

**APPENDIX 12: CHILDREN'S MEDICAL SERVICES BRANCH,
CALIFORNIA DEPARTMENT OF HEALTH SERVICES CALIFORNIA
STATEWIDE STRATEGIC PLAN FOR CHILDREN WITH SPECIAL
HEALTH CARE NEEDS, 2006-2010**

**Children's Medical Services Branch, California Department of Health Services
California Statewide Strategic Plan for Children with Special Health Care Needs
2006 - 2010**

Introduction

In August 2005, the State Children's Medical Services Branch (CMS) of the California Department of Health Services convened a nine-month strategic planning process on behalf of children with special health care needs (CSHCN). The planning effort was funded by the federal Champions for Progress, a Maternal and Child Health Bureau (MCHB) initiative to support state efforts to develop a statewide strategic plan to meet the needs of CSHCN. California's state plan is intended to assist the state in reaching the national MCHB core performance measures for CSHCN. These core performance measures are:

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

The federal MCHB definition of CSHCN is broad and includes children "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." In California, these children and their families are served by a variety of public and private agencies and many children are clients of more than one of these programs, each with its unique procedures for eligibility determination, referral and data collection. This plan focuses on those children eligible for the state California Children's Services (CCS) program within the CMS Branch, while recognizing the importance of improving communication and coordination among systems serving all CSHCN and their families.

The state strategic plan for CSHCN is part of a three-pronged effort by the Children's Medical Services Branch to achieve a statewide system of care for these children:

1. State Children's Medical Services Branch Needs Assessment

The Champions planning process is built on a needs assessment for CSHCN conducted in 2005 by the Family Health Outcomes Project (FHOP) at UCSF for the Children's Medical Services Branch as part of the state's Title V Block Grant application. The needs assessment employed a broadly representative stakeholder group to identify the top priority issues for the Branch (see the list of priorities in the Appendix).

2. Champions for Progress State Strategic Plan

The Champions project convened the stakeholders group from the needs assessment project in order to develop the strategic plan (see stakeholder list in the Appendix). The stakeholder group adopted the following vision statement, developed by an earlier Task Force on Children with Special Health Care Needs, in which many of the Champions members participated, that

was convened by the State Medi-Cal Managed Care Division to improve the quality of care of CSHCN enrolled in managed care plans:

Vision for Children with Special Health Care Needs: All children with special health care needs will be identified and will have access to quality health care that is:

- ***family-centered and supportive***
- ***community-based***
- ***coordinated and seamless***
- ***effective, appropriate, and efficient***
- ***culturally and linguistically effective. (August, 2003)***

The Champions stakeholder group met seven times over nine months in professionally facilitated work group meetings to consider strategies that would assist the state to achieve the six MCHB core performance measures and to meet the priorities identified by the state in its needs assessment process. The core performance measures serve as the goals for the plan, with specific and measurable objectives and action steps, and assignments of responsibility for implementing the objectives. (Note: Some of the performance measures/goals include a section with recommended strategies that require legislative action. While these recommendations are beyond the purview of the State CMS Branch, they may be adopted and pursued by advocacy groups.)

Each stakeholder was charged with assisting in developing strategies for action, circulating draft documents within member organizations for feedback and support, and reaching consensus within the group on a final plan. The Champions planning process was convened by Dr. Marian Dalsey, chief of the Children's Medical Services Branch; facilitated by Carolyn Verheyen of Moore Iacofano Goltsman; and staffed by Juno Duenas, Family Voices of California; Kathryn Smith, Los Angeles Partnership for Special Needs Children; and Laurie A. Soman, Children's Regional Integrated Service System (CRISS) Project.

3. Federal MCHB Grant: "Implementing Integrated Systems of Care for CSHCN"

This federally funded project, conducted by Juno Duenas, Kathryn Smith, and Laurie A. Soman under the auspices of the USC University Center of Excellence in Developmental Disabilities at Children's Hospital Los Angeles in collaboration with Children's Medical Services, will promote implementation of the state plan strategies both statewide and regionally. The Champions stakeholder group will serve as the advisory group to the MCHB grant and will continue to meet on a quarterly basis to review and comment on implementation progress through June, 2008.

Glossary of Terminologies

Acronyms/Abbreviations	
AAP	American Academy of Pediatrics
AAFP	American Academy of Family Physicians
CAFP	California Academy of Family Physicians
CCHA	California Children's Hospital Association
CCS	California Children's Services
CDE	California Department of Education
CHA	California Hospital Association
CHDP	Child Health and Disability Prevention Program
CHEAC	County Health Executives Association of California
CMA	California Medical Association
CMS	Children's Medical Services
CPT	Current Procedural Terminology
CRISS	Children's Regional Integrated Services System
CSCC	Children's Specialty Care Coalition
CSHCN	Children with Special Health Care Needs
CSIM	California Society of Internal Medicine
DMH	Department of Mental Health
DDS	Department of Developmental Services
DME	Durable Medical Equipment
DOR	Department of Rehabilitation
DSS	Department of Social Services
EDS	Electronic Data Systems Corporation
FPL	Federal Poverty Level
FRC	Family Resource Center
FRCN	Family Resource Center Network
FVCA	Family Voices of California
HMO	Health Maintenance Organization
GHPP	Genetically Handicapped Persons Program
HRIF	High Risk Infant Follow-up
ICC	Interagency Coordinating Council
IEP	Individual Education Plan
HRSA/MCHB	Health Resources and Services Administration/Maternal and Child Health Bureau
KP	Kaiser Permanente
LAPSNC	Los Angeles Partnership for Special Needs Children
MH	Medical Home
MC/MC	Medi-Cal Managed Care
MNIHA	Medically Necessary Interperiodic Health Assessment
MOD	March of Dimes
MOU	Memorandum of Understanding
MRMIB	Managed Risk Medical Insurance Board (administers Healthy Families program)
MTP	CCS Medical Therapy Program
NICU	Neonatal Intensive Care Unit
OSHPD	Office of Statewide Health Planning and Development
PAI	Protection and Advocacy, Inc
PHL	Parent Health Liaison
PHN	Public Health Nurse
PPO	Preferred Provider Organization
RC	Regional Center

SCC	Special Care Center
Special Ed	Special Education
SPOE	Single Point of Entry
YSHCN	Youth with Special Health Care Needs
Other Terms	
100% Campaign	A coordinated effort of Children Now, Children's Defense Fund, Children's Partnership, and the California Endowment to ensure that all children in California have access to affordable, comprehensive health insurance.
CAHMI CSHCN Screener©	The CSHCN Screener© is a five item, parent survey-based tool for identifying CSHCN and was developed through the efforts of the Child and Adolescent Health Measurement Initiative (CAHMI), based on the MCHB definition for CSHCN. Children are identified on the basis of experiencing one or more current functional limitations or service use needs that are the direct result of an on-going physical, emotional, behavioral, developmental or other health condition.
First Five California	First Five California is designed to provide, on a community-by-community basis, all children prenatal to five years of age with a comprehensive, integrated system of early childhood development services. Approved by voters in 1998, Proposition 10 was the ballot initiative that established the California Children and Families Program and the State Commission, and authorized the establishment of county commissions, since renamed First Five.
Screening	The examination of a group of usually asymptomatic individuals to detect those with a high probability of having or developing a given disease or condition.
Surveillance	A type of observational study that involves continuous monitoring of disease or condition occurrence within a population.

Core Measure — FAMILY PARTNERSHIP/SATISFACTION: Families of children with special health care needs (CSHCN) will partner in decision-making at all levels and will be satisfied with the services they receive.

S T R A T E G I E S A N D A C T I O N S

1. Promote family-centered care at the local level by creating and promoting best practices standards for relationships between county California Children's Services (CCS) and local Family Resource Centers (FRC):
 - A. Require Parent Health Liaison (PHL) positions with % FTE in state staffing standards
 - Establish family advisory group with regular meetings
 - Consider contracts with local FRCs for position
 - Evaluate best practices for working with family organizations
 - Assist in educating local administrators and supervisors re: importance of funding position
 - B. Conduct random sample interviews with families regarding CCS services
 - C. Develop standard statewide survey to evaluate family satisfaction with CCS services.
 - D. Promote better communications between CCS and families to improve understanding of program and decisions through family contact on all new applications (i.e., person to person) and follow-up phone calls to families regarding official letters (denial for services, service changes)

Responsibility: State CMS, Family Voices of California (FVCA), County Health Executives Association of California (CHEAC)
2. Promote family friendly CCS service delivery in CCS Special Care Centers (SCC) by building standards for family-centered care into SCC standards, e.g.:
 - A. Ensure family participation in SCC team meetings
 - B. Educate families regarding SCC process and services
 - C. Educate professionals regarding family issues
 - D. Include attention to linguistic/cultural appropriateness
 - E. Provide training to SCC office staff in family friendly concepts and approaches

Responsibility: State CMS, Health Resources and Services Administration/ Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB) grant staff
3. Design and implement strategies so that families (including youth) are represented and will partner at all levels, e.g.:
 - A. Collect existing research and analyze prior surveys and focus groups with families to inform strategies
 - B. Consider currently used models such as family-to-family team based decision-making model used for children in out of home placement (Annie E. Casey Foundation) and parent/professional team teaching model
 - C. Customize information for individual child and family
 - D. Determine and communicate a range of opportunities for parent involvement at each level of decision making, including State CMS/FVCA advisory committee
 - E. Involve families in assessing CMS current level of practice and efficacy in family participation and satisfaction
 - F. Increase resources of FRC Councils to expand parent involvement and coordination for families
 - G. Survey different service systems to determine involvement of families in decision-making
 - H. Assess family satisfaction with cross-systems services

Responsibility: State CMS, FVCA, CCS Executive Committee with local programs

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

STRATEGIES AND ACTIONS (FAMILY PARTNERSHIP/SATIS. continued)

4. Design and implement education for families and youth when family/youth enter program and offer ongoing to make sure families stay involved.

** See the Appendix on "Training and Outreach" for details*

Responsibility: State CMS, Family Advisory Council to State CMS, FVCA

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

Core Measure — **MEDICAL HOME**: All children with special health care needs (CSHCN) will receive regular ongoing comprehensive care within a medical home.

S T R A T E G I E S A N D A C T I O N S

1. **Collect data on pediatricians/other medical providers serving CSHCN:**
 - A. **Collect data on number of pediatricians, pediatric sub-specialties, and other providers in the state and by region, their availability geographically and by payer source (including Medi-Cal), percentage of CSHCN seen by pediatricians, etc., e.g. from American Academy of Pediatrics (AAP), Children’s Specialty Care Coalition (CSCC), California Children’s Hospital Association (CCHA), and other sources**
 - B. **Collect information from HMOs/Medi-Cal Managed Care (MC/MC)/Healthy Families/Healthy Kids plans on how they identify CSHCN and policies for assigning CSHCN to primary care providers (PCP)**

Responsibility: State CMS as lead, Electronic Data Systems Corporation (EDS), Office of Statewide Health Planning and Development (OSHPD), AAP, California Medical Association (CMA), CSCC, MC/MC, Managed Risk Medical Insurance Board (MRMIB), Health Plans, CCHA
2. **Identify strategies to retain/increase number of California Children’s Services (CCS) providers (including pediatric specialists, PTs/OTs, and vendored services such as DME), e.g. via work with AAP and CSCC; Identify appropriate pediatric and pediatric sub-specialty providers who are not paneled and assist them in paneling**

Responsibility: State Children’s Medical Services (CMS) as lead, CSCC, AAP

3. **Activate state Medi-Cal billing codes for care coordination**
 - A. **Establish definitions of and standards for care coordination for medical home providers**
 - B. **Collect information regarding Special Care Center (SCC) care coordination billing, e.g., how it is billed, payment received**
 - C. **Determine how to implement use of care coordination Current Procedural Terminology (CPT) codes for billing**

Responsibility: State CMS, Family Voices of California (FVCA)
4. **Define medical home, PCP, and care coordination, including CCS role in each**

Responsibility: State CMS, FVCA

5. **Promote a system that assures that care coordination appropriate to each child is provided (e.g. establishment of a primary care coordinator for each child)**

Responsibility: State CMS, FVCA advisory committee

6. **Ensure that all CSHCN have a PCP and/or medical home (MH)**
 - A. **Develop a set of questions to ask parents to identify the child’s medical home for use by all service systems**
 - B. **Local CCS programs will work with Child Health and Disability Prevention (CHDP) program, health plans, and Healthy Families staff to identify PCP/MH for every CSHCN**
 - C. **Establish PCP/MH as a required field in CMS-Net with at least annual updates**
 - D. **Encourage all systems to ask families regarding their access to a PCP/MH**

Responsibility: State CMS, local CCS/CHDP programs, local CMS, health plans, with Department of Mental Health (DMH), Department of Developmental Services (DDS), etc., FVCA
7. **Ensure that CCS-approved major hospital facilities have on-site CCS care coordinators who can work across county lines and address all children regardless of county of residence.**

Responsibility: State CMS

Items that appear in bold overlap with goals outlined in California’s FFY 2006-2010 Title V Implementation Plan.

STRATEGIES AND ACTIONS (MEDICAL HOME continued)
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8. Enhance CCS SCC standards to include expectations regarding communication with PCPs and provide training to SCC staff regarding strategies to achieve better communication (e.g. improving information flow to specialists from PCPs and reports back to PCPs from specialists)
Responsibility: State CMS
9. **Develop and conduct continuing education and trainings on medical home and system of care for CSHCN**, building on existing trainings and adapting or develop additional materials as necessary, and addressing the following:
 - A. **Providers** including how to partner with clients
 - B. Family and youth regarding medical homes and how to partner with others
 - C. CCS staff training regarding what a medical home is, how to talk about it, and how to partner

** See the Appendix on "Training" for details*
Responsibility: State CMS, Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB) implementation grant staff, FVCA, AAP, Health Plans, county CCS programs
10. Conduct training programs on the use of parent notebooks to enhance records organization and to increase communication between parents and providers
Responsibility: State CMS, HRSA/MCHB grant staff, FVCA
11. Locate funding to support local medical home projects with family and CCS participation
Responsibility: State CMS

Priority Issues that Require Legislative Action

The following recommendations were identified as priorities but require action in the legislative arena. State CMS will monitor progress on these recommendations and provide technical assistance when requested:

1. Pursue separate appropriation/additional funds for care coordination for medical home providers
Responsibility: CSCC, AAP, CCHA, CMA, other advocates
2. Streamline approval process for obtaining Medi-Cal provider number to reduce 180-day wait for PCPs and specialists
Responsibility: CSCC, CCHA
3. Maintain existing carve-out of CCS services from Medi-Cal and Healthy Families managed care plans
Responsibility: CSCC, AAP, CCHA, CMA, other advocates

It is understood that all groups suggested to undertake implementation of legislative priorities must take recommendations to their boards/leadership groups in order to set priorities for legislative action.

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

Core Measure — INSURANCE: All families of children with special health care needs (CSHCN) will have adequate private and/or public insurance to pay for the services they need.

S T R A T E G I E S A N D A C T I O N S

1. Change California Children's Services' (CCS) program policy to refer all children to all sources of available insurance, including Healthy Families, county Healthy Kids programs, Kaiser Permanente (KP) Cares for Kids, and Medicaid waiver programs
** See the Appendix on "Outreach" for details on outreach strategies*
Responsibility: State Children's Medical Services (CMS)
2. Promote CMS participation in health care financing discussions at all levels of state government
Responsibility: State CMS, advocacy groups, health plans
3. Link state and local CCS programs and other agencies serving CSHCN with funded outreach programs and projects promoting insurance coverage for children (e.g. Governor's coverage initiatives, other campaigns)
Responsibility: CMS
4. Review existing Medicaid waivers and consider opportunities for expansion to include additional youth, e.g. for Medi-Cal "deeming" for additional youth with special health care needs (YSHCN)
Responsibility: CMS, Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB) implementation grant staff

Priority Issues that Require Legislative Action

The following recommendations were identified as priorities but require action in the legislative arena. State CMS will monitor progress on these recommendations and provide technical assistance when requested:

1. Protect and increase access to the CCS program via the following legislative steps:
 - A. Deem children enrolled in Healthy Kids programs eligible for CCS
 - B. Restore CCS financial eligibility limit to \$100,000
 - C. Link CCS financial eligibility to Federal Poverty Level (FPL) to consider family size and income*Responsibility: California Children's Hospital Association (CCHA), Children's Specialty Care Coalition (CSCC), American Academy of Pediatrics (AAP), other advocates*
2. Amend State Insurance Code to require private Health Maintenance Organizations (HMO)/Preferred Provider Organizations (PPO) to meet CCS pediatric standards of care
Responsibility: CCHA, CSCC, AAP, other advocates
3. **Increase Medi-Cal and Healthy Families reimbursement for practitioners serving CSHCN and protect against rate cuts**
Responsibility: CSCC, CCHA, AAP, other advocates
4. Ensure insurance coverage for all uninsured CSHCN, regardless of income
 - A. Strengthen and standardize Healthy Kids programs by setting statewide standards and financial eligibility criteria
 - B. Create state buy-in for Medi-Cal for CSHCN (modeled on the federal Family Opportunities Act)
 - C. Eliminate pre-existing condition barriers under private individual insurance coverage for youth aging out of CCS*Responsibility: Advocates*

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

S T R A T E G I E S A N D A C T I O N S (INSURANCE continued)
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5. Advocate for accessible health coverage for YSHCN:
 - A. Modify financial eligibility for Medi-Cal for YSHCN, e.g. by increasing percentage of FPL covered for youth
 - B. Extend benefits for YSHCN under parental coverage to specific age (e.g., 24 years)
 - C. Consider extending CCS-type coverage for certain medical conditions for YSHCN > 21 years of age, e.g.:
 - Maintain coverage for CCS-eligible children with metabolic conditions beyond age 21
 - Cover adrenal hyperplasia/other conditions identified in newborn screenings
 - Add other chronic conditions requiring continued specialty care

Responsibility: AAP, CSCC, CCHA, California Medical Association (CMA), American Academy of Family Physicians (AAFP), California Society for Internal Medicine (CSIM), California Hospital Association (CHA), 100% Campaign, Protection and Advocacy Inc (PAI), other advocates

It is understood that all groups suggested to undertake implementation of legislative priorities must take recommendations to their boards/leadership groups in order to set priorities for legislative action.

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

Core Measure — SCREENING: All children will be screened early and continuously for special health care needs.

S T R A T E G I E S A N D A C T I O N S

1. Ensure that children get both periodic and inter-periodic visits as needed
 - A. Broaden/publicize opportunities for inter-periodic screenings for Child Health and Disability Prevention (CHDP) program for children without other coverage
 - B. Educate providers regarding maximum visits available under CHDP and Medi-Cal (including continuous screening for health, developmental, mental health issues) and how to use Medically Necessary Interperiodic Health Assessment (MNIHA)

Responsibility: American Academy of Pediatrics (AAP)
2. Identify and implement standardized screening tool to identify Children with Special Health Care Needs (CSHCN), e.g., Child and Adolescent Health Measurement Initiative (CAHMI) screener, Health Net screener

Responsibility: State Children’s Medical Services (CMS), Medi-Cal Managed Care (MC/MC), Managed Risk Medical Insurance Board (MRMIB), health plans, Department of Mental Health (DMH)
3. Institutionalize funding and billing mechanism(s) for administration of developmental, behavioral and mental health screenings, using existing standardized tools accepted in the field
 - A. Include screening in annual Special Care Center (SCC) evaluations and institutionalize in SCC standards
 - B. Ensure that appropriate staff, including SCC staff, are trained to administer tools

Responsibility: State CMS, Medi-Cal, County Mental Health Directors, State First 5, Department of Developmental Services (DDS), California Department of Education (CDE), Department of Mental Health (DMH), MRMIB
4. Implement strategies to increase resources for follow-up when screens identify problems
 - A. Identify existing treatment and support resources in communities
 - B. Mobilize existing resources (including other families) to assist families whose children are identified with problems
 - C. Identify service gaps and strategies to address them
 - D. Increase provider knowledge about resources**

Responsibility: State CMS, Los Angeles California Children’s Services (LA CCS) Workgroup, Children’s Regional Integrated Services System (CRISS)
5. Ensure that HRIF and Early Start programs are coordinated by such strategies as HRIF identifying appropriate children and ensuring their referral to Early Start and to the CCS Medical Therapy Program

Responsibility: State CMS, DDS, CDE
6. Create and implement an outreach and education plan to promote early and continuous screening and surveillance for health problems

* See the Appendix for details on “Outreach” and “Training”

Responsibility: State CMS (CCS/CHDP) as lead, local CHDP and CCS, CHDP Executive Committee, Health Education subcommittee, Provider Relations Subcommittee, provider group community, managed care plans, American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), National Association of Pediatric Nurse Practitioners (NAPNAP), children’s insurance plans, Family Voices of California (FVCA), Infant Care Center (ICC), California School Nurses Association (CSNA)

Items that appear in bold overlap with goals outlined in California’s FFY 2006-2010 Title V Implementation Plan.

S T R A T E G I E S A N D A C T I O N S (SCREENING continued)
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Priority Issues that Require Legislative Action

The following recommendations were identified as priorities but require action in the legislative arena. State CMS will monitor progress on these recommendations and provide technical assistance when requested:

1. Align, via budget process, CHDP periodicity schedule with current AAP schedule
Responsibility: 100% Campaign, Children's Specialty Care Coalition (CSCC), AAP, AAFP
2. Create risk-adjusted screening periodicity schedule for CSHCN with number of visits beyond current AAP periodicity schedule, while maintaining current AAP periodicity schedule
Responsibility: AAP
3. Create state performance standards for early/continuous screenings (e.g., CHDP Health Assessment Guidelines) for public and private plans/insurance/HMOs/PPOs, including use of accepted developmental and mental health screening tools
Responsibility: AAP and other advocates
4. Make newborn hearing screening universal by seeking legislation to require that all hospitals that deliver babies participate in the screening program
Responsibility: March of Dimes (MOD), AAP

It is understood that all groups suggested to undertake implementation of legislative priorities must take recommendations to their boards/leadership groups in order to set priorities for legislative action.

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

Core Measure — ORGANIZED SERVICES: Community-based service systems will be organized in ways that families can use them easily.

S T R A T E G I E S A N D A C T I O N S

1. **Create a statewide interdepartmental coordinating body with Departments of Health, Mental Health, Social Services, Developmental Services, Education, etc., to address cross-systems issues, in partnership with family organizations, advocates, and representatives of county departments**

Responsibility: State Children’s Medical Services (CMS) as lead, with other departments, Family Voices of California (FVCA) begin discussions via Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB) implementation grant

2. Increase consistency in inter-county interpretation of state laws/regulations/California Children’s Services (CCS) procedures regarding program and benefits eligibility by such strategies as:
 - A. Conducting regional meetings of CCS staff, followed by state regional office meetings
 - B. Presenting statewide webcasts
 - C. Conducting regional planning with involvement of family organizations and providers

Responsibility: State CMS

3. Develop and implement strategies, including funding, to improve coordination of services used by CCS children, including:
 - A. **Local “roundtables” or other interagency planning bodies to coordinate care and ensure that services are obtained**
 - B. **“Single point of entry” (SPOE) mechanisms to ensure that families can locate and access services**
 - C. **Special Care Center (SCC) sponsored multidisciplinary team meetings to coordinate care with other agencies** (with ability to bill CCS)
 - D. **Neonatal Intensive Care Unit (NICU) discharge planning meetings with all agencies involved with child**
 - E. **Universal consent form with parents to facilitate information sharing among agencies**
 - F. CCS Public Health Nurse (PHN) for positions (modeled after Foster Care PHNs) to **coordinate between CCS and schools**, identify other services needed, facilitate referrals, and act as resource person for families
 - G. Increase support component within CCS (through CCS social workers and/or Parent Health Liaison (PHL) positions)
 - H. Models for a “system navigator” and/or CMS ombudsperson to advise parents on accessing service across systems (e.g. troubleshooting, problem-solving)

Responsibility: CMS with local CCS programs, Department of Developmental Services (DDS), Department of Social Services (DSS), Department of Mental Health (DMH), California Department of Education (CDE), foster care nurses

4. Ensure that families have a hard copy and/or electronic health record for their children and tools to assist them in tracking their medical care, including child health notebooks, and develop training in the use of these tools by reviewing existing materials and tools and adapting or developing additional materials as needed

Responsibility: State CMS as lead, HRSA/MCHB implementation grant

Items that appear in bold overlap with goals outlined in California’s FFY 2006-2010 Title V Implementation Plan.

STRATEGIES AND ACTIONS (ORGANIZED SERVICES continued)
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5. Ensure timely CCS responses to requests for services through such actions as:
- A. Identifying factors influencing the length of time from CCS referral to authorization to receipt of services
 - B. Considering strategies to reduce the length of time from referral to receipt of services, e.g.:
 - Allowing pediatrician to do 2 to 3 visit referral to a specialist before going through lengthy CCS authorization process
 - Outstationing CCS workers in hospitals
 - Letting hospitals start the CCS application process
 - Facilitating provision of medical and financial information from families and providers to expedite eligibility determination and service authorizations

Responsibility: State CMS

6. **Provide education to families, youth and all providers to help them know how services are organized, e.g.:**
- A. **Distribute materials summarizing different programs**, what is covered, how they interact, timelines, referral requirements, links to other programs, etc.
 - B. Design interactive tool/database to help identify which program is appropriate for each child, e.g. through links to other agencies on state CCS website
 - C. **Design education/training** to meet the needs of families, youth and providers with the assistance of stakeholders representing these target populations

* See the Appendix for details on "Training" for details

Responsibility: State CMS, FVCA, Family Resource Centers (FRC)

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

Core Measure — TRANSITION: All youth with special health care needs (YCHCN) will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work, and independence.

S T R A T E G I E S A N D A C T I O N S

1. Create an effective and coordinated transition process for youth including but not limited to the following elements:
 - A. Design structure of transition plans, determine distribution plan, and implement transition process:
 - Develop or adapt existing transition checklist, including access to adolescent well-child care in transition plan (e.g. identifying appropriate primary care physician (PCP) as youth leave pediatric providers) and sensitive issues
 - Create “flag” in Children’s Medical Services network system (CMS-Net, state California Children’s Services (CCS) database) to identify all children at age 14 and trigger assessment of their need for transition plan
 - Reevaluate transition plan in even years to age 18, then annually, e.g. at ages 14, 16, 18, 19, 20, then six months before transition out of CCS
 - Hold exit interviews for CCS enrollees between ages 20 and 21, including anonymous evaluations by clients
 - Complete a checklist for the Medical Therapy Program (MTP) for all youth at age 17 and address, at minimum, conservatorship and application for rehabilitation services
 - B. Establish coordination mechanisms across multiple systems to support transition:
 - Determine transition policies and timelines of other relevant agencies (e.g. California Department of Education (CDE), Regional Centers (RC), Department of Mental Health (DMH), etc)
 - Establish periodic group meetings with transition coordinators identified for their special expertise, at local, regional, and state level; coordinators should participate in transition planning meetings held by other agencies that involve adolescents and invite participation of PCPs and other care providers, including Special Care Center (SCC)
 - Include discussion regarding transition issues at quarterly meetings with managed care plans
 - Work with family resource centers (FRC) to plan transition education meetings for parents
 - Develop a memorandum of understanding (MOU) to bring Department of Rehabilitation (DOR) and Regional Centers into transition process for Medical Therapy Program (use Individual Education Plan (IEP) model)
 - C. Develop and implement training and outreach to support transition:
 - Create manual describing transition benefits available
 - Provide counseling to youth and families regarding benefits, timelines, activities, and continuum of needs (e.g., equipment), and resources available in communities (e.g. other support services)

Responsibility: State CMS, Family Voices of California (FVCA), state interdepartmental coordinating body, Health Resources and Services Administration/Maternal and Child Health Bureau HRSA/MCHB) grant staff
2. **Strengthen network and capacity of adolescent-oriented adult-oriented providers to serve youth and adults with special health care needs** through such strategies as:
 - A. Collect information about transition population such as numbers of youth affected, medical conditions, and other service needs

Items that appear in bold overlap with goals outlined in California’s FFY 2006-2010 Title V Implementation Plan.

- B. Consider possible incentives to maintain and build provider network, including reimbursement and non-reimbursement approaches
- C. Create position in CCS for physician recruitment, including recruitment of adult-oriented providers
- D. Encourage the American Academy of Pediatrics (AAP) to work with the American Academy of Family Physicians (AAFP) and the California Society of Internal Medicine (CSIM) to increase knowledge of/familiarity with YSHCN
- E. **Work with adult primary care and specialty groups to identify providers and ensure understanding of youth and adults with special health care needs, and the medical home model**
- F. Provide mechanisms to assist providers in creating disability-friendly practice environments (e.g. ergonomic review) and consider using existing resources such as Medical Therapy Program staff expertise

Responsibility: State CMS, FVCA

- 3. Incorporate transition standards into SCC standards

Responsibility: State CMS, FVCA

- 4. Consider strategies to assist with transition such as funding of system navigators at FRCs

Responsibility: State CMS, FVCA; state interdepartmental coordinating body

Priority Issues that Require Legislative Action

The following recommendation was identified as a priority but requires action in the legislative arena. State CMS will monitor progress on this recommendation and provide technical assistance when requested:

- 1. Secure provider rates and other incentives to fortify provider network for YSHCN, e.g. by applying increased CCS specialty rate to Genetically Handicapped Persons Program (GHPP) specialists and to other non-physician CCS providers, including Durable Medical Equipment (DME) vendors, etc.

Responsibility: AAP, Children's Specialty Care Coalition (CSCC), California Children's Hospital Association (CCHA), California Medical Association (CMA), AAFP, CSIM, California Hospital Association (CHA), 100% Campaign, Protection and Advocacy, Inc (PAI), other advocates

It is understood that all groups suggested to undertake implementation of legislative priorities must take recommendations to their boards/leadership groups in order to set priorities for legislative action.

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.