

**California Department of Public Health/Maternal, Child and Adolescent Health
Division (CDPH/MCAH)
Children with Special Health Care Needs**

Background and Purpose:

Enacted in 1935 as part of the Social Security Act, Title V is a partnership with State Maternal and Child Health and Children with Special Health Care Needs (CSHCN) programs, reaching across economic lines to support such core public health functions as resource development, capacity and systems building, population-based functions such as public information and education, knowledge development, outreach and program linkage, technical assistance to communities, and provider training.

States are required to use at least 30 percent of Federal Title V funds for preventive and primary care services for children and at least 30 percent for services for children with special health care needs.

In California, CDPH/MCAH allocates a portion of the 30 percent requirement to serve CSHCN to the Department of Health Care Services/Systems of Care Division (SCD) through the California Children's Services Program (CCS). The SCD/CCS program provides diagnostic and treatment services, medical case management, and physical and occupational therapy services to children under age 21 with a CCS- eligible medical condition. The explicit legislative intent of the CCS program is to provide necessary medical services for children with CCS medically eligible conditions whose parents are unable to pay for these services wholly or in part. The other portion of the 30 percent is used by CDPH/MCAH to support non-CCS CSHCN and their families or children enrolled in CCS in need of services not covered by CCS such as developing systems of care, interagency collaboration, especially with SCD/CCS, assisting local health jurisdictions (LHJs) to develop programs that identify and serve all CSHCN, including non-CCS CSHCN, case management, and outreach, screening and linking to appropriate services.

In order to meet the Department of Health and Human Services, Health Resources and Services (HRSA) Administration, Maternal and Child Health Bureau (MCHB) requirement to use 30 percent of Title V funds for services for CSHCN, CDPH/MCAH, along with a workgroup of MCAH Directors, has identified activities that may serve CSHCN.

Federal Definitions¹

CSHCN are defined by HRSA/MCHB as follows:

Children with Special Health Care Needs are defined as infants and children from birth through 21st year who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

This definition is broad and inclusive, and it emphasizes the characteristics held in common by children with a wide range of diagnoses which may include conditions such as, depression, attention deficit disorder, behavioral problems, asthma, diabetes, migraines or frequent headaches, head injury or traumatic brain injury, arthritis, joint problems, allergies, heart problems, autism, and intellectual disability or mental retardation. CSHCN are children who have health problems requiring more than routine and basic care including children with or at risk of disabilities, chronic illnesses and conditions, and health-related education and behavioral problems.

Please see the National Survey of Children with Special Health Care Needs (2009/10) for a list of **some** of the functional difficulties and health conditions that children may experience <http://www.childhealthdata.org/docs/cshcn/2009-cshcn-conds-func-diff.pdf?sfvrsn=4>

The MCHB, together with its partners, has identified six core outcomes to promote the community-based system of services mandated for all children with special health care needs. These outcomes give us a concrete way to measure our progress in making family-centered care a reality and in putting in place the kind of systems all children with special health care needs deserve. Progress toward the overall goal can be measured using these six critical outcomes:

1. Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive
2. Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home
3. Families of CSHCN have adequate private and/or public insurance to pay for the services they need
4. Children are screened early and continuously for special health care needs
5. Community-based services for children and youth with special health care needs are organized so families can use them easily
6. Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

¹ Health Resources and Services Administration, The National Survey of Children with Special Health Care Needs, Chartbook 2005-2006, Retrieved from: <http://mchb.hrsa.gov/cshcn05/>,

CSHCN Constructs of a Service System²

1. State Program Collaboration with other State Agencies and Private Organizations

States establish and maintain ongoing interagency collaborative processes for the assessment of needs with respect to the development of community-based systems of Services for CSHCN, State programs collaborate with other agencies and organizations in the formulation of coordinated policies, standards, data collection and analysis, financing of services, and program monitoring to assure comprehensive, coordinated services for CSHCN and their families.

2. State Support for Communities

State programs emphasize the development of community-based programs by establishing and maintaining a process for facilitating community systems building through mechanisms such as technical assistance and consultation, education and training, common data protocols, and financial resources for communities engaged in systems development to assure that the unique needs of CSHCN are met.

3. Coordination of Health Components of Community-Based Systems

A mechanism exists in communities across the state for coordination of health services with one another. This includes coordination among providers of primary care, facilitative and rehabilitative services, and other specialty medical treatment services, mental health services and home health care.

4. Coordination of Health Services with other Services at the Community Level

A mechanism exists in communities across the State for coordination and service integration among programs serving CSHCN, including early intervention and special education, social services, and family support services.

Suggested Activities for Children with Special Health Care Needs:

Community-Based Services:

1. Work with CCS and/or collaboratives to:
 - a. Improve care coordination for CSHCN, especially non-CCS eligible children or children enrolled in CCS in need of services not covered by CCS
 - b. Link children with positive screens to needed services
 - c. Disseminate standard messaging regarding developmental screening to increase community awareness of the need for early identification and intervention of CSHCN

² Health Resources and Services Administration, Maternal and Child Health. Title V Information Glossary. Retrieved from: <https://mchdata.hrsa.gov/tvisreports/Glossary.html>

2. Outreach activities to enroll children into public and private insurance coverage
3. Facilitate continuity of care during periods of enrollment or changes in insurance coverage to ensure that a mechanism is in place for identifying and referring CSHCN to appropriate enhanced care
4. Enhance collaboration at the local level by including CCS in the dissemination of health communications, statistical reports, and local MCAH and home visiting advisory group meetings
5. Inform providers of existing services for CSHCN
6. Develop mechanisms for providers to refer clients to appropriate programs, such as the California Home Visiting Program and to refer clients from home visiting and health screening programs to CCS
7. Partner with local organizations that provide services to CSHCN to improve systems of identification, referral, and linkage of CSHCN to needed services
8. Build systems to link CSHCN and their families to needed services
9. Identify barriers and opportunities to improve services for CSHCN
10. Work with school districts to identify and refer children with specialized health and developmental needs
11. Develop resource information about services available for CSHCN

Identifying CSHCN – Screening, Assessment, and Referral

1. Promote health and developmental monitoring, screening, identification, and referral, including social-emotional (mental health) for infants and children using a validated screening tool. Assist providers to institute policies/protocols to perform routine screening on all children
2. Promote routine screening for physical health, oral health, mental health, developmental and psychosocial needs, and culturally and linguistic needs, as part of a well-child visit or other preventive visit and in response to triggering events (trauma, new symptoms, hospitalization) in order to identify non-CCS CSHCN or children at risk
3. Facilitate communication of health and developmental screening results and any identified referral needs to the child's medical home and family and, as feasible, coordinate among screening entities
4. Develop and ensure protocols are in place for routine screening, referral, and follow-up to ensure care is received and barriers are addressed.

Providing Services

1. Assist parents/caregivers to access appropriate services for CSHCN
2. Teach parents/caregivers how to care for and advocate for their child with special health care needs.
3. Identify and provide training regarding special equipment available for children in need, such as automobile child restraint systems for physically impaired children.
4. Provide home visiting services to support parents/caregivers as they care for CSHCN. Coordinate with other service providers to ensure that the plan of care is followed.

5. Develop or facilitate support groups for parents/caregivers of CHSCN
6. Facilitate referrals and linkages to specialty health and developmental services for high-risk infants due to prematurity or other health-related conditions
7. Facilitate referrals and linkages for parents/caregivers of infants to specialty services to address bonding or attachments issues
8. Conduct activities to support CSHCN and their families in self-management and advocacy of the child's needs
9. Conduct activities for CSHCN to promote quality of life, healthy development, and healthy behavior across the lifecourse, including the prevention of secondary conditions to prevent and avert deterioration
10. Assist parents/caregivers to identify appropriate child care providers for their CSHCN as they return to work or school
11. Provide information to parents/caregivers of young children about the signs of healthy development and the need to act early if they feel there is a problem or are concerned
12. Develop programs using public health nurses to provide case management and/or home visiting to high risk pregnant and parenting women and their families, the uninsured, underinsured, families with complicated lives, etc. Include policies to monitor, screen and refer all children for health and developmental delays using a validated screening tool.
13. Develop relationships with providers, school administrators and other organizations that work with children to facilitate understanding of school readiness, developmental milestones, mental health issues, signs of child abuse/neglect and the process to monitor, screen, refer and link a child to appropriate services

Facilitating Care Coordination

1. Ensure staff working with families and children demonstrate competency by providing and/or attending training appropriate programs
2. Facilitate and/or participate in interagency coordination and collaboration, For example, work with CCS, Family Resource Centers, Head Start, Local Educational Agencies, Early Start, Regional Centers (Department of Developmental Services), hospitals, school nurses, Federally Qualified Health Centers, Rural Health Clinics, First 5 and other agencies serving CSHCN to improve the system of care
3. Explore opportunities to fund staff positions in other agencies to facilitate interagency coordination focused on CSHCN
4. Educate agencies and individuals regarding the rights of CSHCN
5. Standardize data collection/reporting on care coordination services for CSHCN
6. Involve parents/caregivers and families in care coordination for CSHCN
7. Provide forums for families to identify ways services for CSHCN can be better coordinated and delivered, including transportation assistance
8. Assist to develop policies, processes and resources for youth with special health care needs as they transition to adult care systems to ensure continuity

- of medical care, continued skill building, and access to other community supports
9. Work with organizations that serve adults with special health care needs to develop an effective referral system and services for youth transitioning to adult service
 10. Develop relationships with organizations that work with foster or incarcerated youth to screen, refer, and link youth with positive screens for physical, mental or developmental needs to appropriate services
 11. Involve CSHCN in a Youth Advisory Council providing input to programs serving children and youth

Resources:

1. Standards for Systems of Care for Children and Youth with Special Health Care Needs, March 2014. A product of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project. Retrieved on February 12, 2015 from <http://www.amchp.org/AboutAMCHP/Newsletters/member-briefs/Documents/Standards%20Charts%20FINAL.pdf>
2. Utah Department of Public Health; Children with Special Health Care Needs: Retrieved on February 12, 2015 from <http://www.health.utah.gov/cshcn/>
3. National Center for Medical Home Implementation: Children and Youth with Special Health Care Needs: Retrieved on February 12, 2015 from: http://www.medicalhomeinfo.org/how/care_delivery/cyshcn.aspx
4. Lucille Packard Foundation for Children's Health: Program for Children with Special Health Care Needs: Retrieved on February 12, 2015 from: <http://lpfch-cshcn.org/>