3. Some plans have specialized teams who case manage those with complex needs; these teams interact closely with the families to understand all programs for which the child may qualify e.g., CCS, Regional Center and refer as appropriate. They assign primary care physicians who have the skills and office capacity to care for children with complex needs. 4. Educate network providers about programs such as CCS