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<th>PROGRAM</th>
<th>LOCATION</th>
<th>SETTING</th>
<th>POPULATION SERVED</th>
<th>USE OF CARE PLANS</th>
<th>REQUIREMENTS FOR CARE COORDINATOR</th>
<th>PROGRAM DESCRIPTION</th>
<th>CONTACT</th>
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| 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. | 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. 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:  
- 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.ccshrif.org/ |  
2/20/2014 |
| California Children’s Services (CCS) | Statewide, with county-based program administration | CCS-approved specialty care centers and hospitals, CCS paneled providers, and Medical Therapy Units (MTUs) in schools | Yes | 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. | Diagnosis-based eligibility for children with:
- 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

Types of Services:

Laurie A. Soman
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<p>| Comprehensive Hemophilia Diagnostic and Treatment Centers, supported by the federal Health Resources and Services Administration (HRSA) | 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. | <a href="https://www2a.cdc.gov/ncbddd/htcweb/Dir_Report/Dir_Search.asp">https://www2a.cdc.gov/ncbddd/htcweb/Dir_Report/Dir_Search.asp</a> |</p>
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<tr>
<th>Model Care Coordination Programs for CSHCN in California as Suggested by CA Advocacy Network Survey Respondents</th>
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<tr>
<td><strong>First 5 San Diego, Healthy Development Services</strong></td>
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<tr>
<td>San Diego County</td>
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<td>Children residing in San Diego County who are under age 6 and not yet attending kindergarten.</td>
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<tr>
<td><strong>Kaiser Permanente, Orange County Service Area, Pediatric Special Care Team</strong></td>
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referrals to community resources
• Collaborate and coordinate with the child’s parent/caregiver in the development of a treatment plan

The program activities are:
• 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.

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.
• Pediatrician
• Pediatric Sub-specialists
• Registered Nurse
• Social Services
• Physical Therapy
| Model Care Coordination Programs for CSHCN in California as Suggested by CA Advocacy Network Survey Respondents |
|---|---|---|---|---|---|
| Kern County Medically Vulnerable Care Coordination Project (MVCCP) | Kern County | Monthly, hospital-based meetings to review client cases. Most cases are referred from the four local Neonatal Intensive Care Units. | Children with special health care needs (CSHCN) aged 0 through 5, and their families and providers. | No, but referrals incorporate hospital discharge summaries and an MVCCP Acuity Scale scoring sheet which are used to identify resources and treatments that may be required. | 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. 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. 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. |

- Occupational Therapy
- Home Health
- Dietary
- Speech Therapy

Marc Thibault 949-842-5671 marc.thibault.llc@gmail.com http://kerncountymvccp.blogspot.com/

2/20/2014
<p>| KidSTART at Rady Children’s Hospital, San Diego | San Diego County | Multiple settings; on-site (diagnostic/treatment rooms and sensory gym) and in-home | Children with multiple, complex delays residing in San Diego County who are under the age of 6 and not yet in kindergarten. | 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. | Masters level training in Social Work or a related field. Bilingual, Spanish-speaking is preferred. | 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. 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. 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. | Jeanne Gordon 858-966-5990 <a href="mailto:jngordon@rchsd.org">jngordon@rchsd.org</a> <a href="http://www.rchsd.org/programs/services/a-z/i-k/kidstart/index.htm">http://www.rchsd.org/programs/services/a-z/i-k/kidstart/index.htm</a> |</p>
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<tr>
<th>Partners for Children, Medi-Cal Pediatric Palliative Care Program</th>
<th>Fresno, Los Angeles, Marin, Monterey, Orange, San Francisco, Santa Clara, Santa Cruz, and Sonoma Counties</th>
<th>In home</th>
<th>Medi-Cal and CCS recipients with life-threatening diseases.</th>
<th>Yes, each child has an F-CAP (Family-Centered Action Plan) which is used for assessment and documenting needs and services.</th>
<th>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.</th>
<th>Care coordination provided by a home health or hospice provider. Other services include expressive therapies, pain &amp; 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.</th>
<th>Devon Dabbs 831-763-3070 x204 <a href="mailto:devon@childrenshospice.org">devon@childrenshospice.org</a> <a href="http://www.chpcc.org/initiatives/">http://www.chpcc.org/initiatives/</a></th>
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<tr>
<td>Pediatric Medical Home Program at University of California Los Angeles Children’s Health Center (UCLA)</td>
<td>Los Angeles Clinic based – part of the Medical Resident Teaching Clinic at UCLA</td>
<td>Clinic based</td>
<td>Medi-Cal recipients age 0 through 21 years (up to 25 years in the Adolescent/Youn g 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.</td>
<td>Yes, care plans are maintained for each patient and integrated into the patient’s Electronic Medical Record.</td>
<td>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.</td>
<td>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.</td>
<td>Carlos Lerner, MD 310-825-9346 <a href="mailto:clerner@mednet.ucla.edu">clerner@mednet.ucla.edu</a> <a href="http://www.uclahealth.org/medicalhome">http://www.uclahealth.org/medicalhome</a></td>
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<td>Pediatric Patient-Centered Medical Home Program, AltaMed General Pediatrics Clinic at Children’s Hospital Los Angeles (CHLA)</td>
<td>Los Angeles</td>
<td>General Pediatrics Outpatient Clinic at CHLA</td>
<td>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.</td>
<td>Yes</td>
<td>Licensed Nurse</td>
<td>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.</td>
<td>Mona Patel, MD 323-361-2990 <a href="mailto:mpatel@chla.usc.edu">mpatel@chla.usc.edu</a></td>
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<td>Regional Centers, California Department of Developmental Services</td>
<td>21 centers with more than 40 field offices statewide.</td>
<td>Regional Centers and field offices</td>
<td>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</td>
<td>Yes</td>
<td>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.</td>
<td>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.</td>
<td><a href="http://www.dds.ca.gov">www.dds.ca.gov</a></td>
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### Model Care Coordination Programs for CSHCN in California as Suggested by CA Advocacy Network Survey Respondents

| 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/](http://neonatology.stanford.edu/developmental/community/) |

services.

by the regional centers include:

- 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

at risk of having developmental disabilities or who have a developmental delay may also qualify for services.
Model Care Coordination Programs for CSHCN in California as Suggested by CA Advocacy Network Survey Respondents

| 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 multicultural 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:  
- 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 |

2/20/2014
| with special health care needs. Experience working on a collaborative team or project. Demonstrated ability to build and maintain relationships with families and providers. | • 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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<td></td>
<td><strong>Community engagement through partnerships with local providers and Community Team meetings.</strong></td>
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