

Model Care Coordination Programs for CSHCN in California as Suggested by CA Advocacy Network Survey Respondents

PROGRAM	LOCATION	SETTING	POPULATION SERVED	USE OF CARE PLANS	REQUIREMENTS FOR CARE COORDINATOR	PROGRAM DESCRIPTION	CONTACT
California Children's Medical Services (CMS)/California Children's Services (CCS) High Risk Infant Follow-up (HRIF) Program	Each CCS-approved NICU is to have an organized HRIF Program for the provision of core diagnostic services, or a written agreement with another CCS-approved HRIF Program to provide these services.	Clinical Outpatient	Infants and children up to age 3 who have been discharged from a CCS-approved NICU.	Yes, dependent upon condition.	HRIF Coordinator must be one of the following: CCS-approved pediatrician or neonatologist; registered nurse, nurse specialist, or pediatric nurse practitioner (PNP); social worker (SW); occupational therapist (OT); physical therapist (PT); or a psychologist. The PNP can only be CCS-approved when functioning in the CCS HRIF Program as a HRIF Coordinator.	<p>The California Children's Services (CCS) HRIF program was established to identify infants who might develop CCS-eligible conditions after discharge from a CCS-approved Neonatal Intensive Care Unit (NICU). CCS Program standards require that each CCS-approved NICU ensure 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.</p> <p>The CCS Program's goal of identifying infants who may develop a CCS eligible medical condition with the CCS HRIF program provides for a number of diagnostic services for children up to three years of age. The following are reimbursable diagnostic services:</p> <ul style="list-style-type: none"> • Comprehensive history and physical examination with neurologic assessment; • Developmental assessment; • Family psychosocial assessment; • Hearing assessment; • Ophthalmologic assessment; and • Coordinator services (including assisting families in accessing identified, needed interventions and facilitating linkages to other agencies and services). 	Cynthia Ramirez, RN, MS 916-324-8906 HRIF@dhcs.ca.gov http://www.dhcs.ca.gov/services/ccs/Pages/HRIF.aspx#overview https://www.ccsrif.org/

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<p>California Children's Services (CCS)</p>	<p>Statewide, with county-based program administration</p>	<p>CCS-approved specialty care centers and hospitals, CCS paneled providers, and Medical Therapy Units (MTUs) in schools</p>	<p>1. Specialty Care for children aged 0 through 21 with a serious, eligible medical condition.</p> <p>2. Medical Therapy Program for children aged 0 through 21 with neuromuscular disease or with abnormal neurological examination or delays in motor skills.</p>	<p>Yes</p>	<p>CCS-approved pediatrician or pediatric specialist; registered nurse, nurse specialist, or pediatric nurse practitioner (PNP); social worker (SW); occupational therapist (OT); physical therapist (PT); or a psychologist.</p>	<p>Diagnosis-based eligibility for children with:</p> <ul style="list-style-type: none"> • Malignant neoplasms; benign in some circumstances • Endocrine, metabolic and immune system disorders • Most diseases of blood and blood-forming organs (e.g. hemophilia, sickle cell anemia) • Infections (congenital) • Disabling nervous system disorders (e.g. cerebral palsy); some seizure disorders (e.g. uncontrolled epilepsy) • Disease of the eye leading to blindness; strabismus when surgery required • Hearing loss; cholesteatoma • Most diseases of the heart, blood vessels, and lymphatic system • Respiratory diseases if they are chronic, disabling, or complicate other CCS eligible conditions (e.g. cystic fibrosis, chronic lung disease) • Chronic, inflammatory diseases of the liver, intestines, and chronic intestinal failure • Skin disorders if they are disabling or disfiguring • Chronic musculoskeletal and connective tissue diseases • Congenital anomalies if disfiguring or disabling and amenable to amelioration • Newborns requiring some NICU interventions • Accidents, poisonings, violence, immunization reactions which left untreated can result in permanent loss of function, disability or death <p>Types of Services:</p>	<p>Laurie A. Soman</p> <p>510-540-8293</p> <p>Lsoman@lpch.org</p> <p>www.criss-ca.org</p>
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						<ul style="list-style-type: none"> • Diagnostic services • High Risk Infant Follow-up • Treatment Services for CCS eligible conditions that may include: <ul style="list-style-type: none"> -Hospital and physician care -Laboratory and x-ray services -Durable medical equipment -Pharmacy -Home health -Home infusion -Interdisciplinary center care <p>Medical Therapy Program (typically in school-settings) provides occupational and physical therapy with no income eligibility limit.</p> <p>The level of CCS care coordination beyond medical case management varies among counties, given their different sizes and staffing capacity, but can include coordination of CCS and other services for the child and family by social workers, nurse case managers, and, in several counties, parent health liaisons under contract with local family resource centers.</p>	
<p>Comprehensive Hemophilia Diagnostic and Treatment Centers, supported by the federal Health Resources and Services Administration (HRSA)</p>	11 centers in California	Hospital-based centers	Children with hemophilia.	Yes	There are federal requirements for the composition of the care team, including: physicians (hematologists or blood specialists), nurses, social workers, and physical therapists.	There are 11 comprehensive hemophilia diagnostic and treatment centers (HTCs) in California. All are CCS Special Care Centers. HTCs are specialized health care centers that bring together a team of doctors, nurses, and other health professionals experienced in treating people with hemophilia in a comprehensive manner.	https://www2a.cdc.gov/ncbddd/htcweb/Dir_Report/Dir_Search.asp

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<p>First 5 San Diego, Healthy Development Services</p>	<p>San Diego County</p>	<p>County-wide service network with 6 regional coordination sites</p>	<p>Children residing in San Diego County who are under age 6 and not yet attending kindergarten.</p>	<p>Yes, based on initial assessment, clients are ranked by level of care needed. Those needing the lowest level of services may simply need a referral made on their behalf, compared to clients with higher levels of need who may benefit from help setting goals and overcoming barriers to services through a care plan.</p>	<p>Bachelor's Degree in a related field for Care Coordinator; Master's Degree is required for Lead Care Coordinator.</p>	<p>First 5 San Diego Healthy Development Services offer a comprehensive continuum of developmental and behavioral screening, assessment and treatment services, as well as vision and hearing screenings using 6 regional coordination sites.</p> <p>Trained Care Coordinators work closely with families, meet with team service providers on alternate months and hold quarterly Community Multidisciplinary Team Meetings to review client cases.</p> <p>Most care coordination is done by phone, including initial intake, assessment of family concerns, basic needs, and barriers. Motivational interviewing techniques are used to elicit detailed information regarding family needs and barriers. Care coordinators have access to appointment schedules and can reach out to providers to further coordinate care.</p>	<p>Nancy Page 619-230-6491 Nancy.page@sdcounty.ca.gov www.first5sandiego.org</p>
<p>Kaiser Permanente, Orange County Service Area, Pediatric Special Care Team</p>	<p>Orange County</p>	<p>Monthly, hospital-based meetings to review cases with active needs and evaluate systems and effectiveness.</p>	<p>Medi-Cal recipients with high-risk diagnoses, based on a list of potential conditions, which require collaboration and care coordination.</p>	<p>Yes, after each case discussion, a Recommendation and Action plan is developed and a participant is designated for follow-up about plan implementation at the next meeting.</p>	<p>Registered Nurse (RN) or Bachelor of Science in Nursing (BSN)</p>	<p>Aim is to improve quality of care and provide support to the families of pediatric patients affected by serious medical conditions using a coordinated, multidisciplinary approach to effectively manage these patients, preferably in the ambulatory setting.</p> <p>The goals of the program are to:</p> <ul style="list-style-type: none"> • Identify patients who would benefit from a multidisciplinary, multispecialty approach to care • Improve transitional care for patients and families who may require care in multiple settings • Enhance effective resource management by coordination of care among multiple specialties and settings • Coordinate and document 	<p>Manal Alawneh RN, MSN,CFSR (714) 572 -7084 Tie- Line 216</p>

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						<p>referrals to community resources</p> <ul style="list-style-type: none"> • Collaborate and coordinate with the child’s parent/caregiver in the development of a treatment plan <p>The program activities are:</p> <ul style="list-style-type: none"> • Conduct multidisciplinary care conferences for children diagnosed with complex medical conditions. Based upon the care conference a written treatment plan will be developed. The treatment plan will be included within the member’s ambulatory medical record. • Development of a comprehensive discharge plan for children identified as high risk for complications or re-admission. • Review cases at monthly meeting to review children’s cases with active needs and evaluate current systems and effectiveness. <p>The committee is multidisciplinary with expertise relevant to the medical condition of the child and family receiving services. The committee must include at a minimum three or more health care professionals from the disciplines below. Ad hoc members may be invited to the meeting based upon expertise and knowledge of patient and family.</p> <ul style="list-style-type: none"> • Pediatrician • Pediatric Sub-specialists • Registered Nurse • Social Services • Physical Therapy 	
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						<ul style="list-style-type: none"> • Occupational Therapy • Home Health • Dietary • Speech Therapy 	
<p>Kern County Medically Vulnerable Care Coordination Project (MVCCP)</p>	Kern County	<p>Monthly, hospital-based meetings to review client cases. Most cases are referred from the four local Neonatal Intensive Care Units.</p>	<p>Children with special health care needs (CSHCN) aged 0 through 5, and their families and providers.</p>	<p>No, but referrals incorporate hospital discharge summaries and an MVCCP <i>Acuity Scale</i> scoring sheet which are used to identify resources and treatments that may be required.</p>	<p>Registered Nurse and/or Public Health Nurse with at least 3 years of work experience.</p> <p>The care coordinator is housed in the Public Health Nursing division and charged with monitoring and improving care coordination between and among case managers working on behalf of the child and his/her family.</p>	<p>The Medically Vulnerable Care Coordination Project (MVCCP) facilitates coordinated services to measurably improve long term outcomes for children 0 through 5 years of age who are at risk of costly, lifelong medical and developmental issues. Begun in 2008, MVCCP is a collaboratively managed project between a First 5 Kern funded Project Director and the Kern County Public Health Services Department. The project has 40+ local and regional partner organizations who meet twice a month as a Workgroup of equal partners.</p> <p>The care coordinator completes regular tracking (at 6 – 12 month intervals) of referrals, including regularity and completion of health related appointments, medical and developmental procedures and services, and family access issues – with the goal of improving the system serving CSHCN and their families.</p> <p>An annual MVCCP conference brings together up to 200 local and regional partners, in Bakersfield for one day in November, to review the latest developments in care coordination and identify additional strategies to improve the system of services to CSHCN and their families.</p>	<p>Marc Thibault</p> <p>949-842-5671</p> <p>marc.thibault.llc@gmail.com</p> <p>http://kerncountymvccp.blogspot.com/</p>

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<p>KidSTART at Rady Children’s Hospital, San Diego</p>	<p>San Diego County</p>	<p>Multiple settings; on-site (diagnostic/treatment rooms and sensory gym) and in-home</p>	<p>Children with multiple, complex delays residing in San Diego County who are under the age of 6 and not yet in kindergarten.</p>	<p>Yes, providers share diagnostic impressions and then meet with the family to draft the care plan. The parent determines which steps to take first. The care plan is written to be parent-friendly and updated over time.</p>	<p>Masters level training in Social Work or a related field. Bilingual, Spanish-speaking is preferred.</p>	<p>An intensive program that performs triage, assessment, referrals and treatment for children with multiple, complex delays. Eligibility is based on four domains: developmental, social-emotional/mental health, family functioning and medical/physical health. Children are typically referred to KidSTART with one or more of the following: inconclusive assessment results (e.g. conflicting diagnoses provided by different providers), poor response to intervention, expulsions from preschool/childcare, chaotic family functioning, medical factors that contribute to developmental or social-emotional concerns. Treatment can include physical, occupational, speech, language and behavior therapies as well as parent/ child therapy and intensive parent support.</p> <p>Teams of clinicians are brought together based on the needs of each child, along with a care coordinator who serves as a liaison. Of the current open cases, approximately 46% of children in the program are also involved in the child welfare system. Care coordinators use motivational interviewing and reflective practice extensively to build trust, learn from the family and improve child-caregiver interactions. KidSTART also uses peer family partners to engage and support participants.</p> <p>The care coordinator may attend therapy appointments, meet with providers to update them on the family, and integrate other partners into the team. Families are typically involved with the program for up to 18 months, but may re-enter as other issues arise. Biological parents, foster parents, and relative caregivers are all involved in the treatment process.</p>	<p>Jeanne Gordon 858-966-5990 ingordon@rchsd.org http://www.rchsd.org/programs/services/a-z/i-k/kidstart/index.htm</p>
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Partners for Children, Medi-Cal Pediatric Palliative Care Program	Fresno, Los Angeles, Marin, Monterey, Orange, San Francisco, Santa Clara, Santa Cruz, and Sonoma Counties	In home	Medi-Cal and CCS recipients with life-threatening diseases.	Yes, each child has an F-CAP (Family-Centered Action Plan) which is used for assessment and documenting needs and services.	Minimum of three years clinical pediatric experience, a minimum of one year clinical End-of-Life experience and End-of-Life Nursing Education Consortium training (or equivalent) within the last five years.	Care coordination provided by a home health or hospice provider. Other services include expressive therapies, pain & symptom management, 24/7 on-call nursing, family support and training, grief and bereavement support, and respite. Home health aide services have been approved and will be an added service soon. Services are concurrent with curative and/or life-prolonging treatment. Children do not have to meet hospice eligibility prognosis of likely less than six months to live. Many children have been on the program for several years. Recent UCLA study demonstrated better outcomes and lower costs for children on the program.	Devon Dabbs 831-763-3070 x204 devon@childrenshospice.org http://www.chpcc.org/initiatives/
Pediatric Medical Home Program at University of California Los Angeles Children's Health Center (UCLA)	Los Angeles	Clinic based – part of the Medical Resident Teaching Clinic at UCLA	Medi-Cal recipients age 0 through 21 years (up to 25 years in the Adolescent/Young Adult Medical Home Program) with a CCS eligible condition and at least one other diagnosis requiring active subspecialty care. Patients must agree to receive their primary care through the UCLA Resident Clinic or the Adolescent Clinic.	Yes, care plans are maintained for each patient and integrated into the patient's Electronic Medical Record.	Administrative staff from a variety of backgrounds, including special education and hospice. They have previous experience in the medical setting and are bilingual in Spanish and English.	The Pediatric Medical Home Program at UCLA Children's Health Center helps families with chronically ill children to navigate the complicated health care system. Medical home patients are assigned a primary pediatric resident for their primary care physician. Patients work with a family liaison who facilitates communication with the UCLA medical team and helps coordinate follow-up appointments and procedures.	Carlos Lerner, MD 310-825-9346 clerner@mednet.ucla.edu http://www.uclahealth.org/medicalhome

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Pediatric Patient-Centered Medical Home Program, AltaMed General Pediatrics Clinic at Children's Hospital Los Angeles (CHLA)	Los Angeles	General Pediatrics Outpatient Clinic at CHLA	The program works with an underserved population with multiple ethnicities represented, and prioritizes children with complex special healthcare needs. As of November 2013, approximately 750 patients are receiving active case management through the program. 40% of the patients are CSHCN; 95% have Medi-Cal and 12.5% have California Children's Services benefits.	Yes	Licensed Nurse	A primary care model focused on providing intensive care coordination for medically complex CSHCN, modeled on the American Academy of Pediatrics medical home principles. Families are referred from pediatricians within AltaMed and other clinic settings. Once referred, families meet with a Care Coordinator to develop an individualized care plan and are provided with supportive services. Families receive follow-up every 3 months.	Mona Patel, MD 323-361-2990 mpatel@chla.usc.edu
Regional Centers, California Department of Developmental Services	21 centers with more than 40 field offices statewide.	Regional Centers and field offices	Person must have a developmental disability that begins before the person's 18th birthday, be expected to continue indefinitely and present a substantial disability. Infants and toddlers (age 0 through 36 months) who are	Yes	The requirements for "care coordinator" vary from center to center. Some require a BA in Social Work or a related field, with an MSW preferred.	Regional Centers provide diagnosis and assessment of eligibility and help plan, access, coordinate and monitor the services and supports that are needed because of a developmental disability. There is no charge for the diagnosis and eligibility assessment. Once eligibility is determined, a case manager or service coordinator is assigned to help develop a plan for services, tell clients where services are available, and help them get the services. Most services and supports are free regardless of age or income. Some of the services and supports provided	www.dds.ca.gov

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			at risk of having developmental disabilities or who have a developmental delay may also qualify for services.			by the regional centers include: <ul style="list-style-type: none"> • Information and referral • Assessment and diagnosis • Counseling • Lifelong individualized planning and service coordination • Purchase of necessary services included in the individual program plan • Resource development • Outreach • Assistance in finding and using community and other resources • Advocacy for the protection of legal, civil and service rights • Early intervention services for at risk infants and their families • Genetic counseling • Family support • Planning, placement, and monitoring for 24-hour out-of-home care • Training and educational opportunities for individuals and families • Community education about developmental disabilities 	
Watch Me Grow Collaborative Roundtable through Lucile Packard Children's Hospital, Developmental-Behavioral Pediatrics	San Mateo County	Regional Center Conference Room	Children aged 0 through 5 at risk for, or with, special health care needs.	Yes	Case-dependent, the child may have multiple care coordinators from different agencies working together with different requirements.	The Watch Me Grow Collaborative Roundtable is part of a comprehensive program funded by First 5 San Mateo County designed to develop the capacity of child-and family-serving systems in San Mateo County to serve and support children with special needs. The Roundtable is run by Developmental-Behavioral Pediatrics at the Lucile Packard Children's Hospital. The goal of the Roundtable is to develop the best plan of	Anne DeBattista, RN, MS, PhD(c) 650-725-8379 ADebattista@LPCH.ORG http://neonatology.stanford.edu/developmental/community/

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						care to address complex medical, developmental-behavioral, and educational needs for children birth through 5 years at risk for, or with special needs, using a case conference process. During a monthly case conference, agencies involved with the families provide information to the group. Experts from the field contribute to the discussion and help form a plan of action to alleviate problems the family is facing. This plan is then documented in the Roundtable minutes and reviewed at the end of each case discussion. Some children are then scheduled for follow-up discussions at the Roundtable.	
Watch Me Grow Demonstration Site through Community Gatepath	South San Francisco	This program has three settings: -Office site 1.5 blocks from South San Francisco Health Clinic -Two San Mateo Medical Center pediatric clinics (pilot: 10/2013) - One private pediatric clinic (pilot: 10/2013)	Children aged 0 through 5 living in catchment area and children 0 through 5 who are patients of the San Mateo Medical Center.	Yes	A Bachelor's degree is required or graduate degree preferred. Knowledge of typical and atypical development of children 0-5 years. Understanding of parent-child and family dynamics and the early intervention system. Extensive experience in multi-cultural service settings. Case management experience with families with children ages birth through five years. Bilingual Spanish/English oral and written fluency. Experience and knowledge of the range of agencies and services in San Mateo County for children	The Watch Me Grow Demonstration Site is part of a comprehensive program funded by First 5 San Mateo County designed to develop the capacity of child-and family-serving systems in San Mateo County to serve and support children with special needs. The Demonstration Site provides free developmental screening and coordinates and secures access to services and supports for children with special needs and their families in a designated community. The Demonstration Site community was selected based on school catchment areas with low API scores that lacked access to school readiness services. The program elements include: <ul style="list-style-type: none"> • Coordination with partner agencies and service providers, including a HIPAA compliant consent form to share and receive information • Outreach to families of children 0-5 years and providers re: developmental milestones and the benefits of early identification 	Cheryl Oku 650-635-0878 coku@gatepath.com www.gatepath.org

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					<p>with special health care needs. Experience working on a collaborative team or project. Demonstrated ability to build and maintain relationships with families and providers.</p>	<ul style="list-style-type: none"> • Screening: universal access to free developmental screening in English and Spanish for families in the demonstration site community, including 6 month follow-up & re-screening for children under 24 months and 12 month follow-up and re-screening for children 24-66 months. • Online developmental screening for children 0-5 whose family are San Mateo County residents (Pilot: 10/2013) • Triage and Referral: children identified through screening with developmental concerns and risk factors are discussed at a monthly interdisciplinary, multi-agency Child Study Team (including health, mental health and child development) which makes recommendations for further assessment or referral for services. • Care Coordination: families of children with developmental concerns and risk factors meet with a Care Coordinator to discuss their child's individual needs and to provide linkage to further assessment and services. • Parent Services: weekly parent-child groups support children identified with social-emotional needs, parents experiencing unusual stress and parents seeking support for parenting a young child. • Capacity Building: training for local providers on developmental screening tools (ASQ-3 and ASQ: SE) and systems 	
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						<ul style="list-style-type: none">• Community engagement through partnerships with local providers and Community Team meetings.	
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