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California Children's Services Needs Assessment

Looking Back to Move Forward

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Acronyms

ACA	Affordable Care Act	MTP	Medical Therapy Program
CCS	California Children’s Services	NA	Title V Needs Assessment
CDPH	California Department of Public Health	NICU	Neonatal Intensive Care Unit
CHLA	Children’s Hospital Los Angeles	NPM	National Performance Measure
CMS	Children’s Medical Services	NSCH	National Survey of Children’s Health
CRISS	Children’s Regional Integrated Service System	NS-CSHCN	National Survey – Children with Special Health Care Needs
CYSHCN	Children and Youth with Special Health Care Needs	OFP	Office of Family Planning
DME	Durable Medical Equipment	PCP	Primary Care Physician
DHCS	Department of Health Care Services	PED	Provider Enrollment Division
FCC	Family-Centered Care	RFP	Request for Proposals
FVCA	Family Voices of California	RSAB	Redesign Stakeholder Advisory Board
FQHC	Federally Qualified Health Centers	SCC	Special Care Centers
HPSM	Health Plan of San Mateo	SCD	Systems of Care Division
HRSA	Health Resources and Services Administration	SPM	State Performance Measure
IP	Implementation Plan	TWG	Technical Workgroups
ISCD	Integrated Systems of Care Division	UCEDD	University Center for Excellence in Developmental Disabilities
MCAH	Maternal, Child and Adolescent Health	WCM	Whole Child Model
MCHB	Maternal and Child Health Bureau	YSHCN	Youth with Special Health Care Needs
MCH	Maternal and Child Health		
MCMC	Medi-Cal Managed Care		

Executive Summary

Overseen by the United States Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB), the Title V Maternal and Child Health (MCH) Services Block Grant Program is a key source of support for improving the health and well-being of mothers, children, and adolescents, including children and youth with special health care needs (CYSHCN). Title V funding creates federal and state partnerships that support CYSHCN’s access to quality health care. This includes health assessment, follow-up diagnostic and treatment services; preventive and rehabilitative services; and family-centered community-based systems of coordinated care.

In California, the Department of Health Care Services (DHCS) receives a portion of the one-third of the state’s Title V funding earmarked for CYSHCN to support California Children’s Services (CCS). Title V funding helps support program improvement, outreach, needs assessment, and data systems, and covers a limited portion of county administrative costs for CCS. Relative to the total CCS budget — most of which is funded by counties and the state — Title V funding is only a small part.

CCS provides case management, authorizes medical and dental services related to CCS-eligible conditions, and pays for services for qualifying CYSHCN who meet certain medical, residential, and financial criteria. It also establishes standards for providers, hospitals, and Special Care Centers (SCCs) providing care in the community and tertiary medical settings. Through the SCCs, located in outpatient departments of tertiary care hospitals, CCS provides access to quality specialty and subspecialty providers and uses multidisciplinary teams to address health needs and provide coordinated care for CCS children.

Every California county has a CCS program and eligible families depend on CCS to maintain and improve quality of life and care for their children and to help alleviate the financial burdens for these families.

Title V legislation requires a comprehensive, statewide needs assessment (NA) every five years to identify needs in the areas of preventive and primary care services for pregnant women, mothers, infants and children, and service needs for CYSHCN. From the assessments, states select priorities for focused programmatic improvement efforts over the five-year reporting cycle.

This case study addresses issues related to CYSHCN identified via the Title V five-year NA and how these issues have impacted the systems and service delivery process for CYSHCN served by CCS. The first component of this project was a document review of California’s Title V NAs and Action Plans from the past three NA cycles (2005-10, 2010-15, and 2015-20), annual Title V Applications and Reports from 2005 through 2020 (referred to as Annual Reports throughout this document). The second component was a retrospective environmental scan to identify contextual factors, including capacity issues, that may have impacted California’s progress acting on issues and needs identified in each cycle to better understand why significant progress was not made on some priorities from the NAs.

Key challenges affecting progress across the cycles included internal program factors, such as the availability of existing data to track progress and CCS' ability to develop new methods to regularly collect data for state performance measure (SPMs). In many instances, the objectives and strategies developed to address the objectives appear to be more ambitious than the ability and capacity that CCS had to implement them.

Priorities identified by stakeholders repeatedly across the NA cycles represent complex and challenging problems affecting medical care provision, case management, and care coordination for CYSHCN in CCS programs. External factors beyond the control of CCS such as Medi-Cal rates, California's high cost of living, and the Great Recession that began in December of 2007 and continued into 2009 profoundly impact the ability of CCS to provide medical homes for CCS children, to recruit the qualified pediatric subspecialists, and to ensure smooth transitions to adult providers as CCS youth age out of the program.

While these challenges may be worse in California due to the high cost of living and low Medi-Cal rates, they are not unique. They reflect national health care policies that undervalue and underfund primary care clinicians and specialists caring for Medicaid beneficiaries. Since these providers receive lower salaries compared to those in other specialties, fewer medical students choose these areas of practice, affecting provider availability over time. Action at national and state levels is needed to address these important issues.

This work leads to us to provide several recommendations for DHCS for improving the NA process and advancing progress to improve the service system for CYSHCN.

- Begin each NA cycle with a convening of NA stakeholders to recap the findings from the previous NA, review what was and wasn't accomplished in the preceding five years. Explore and explain why objectives weren't met and/or plans weren't implemented.
- Prior to developing an action plan(s), work with NA stakeholders to conduct a problem analysis for each of the NA priorities.
- Involve the NA stakeholders not only in the development of action plans to address NA priorities but also in the revision of action plans over the cycle.
- Enlist stakeholders and others to take on key roles and activities to achieve action plan objectives. CCS has limited funding and capacity to address priority issues. Coordinated partnerships can help advance progress.
- Increase strategic partnerships and leverage the resources other partners have or may be able to secure. Resources such as grant funds that could be used for specific activities that would advance progress in addressing NA priorities (e.g., thoroughly exploring how other states provide medical homes to CYSHCN).
- Have an ongoing CCS Title V advisory group that includes NA stakeholders and provide the group with regular updates on progress and challenges addressing NA priorities.

- Give careful consideration to selecting the measures used to track progress in addressing objectives. Invest in building state and local data infrastructure to ensure that the necessary resources are available to collect the data needed to regularly and reliably report on measures.
- Increase State CCS’s partnership with local CCS programs and partnerships among local programs to implement strategies to achieve objectives. Solicit promising practices from and provide more opportunities (e.g., fund meetings) for local CCS programs to share these practices and related materials amongst themselves. Develop a scope of work (SOW) for local CCS programs that contains activities that can be implemented locally to help achieve statewide objectives.
- Be more realistic and less ambitious when developing plans and strategies to address NA priorities and take into consideration other DHCS priorities, e.g., shifting Medi-Cal enrollees into Medi-Cal Managed Care (MCMC) plans.

CCS has been helping CYSHCN receive needed medical care for almost 100 years, and millions of CYSHCN and their families have benefitted from these services. An ongoing focus on program improvements within CCS, combined with strong advocacy on issues beyond CCS’s control, will help ensure that the program continues to benefit CYSHCN and their families for years to come.

Introduction

Many stakeholders who participated in past Title V Needs Assessments of California Children’s Services (CCS) have perceived a lack of significant progress in addressing the needs and issues that were prioritized for improvement during the last three needs assessment (NA) cycles. In this report, we look at what issues and needs have and have not been addressed. Through an environmental scan, we explore potential reasons why some were not addressed. Lastly, we provide recommendations aimed at improving the NA process and enhancing progress to address future needs and issues.

Background

Overseen by the United States Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB), the Title V Maternal and Child Health Services Block Grant Program is a key source of support for promoting and improving the health and well-being of our country’s mothers, children, adolescents — including children and youth with special health care needs (CYSHCN). More specifically for CYSHCN, Title V funding is designed to create federal and state partnerships that support access to quality health care, including health assessment and follow-up diagnostic and treatment services; preventative and rehabilitative services for CYSHCN; and family-centered community-based systems of coordinated care, especially for CYSHCN with low incomes and/or limited availability of care.

CCS is California's oldest and largest public health program. It started in 1927 in response to the polo epidemic and expanded since then to include many other serious and chronic conditions. CCS provides case management, authorizes medical and dental services related to the CCS eligible condition, and issues payments for services for qualifying CYSHCN who meet certain medical, residential, and financial criteria. It also establishes standards for providers, hospitals, and Special Care Centers (SCCs) to provide care in the community and in tertiary medical settings. Through the SCCs, which are in outpatient departments of tertiary care hospitals, CCS provides access to quality specialty and subspecialty providers and uses multidisciplinary teams to address health needs and provide coordinated care for CCS children and youth. At selected public-school sites, the CCS Medical Therapy Program (MTP) provides physical and occupational therapy and medical case conference services for children with specific medically eligible conditions. There are no financial eligibility criteria for MTP services.

Every county in the state has a CCS program. The program is fully administered in 31 "independent" counties. In the remaining 27 "dependent" counties, administrative and case management activities are currently shared with the Department of Health Care Services (DHCS) Integrated Systems of Care Division (ISCD).

As stated by Dr. Louis Girling Jr., Medical Director for Alameda County CCS:

Families of children with serious diseases and physical disabilities should not have to guess where they should take their children to obtain the best services. They need a system that facilitates their access to those services in a coordinated and timely way, and that is what CCS is about. A child who has CCS eligibility can access the right physician, the right hospital, the right clinic anywhere in the state of California. If we think that the best place to serve that child is a children's clinic in Los Angeles, that is where we will send that child.

Many California CYSHCN and their families depend on CCS services to maintain and improve the quality of care and quality of life for their children. Enrollment in CCS alleviates the significant financial burden on families of children with complex medical issues.

Title V of the Social Security Act provides funding for programs to improve the health of all mothers and children, including CYSHCN. Title V programs are implemented through a federal-state partnership administered by MCHB under HRSA. In California, the Department of Health Care Services (DHCS) receives a portion of the one-third of the state's Title V funding earmarked for CYSHCN to administer the CCS program. Title V funding helps support program improvement, outreach, needs assessment, data systems. It also covers a small portion of county administrative costs for the CCS program, the vast majority of which is funded by the state and counties. Title V currently provides approximately \$5 million in funding to the CCS program budget. DHCS collaborates on CYSHCN issues with the Maternal, Child and Adolescent Health (MCAH) Division of the California Department of Public Health (CDPH), the state's Maternal and Child Health lead agency.

The Title V legislation requires states to conduct a comprehensive, statewide Title V MCH needs assessment every five years to identify the need for preventive and primary care services for pregnant women, mothers, infants and children, and CYSHCN. From the assessments, States select priorities for focused programmatic efforts over the five-year reporting cycle.

Figure I: The Needs Assessment Cycle



With this report, we hope to build on the efforts of past NA and identify areas where progress has been slow or negligible over time. As the research group contracted to conduct the NA of CCS for the past four cycles, we have noticed many of the same issues and needs came up as priority areas from cycle to cycle. It is helpful to take a step back from the NA process and explore potential reasons why this is the case. It is the main goal of the project to address gaps in progress so that CCS can better serve CYSHCN and their families.

Methods

This project is a case study that addresses issues related to CYSHCN, specifically how the five-year NAs have impacted the system and service delivery process for CYSHCN served by CCS. We have taken a qualitative approach to this project, described in greater detail below, that involves two main components.

1. Reviewing California's past NAs and Annual Reports in relation to CYSHCN, specifically those CYSHCN in CCS, and progress on action plan implementation
2. Conducting a retrospective environmental scan

We chose this approach to enable us to both learn from what happened in the past and to understand and describe how factors identified in the environmental scan may have impacted progress. Our goal in improving the NA and action plan development and implementation process is to achieve improvements in the services and system for CYSHCN that will ultimately result in better health and well-being for these children/youth and their families.

Component One: Review California's Past NAs and Progress on Action Plans

The first component of this project was a document review of California's Title V NAs and Action Plans from the past three NA cycles (2005-10, 2010-15, and 2015-20) and California's annual Title V Applications and Reports from 2005 through 2020 (referred to as Annual Reports throughout this document). We reviewed activities undertaken, progress made, changes to policies, and resulting outcomes and impacts related to addressing the top priorities identified for CYSHCN served by CCS in the 2005, 2010, and 2015 NAs. Organizational charts and other administrative documents submitted with Annual Reports that illustrate changes in state CCS and DHCS leadership and policy priorities were reviewed as needed, to the extent they were available, and resources allowed. We compiled a summary of the top priorities identified for CYSHCN served by CCS, plans and activities strategized and prioritized across California's past three NA cycles. We identified which of these were addressed and what was accomplished. Also included is a discussion of needs and issues not adequately addressed and some potential reasons for these shortcomings.

Component Two: Retrospective Environmental Scan

As the document review was taking place, we conducted a retrospective environmental scan to identify additional contextual factors, including capacity issues, that may have impacted California's progress addressing identified issues and needs. This was done to address the question of why significant progress was not made on some priorities from the NAs. These factors include key events (e.g., economic recession) and policies that were implemented (e.g., the Affordable Care Act and Medicaid expansion, shifting Medicaid populations from fee-for-service to Medicaid Managed Care). Additional contextual factors examined include the other focuses and initiatives of DHCS (e.g., 1115 Waiver) that may have diverted attention and resources from action plan implementation. Conducting the environmental scan involved reviewing additional documents such as briefs, reports, and news articles and informal conversations with knowledgeable stakeholders, including those from the Project Advisory Group formed to provide input on this project.

Findings

2005 – 2010 Cycle

The Title V CCS NA in 2005 added three priority needs for the state.

1. Coordinate to develop and implement a system of timely referral between Mental Health, Developmental Services, Special Education, Social Services, and the CCS system for CCS eligible children.
2. Expand the number of qualified providers participating in the CCS program.
3. Increase the number of family-centered medical homes for children with special health care needs and the number and percent of CCS children who have a designated medical home.ⁱⁱⁱ

These priorities, all related to access to services and the quality of those services, were selected because the NA stakeholders believed that addressing these priorities would greatly enhance the quality and timeliness of medical care for CCS eligible CYSHCN. The 2005 NA noted that these priorities are very similar to priority needs identified in 2000 with the main difference being the near completion of the implementation of the statewide case management and data collection system for CCS known as CMS Net. At that time, the system was used in all but three counties, with those three expected to join CMS Net within a year.

In the year following the NA, the Children’s Medical Services (CMS) Branch which housed CCS partnered with the California Champions of Progress project to develop an implementation plan with objectives and strategies to address the CYSHCN/CCS priorities from the NA.ⁱⁱ Funded by HRSA, the Champions project also included Family Voices of California (FVCA), Children’s Regional Integrated Service Systems (CRISS), and the Los Angeles Partnership for Special Needs Children at the University of Southern California (USC) University Center of Excellence in Developmental Disabilities (UCEDD) at Children’s Hospital Los Angeles (CHLA), as well as representatives local education, mental health, regional center, county welfare, managed health care across the state.

There were national performance measures (NPMs) and state performance measures (SPMs) reported on in the Maternal and Child Health Services Title V Block Grant State Report for California submitted annually for the years 2006-2010. The NPMs were developed by MCHB/HRSA. They use data from the National Survey of Children’s Health (NSCH) and/or the National Survey – Children with Special Health Care Needs (NS-CSHNC), which covers children ages 0-17 years, and states are required to report on the measures annually.¹ The SPMs were developed by the CMS Branch and more closely align with priorities from the NA and for the most part, were more suitable for tracking progress to address priorities than the NPM. The Narrative Reports provided no explanations for how the SPMs were determined, and we had no access to other documents that might have provided an explanation.

¹ After 2010, the NS-CSHNC was no longer conducted and was combined with the NSCH.

The associated NPM and SPM for each of the three priorities for CYSHCN served by CCS were listed in the 2006 Annual Reportⁱⁱ were:

Priority 5: Coordinate to develop and implement a system of timely referral between mental health, developmental services, social services, special education services and CCS.

- **NPM 02** - The percent of CYSHCN age 0-18 years whose families partner in decision making at all levels and are satisfied with the services they receive
- **NPM 03** - The percent of CYSHCN age 0-18 who receive coordinated, ongoing, comprehensive care within a medical home
- **NPM 05** - The percent of CYSHCN age 0-18 whose families report the community-based service systems are organized so they can use them easily
- **SPM 01** - The percent of children 0-21 years enrolled in the CCS program who have a designated medical home
- **SPM 07** - The percent of newly referred clients to the CCS program whose cases are opened within 30 days of referral

Priority 7: Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists, and nutritionists.

- **NPM 03** - The percent of CYSHCN age 0-18 who receive coordinated, ongoing, comprehensive care within a medical home
- **NPM 04** - The percent of CYSHCN age 0-18 whose families have adequate private and/or public insurance to pay for the services they need
- **NPM 05** - The percent of CYSHCN age 0-18 whose families report that the community-based service systems are organized so they can use them easily
- **NPM 06** - The percentage of youth with special health care needs (YSHCN) who received the services necessary to make transition to all aspects of adult life
- **SPM 01** - The percent of children 0-21 years enrolled in the CCS program who have a designated medical home
- **SPM 02** - The ratio of pediatric cardiologists authorized by the CCS program to children 0-14 years of age receiving cardiology services from these pediatric cardiologists

Priority 8: Increase the number of family-centered medical homes for CYSHCN and the number/percent of CCS children who have a designated medical home:

- **NPM 02** - The percent of CYSHCN age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive
- **NPM 03** - The percent of CYSHCN age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home
- **SPM 01** - The percent of children birth to 21 years enrolled in the CCS program who have a designated medical home

Progress Addressing Priorities from the 2005 Needs Assessment

Priority 5: Coordinate to develop and implement a system of timely referral between mental health, developmental services, social services, special education services and CCS.

The CMS stakeholder group established three objectives for Priority 5, and they were listed in the 2006 Implementation Plan² (IP) to help guide activities over this five-year cycle. The group also developed a list of strategies for each objective as follows^{iv}:

1. convene and facilitate a policy committee of representatives from state agencies that serve children and youth with special health care needs together with parents of CSHCN.
2. encourage local coordination to improve services to CYSHCN;
3. educate providers, in partnership with families, about the need for coordinated care for CYSHCN.

In reviewing plans and progress related to this priority, it seems that there is a disconnect between the priority and the objectives developed to address the priority, and the SPM developed for this priority and the activities undertaken in this cycle. The objectives from the IP were never referred to or discussed in subsequent Annual Reports for this cycle. Instead, in the 2006 Annual Report, in the section on “Last Year’s Accomplishments” for SPM 07 (which was a new SPM in 2006), it notes that decreasing the time interval between referral to the CCS program and receipt of CCS services has been identified as one of “the top 10” [italics included] state priorities for the next five years. Subsequent reports include plans and progress addressing SPM 07.ⁱⁱ Thus, it appears that the original priority of “Coordinate to develop and implement a system of timely referral between mental health, developmental services, social services, special education services and CCS” was essentially replaced. Although there was never any discussion of replacing the priority in the reports and each report in this NA cycle continues to list the original priorities selected by stakeholders, what was included the plans and accomplishments clearly focused on activities related to SPM 07 and not on referrals to services outside of CCS (e.g., mental health or developmental services).

² The term “Implementation Plan,” which was used during the 2005-10 NA cycle, was replaced by the term “Action Plan” in later NA cycles.

In the 2005 NA Submission, under Priority 5, it is noted:

This [priority] represents a new leadership activity for the CMS Branch. Most of the resources in the past have been focused on addressing service issues within the CMS programs. This priority provides an opportunity for CMS to take an active role in building systems with community and state partners for the broader population of CYSHCN. The internal capacity assessment revealed that this is an area in which additional resources and training are required.ⁱⁱⁱ

Perhaps it was because the original priority represented a new leadership activity for the CMS Branch that the original objectives and activities listed in the IP were never pursued. By focusing instead on SPM 07, the CMS Branch worked on an issue that was more clearly within its sphere of influence.

The 2005 NA did identify that there was considerable variation among counties in the time between referral to the CCS program and when a child received CCS services, and that it was a multifactorial issue that needed to be addressed with multiple strategies. Application processing, receipt of medical reports, determining program eligibility, issuing authorizations, appointment availability, and scheduling with providers were all areas where delays occurred.

Plans to address SPM 07 in the Annual Reports for this cycle included:

- analyzing cases that took more than 30 days to open to identify reasons for the delays and possible actions that could be taken to reduce the delays;
- developing a tool to enable county and regional CCS offices to randomly audit cases opened after 30 days, categorize the reasons for the delay and initiate possible interventions discussions with Los Angeles County and six other counties to determine and share their best practices as these counties opened more than 76% of their referrals within 30 days;
- stationing CCS workers in hospitals to facilitate the provision of medical and financial information from families and providers with the goal of expediting eligibility determinations and service authorizations.

In later years of this cycle, plans evolved to include:

- continuing to station CCS workers in hospitals to streamline referrals as budgets allowed [emphasis added];
- evaluating the effectiveness of stationing these workers in hospitals;
- filling vacant positions to process referrals;
- prioritizing referrals identified as “expedite.”

The progress addressing the objective of reducing the time between referral to CCS and receipt of services was mixed over the course of the cycle. SPM 07 was implemented (see Table 1) and measured “the percent of newly referred clients to the CCS Program whose cases are opened with 30 days of referral” (pg. 137).

Table 1: SPM 07: Percent of newly referred clients to the CCS program whose cases are opened within 30 days of referral, 2005-2010 Cycle

Measure	Notes
2004-2005 = 75.7%	<ul style="list-style-type: none"> • 55 counties using CMS Net opening 56% of their \leq 30 days • Los Angeles County — not yet on CMS Net but collected comparable data that was added, opening 96% of their cases \leq 30 days • Sacramento and Orange counties not included
2005-2006 = 70.4%	<ul style="list-style-type: none"> • Decrease attributed to 55 counties using CMS Net opening 60.3% of their \leq 30 days • CCS identified cases in CMS Net pending for over a year and determined if program eligibility was met/not met and opened/closed the cases accordingly
2006-2007 = 76.2%	<ul style="list-style-type: none"> • Increase attributed to counties reviewing and evaluating their processes for opening cases
2007-2008 = 81.1%	<ul style="list-style-type: none"> • This was the highest percent achieved and just prior to the Great Recession and staffing cuts
2008-2009 = 78.4%	<ul style="list-style-type: none"> • Decrease attributed to staffing cuts in CCS programs

As planned, local CCS programs did develop a process to prioritize referrals identified as “expedite”. Since progress implementing other plans was not discussed in Annual Reports for this cycle, it is unclear if they were implemented. This included plans to develop a tool to randomly select and audit cases that took longer than 30 days to open and plans to evaluate the effectiveness of stationing CCS workers at hospitals to facilitate eligibility determinations.

Priority 7: Expand the number of qualified providers participating in the CCS program.

The CMS stakeholder group established three objectives for Priority 7 to help guide activities over this five-year cycle.

1. Maintain and strengthen the provider network for CYSHCN.
2. Improve CCS program capacity to serve older teens and youth with special health care needs who are transitioning to adult services.
3. Advocate for enhanced physician training regarding CYSHCN.

Initial plans to address these objectives included:

- overhauling the CCS provider database;
- exploring strategies to attract and retain pediatric and sub-specialty providers used by other states;

- partnering with the American Academy of Pediatrics, the Children's Specialty Care Coalition, the CCS Transition Workgroup, and others to evaluate and implement strategies and activities;
- utilizing the Federal MCHB grant awarded to USC's UCEDD at Children's Hospital Los Angeles (CHLA) for collaboration with CRISS, CMS Branch, and FVCA to implement the objectives through identified activities to expand the number of qualified providers participating in the CCS program;
- working with the Cardiac Technical Advisory Committee to develop a SPM for this priority;
- improving the methodology for determining the SPM;
- increasing provider capacity.

Over the course of this cycle, plans were updated to include: ^{iv,iii,iii}

- CMS working on a method to annually update the core team members of CCS approved SCCs . Mentioned in particular are Pediatric SCCs, where they are trying to ensure that the number of active pediatric cardiologists is accurate so the CMS Branch can best evaluate the number of pediatric subspecialty physicians in the state available to CYSHCN;
- maintaining the CMS Cardiac Technical Advisory Committee to consult by telephone as CMS staffing does not allow for face-to-face committee meetings [emphasis added];
- updating the directory of core team members at the Pediatric CC to evaluate the availability of pediatric subspecialty physicians available to CYSHCN in the state as staffing allows [emphasis added];
- CCS coordinating with the Transition Workgroup and other partners electronically to evaluate and implement strategies to address provider capacity, as CCS no longer has staff to attend Transition Workgroup meetings;
- the Transition Workgroup disseminating a Transition Toolkit in FY 2009-2010;
- CCS improving program capacity to serve youth with special health care needs who are transitioning to adult providers and plans to evaluate the CCS provider network to care for teens in transition to adult services;
- the Transition Workgroup continuing to work on the Transition Toolkit with a goal of completing it by the fall of 2010.

Progress addressing this priority began with CMS developing a new SPM. As identified in the 2005 NA and explained in the Annual Report submitted in 2006, there was growing concern over the shortage of pediatric subspecialty care providers in the state, particularly for CYSHCN with complex medical conditions.^{ii,i} Children with diagnoses related to congenital heart disease made up the largest group of children enrolled in CCS at the time, and the subspecialty

of pediatric cardiology was selected for the SPM as it appeared that the number of pediatric cardiologists was decreasing throughout the state. CMS worked with the CMS Cardiac Technical Advisory Committee to “ascertain the best methodology for determining the SPM; to identify the benchmark or annual indicator; to determine the number of pediatric cardiac fellows trained in the state over the past five years; and to help explore what is working in other states (without pediatric cardiology shortages) to attract providers and what can be done in California to attract more subspecialty providers.” (pg. 124)ⁱⁱ. Suspected reasons for the decreasing pool of cardiologists in California were the challenges of recruiting these specialists to the state due to the high cost of living and lower reimbursement rates for their services.

SPM 02 was developed as the ratio of pediatric cardiologists authorized by the CCS program to children 0-14 years of age receiving cardiology services from these pediatric cardiologists. For FY 2005-2006, the ratio was considered the benchmark, however, because some pediatric cardiologists continue to see an unknown number of children 14 years and older, the ratio was known to underestimate the caseload. A benchmark for this ratio had not been found in the literature.

As the pediatric subspecialty providers that care for CCS children are primarily associated with CCS SCCs, they not only care for CCS children but also the majority of CYSHCN with medical needs in the state. Therefore, CMS anticipates that progress improving SPM 02 will also impact non-CCS CYSHCN.

Table 2 shows the progress on SPM 02.

Table 2. SPM 02: Ratio of pediatric cardiologists authorized by the? CCS program to children 0-14 years of age receiving cardiology services from these pediatric cardiologists, 2005-2010 Cycle

Measure	Notes
2005-2006 = 1:491	<ul style="list-style-type: none"> • baseline is an underestimate
2006-2007 = 1:445	<ul style="list-style-type: none"> • represents a 5% increase in the number of pediatric cardiologists and a 3% decrease in the number of children being seen by these pediatric cardiologists
2007-2008 = 1:408	<ul style="list-style-type: none"> • CCS had been intentionally closing cases where CCS clients no longer needed follow-up by specialists, which may have resulted in a lower number of active cases with cardiac care needs in CMS Net
2008-2009 = 1:366	<ul style="list-style-type: none"> • 10% increase in the number of cardiologists and a 1% decrease in the number of children seen by cardiologists • increase in pediatric cardiologists was specific to the northern part of California, the result of a particularly aggressive recruitment effort at Stanford • rest of the state, especially the southern part, continued to have an insufficient number of pediatric cardiologists
2009-2010 = 1:325	<ul style="list-style-type: none"> • 7% increase in the number of pediatric cardiologists and a 5% decrease in the number of children seen by these cardiologists compared to the prior year

The 2009 Report also stated that one of the consequences of not having enough pediatric cardiologists was that, with increases in childhood obesity, the pediatric cardiologists are not able to evaluate children who may be experiencing cardiovascular disease because of their obesity.^v

Overall, it appears that some progress was made in improving SCC directories to provide a better assessment of the number of pediatric cardiologists. However, it is unclear whether the directories have improved to be able to better assess the number of other pediatric subspecialists. Regarding investigating strategies used by other states to attract and retain pediatric providers, the 2008 Annual Report noted these were superficially explored, with no mention of additional work on this in subsequent years.^{vi} Because of staffing shortages, some of which may be attributable to the Great Recession that began in December of 2007 and continued into 2009, CMS was not able to devote time to work with pediatric cardiologists on ways to increase their numbers. The 2010 Annual Report noted that there had been an increase in cardiac internists at the SCCs, which would improve CCS' capacity to service older teens and youth transitioning to adult services.^{vii} Transition guidelines were distributed to local CCS programs, regional offices, and Medical Therapy Units in April of 2009 and work was continuing on the Transition Toolkit.

In reviewing progress for this priority, the pediatric cardiology network was strengthened to some degree, particularly with being able to better assess the actual number of CCS pediatric cardiologists and the number of CCS children requiring their services. Stanford did recruit an additional pediatric cardiologist, and cardiology internists were added to SCCs, although the exact number was never specified. The addition of cardiology internists did improve CCS's capacity to serve older teens and YSHCN who were transitioning to adult services. There was no mention in the Annual Reports of any progress on the final objective, advocating for enhanced physician training regarding CYSHCN.

In terms of implementing strategies to address priorities listed in the 2006 IP, most strategies were not included in the "Plans for the Coming Year" sections nor discussed elsewhere in the Annual Reports suggesting that they were not implemented. Of note, no mention was made of any efforts to address reimbursement issues or evaluate incentives to maintain and build the provider network.

Priority 8: Increase the number of family-centered medical homes for CYSHCN and the number/percent of CCS children who have a designated medical home.

The CMS stakeholder group developed five objectives for this priority and many strategies for each objective in the 2006 IP. The objectives were:

1. Develop definition of a medical home.
2. Identify a medical home for every CCS client.
3. Identify a medical home for every CYSHCN.
4. Address reimbursement issues related to providing medical home services.
5. Educate providers and parents regarding care coordination and medical home.

Plans to address this priority included:

- also utilizing the Federal MCHB grant awarded to USC's UCEDD at CHLA for collaboration with CRISS, CMS Branch, and FVCA to implement strategies and activities to increase the number of family centered care (FCC) medical homes for CYSHCN and the number/percent of CCS children/youth who have a designated medical home;
- identifying and collecting data, so CCS would be able to identify true medical homes that provide coordinated, ongoing, and comprehensive health care across all payer sources;
- develop a mechanism to update medical home information regularly;
- collaborating with CHLA and the California Epilepsy Foundation on Project Access, an access to care grant for CYSHCN with epilepsy by facilitating the development of state-wide comprehensive, family-centered, culturally effective care in medical homes;
- developing a policy letter for CCS medical homes for CCS clients;
- consideration of the ramifications of authorization of medical homes;
- review of the medical homes recommendations from the CCS Medical Homes Workgroup;
- County CCS programs evaluating whether CCS children have a medical home and exploring improvement strategies.

Additional plans made in subsequent years included:

- work to identify children with a true medical home and not just a primary care provider was planned;
- CMS launching a medical homes initiative in FY 2008-2009 with 2 components:
 - a policy letter regarding medical homes for CCS clients, authorizations of the medical homes, phone consultation for care coordination, billing codes, and designation of county-based CCS medical homes liaisons to serve as a single point of contact for the primary care providers of CCS children
 - a letter to CCS paneled physicians introducing the medical homes concept, alerting them to the services and assistance they and their patients can receive from CCS and the designated CCS medical homes liaison, and providing medical homes information and tools;
- 2009 Annual Report noting FVCA would continue provider trainings for families and professionals on the medical homes, distribute binders to help families organize medical records and other health care information, and provide 'resource referral pads' to physicians that listed local resources for families.

Many activities were undertaken to address the objectives for this priority. County CCS programs completed a survey regarding the degree to which CYSHCN receive regular, ongoing, and comprehensive care within medical homes, and the survey data was analyzed. Work was done on the policy letter. The CMS Branch collaborated with CHLA on the HRSA grant focused on children with epilepsy, and Sonoma County CCS continued to collaborate with a local Federally Qualified Health Centers (FQHC) to support medical homes development for children with epilepsy after the HRSA grant ended.

Progress made addressing this medical home priority and accomplishing the objectives included the following: SPM 01 was created and measured the percent of children 0-21 years enrolled in the CCS program who have a designated medical home. This measure appeared to be similar to NPM 3, but the CCS program was using having a primary care physician (PCP) instead and stated that over time the goal was to align with the NPM such that SPM 01 would reflect where the CCS client receives comprehensive coordinated and ongoing medical care. It was noted that the switch to the definition of medical homes used for the NPM was unlikely to be achieved within the current cycle. See Table 3 for changes in SPM 01 over the cycle.

Table 3. SPM 1: Percent of children birth to 21 years enrolled in the CCS program who have a designated medical home (actual data used was whether a child had a PCP)

Measure	Notes
2005-2006 = 57.9%	<ul style="list-style-type: none"> Anticipated that percentage would likely go down in future with the shift to more comprehensive definition of medical home
2006-2007 = 76.4%	<ul style="list-style-type: none"> Increase attributed to improved reporting
2007-2008 = 84.2%	<ul style="list-style-type: none"> Still reflected only having a PCP, not a true medical home
2008-2009 = 88.9%	<ul style="list-style-type: none"> Still reflected only having a PCP, not a true medical home
2009-2010 = 83.5%	Decrease attributed to adjustments made to the medical home field in CMS Net so it would only accept the name of a provider in provider master file (previously anything could be entered into medical home field, including a comment, and it was considered a “medical home”)

The 2008 Annual Report noted that CMS had finalized the state strategies for increasing the number of FCC medical homes for CYSHCN and the percentage of CCS clients who have a designated medical home.^{iv} It also stated that FVCA had distributed 146 binders to help families organize health care information and had developed “resource referral pads” for physicians in 14 counties.

At the end of the cycle, having a primary care provider was still being used as a proxy for a medical home and county CCS programs had no way to distinguish between a PCP and a true medical home. Work still was needed on the goal of completing the data definition for the medical home field to reflect where the CCS child received comprehensive and coordinated ongoing medical care, including having physicians identify if their practices are medical homes and local programs assist in identifying medical homes.

Both the 2009 and 2010 Annual Reports reference budget cuts to the CCS program that impacted progress.^{iii,v} The 2009 Report stated that work using the Federal MCAH awarded to USC to implement strategies to increase the number of FCC medical homes was on hold due to budget cuts, as was the policy letter for CCS regarding medical homes for CCS clients. The holds on the work continued in the last year of the cycle and consequently, some of the major progress on medical homes that had been planned was not actually achieved.

Plans and progress reported for NPM 3: the percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home, are essentially the same as above with the addition of data on how the state performed on this measure from the NS-CYSHCN. This data represents a broader group of CYSHCN than CCS covers, as the definition used at the federal level for CYSHCN is "those 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." At the beginning of the cycle, the data reported for NPM 3 was from the 2002-2004 survey, at NPM 3 was 44.7% of CYSHCN having a medical home. Data collected in the 2005-2006 survey and reported in 2007 for NPM 3 indicated that 44.2% of CYSHCN have a medical home.^{vii} While this may appear to be a decrease in this measure, the change is not statistically significant.

Contextual Factors

For the 2005-2010 cycle, three factors identified in the environmental scan stand out as likely affecting progress addressing the priorities from the 2005 NA. The first was the **reorganization of the California Department of Health Services (CDHS) into two departments: the Department of Health Care Services (DHCS) and the California Department of Public Health (CDPH)**. This change was discussed in the 2006 Annual Report:

Governor Schwarzenegger has called on the Legislature to work with him to reorganize the existing California Department of Health Services into two departments: a California Department of Public Health (CDPH) and a Department of Health Care Services (DHCS). The new CDPH would protect and promote health through a focus on population-wide interventions while the DHCS would focus on the financing and delivery of individual health care services (pg. 19).

Prior to the reorganization that went into effect in July of 2007, two branches within CDHS were jointly responsible for carrying out the Title V functions: the MCAH Branch/Office of Family Planning (MCAH/OFP) and CMS. Both branches were in the Primary Care and Family Health Division of CDHS. As described in the 2006 Annual Report submission, programs of the MCAH/OFP and CMS Branches were developed to address three core public health functions: "needs assessment, development of program policies to address needs and improve health outcomes, and assurance of the availability of accessible and appropriate high-quality services" (pg. 19).ⁱⁱ

Indeed, one of the most important functions of CCS is setting policy and standards for CCS providers, including hospitals, Neonatal Intensive Care Units (NICUs), SCCs, and physicians. This also benefits the broader group of CYSHCN who are cared for by these providers but do not have CCS.

With the reorganization, the MCAH/OFH Branch moved to the CDPH and the CMS Branch, which included CCS, was moved to DHCS along with Medi-Cal. An interagency agreement was signed prior to the move to ensure a seamless transition and provide for continuing Title V funds to CMS. It was not initially clear if, or how, the reorganization would affect this prior partnership between MCAH/OFP and CMS. Given the complexity of the reorganization and the work necessary for implementation, it is reasonable to conclude that this process likely took attention and resources away from regular program activities, such as addressing NA priorities for CCS.

Since the reorganization, stakeholders consulted as part of the environmental scan have suggested that this shift may have resulted in people thinking of CCS as an insurance program instead of a population-based public health program that provides medically-based case management and other services to CYSHCN with medically complex conditions. When perceived as an insurance program or a 'payer,' the focus can shift to utilization and cost management instead of a focus on how to best meet the needs of CCS children and improve their health outcomes, thus potentially affecting decisions that previously had not been viewed through a lens of cost containment. As CCS is now housed in DHCS along with Medi-Cal, there are concerns that the program is viewed as a subset of Medi-Cal even though a child can be privately insured and have CCS.

The second factor that affected progress during this cycle is **funding**, specifically **cuts to Title V funding** that started in FY 2006-2007 and continued into the **Great Recession**, which started to impact California in December of 2007 and officially ran through June 2009.^{ix} Title V funding cuts started in 2008 and continued for several years and were compounded further by cuts in California's State General Fund budget to address the state's growing budget deficit. The resulting fallout from these budget cuts was laying off CCS staff at both the state and local levels and furloughs of 2 days per month for state employees from January 2009 through June 2010. With this loss of staff, there was also a loss of expertise and capacity, impacts that would be felt for years to come, especially at the local level. It also led to the suspension of work on key initiatives, including the policy letter on medical homes for CCS clients and the exploration of authorizing medical homes and the impact of these authorizations. Work utilizing the Federal MCAH grant awarded to USC's UCEDD at Children's Hospital Los Angeles to implement strategies to increase the number of FCC medical homes for CSS clients and the other CYSHCN was also halted.

The third factor in this cycle and continued into the next was the **accelerated move of Medi-Cal beneficiaries into Medi-Cal managed care**; already a major goal of the state and given additional power by the flow of large numbers of adults with low incomes into Medi-Cal system due to the recession.

2010 – 2015 Cycle

From 2010 CCS Title V NAv, the top three priority needs for CCS were:

1. **Modify the CCS program, with appropriate funding, to cover the whole child.**
2. **Expand the number of qualified providers of all types in the CCS program.**
3. **CCS will work with appropriate partners to define, create, and implement standards for medical homes for CCS children.**

Except for the first priority, the other two are very similar to priorities from the last NA indicating that work was still needed to increase the number of CCS providers and develop medical homes for CCS children. Three new state performance measures were developed as measures of progress on the priorities. States still were required to report on the NPMs, and while these measures are important for monitoring progress on meeting the national MCHB goals for CYSHCN, in most cases the NPM were not as useful for tracking progress addressing priorities identified in the NA.

State and national performance measures associated with the priorities from the 2010 Annual Report were:

Priority 1: Modify the CCS program, with appropriate funding, to cover the whole child:

- **SPM 1 (new)** - The percent of children 0-21 years enrolled in the CCS program who have all their health care provided by and coordinated by one health care system.
- **SPM 3 (new)** - The percent of families of children, 0-21 years enrolled in the CCS program (randomly selected by region) who complete an annual satisfaction survey.
- **NPM 4** - CYSHCN age 0-18 whose families have adequate private and/or public insurance.
- **NPM 5** - CYSHCN whose families report the community-based service systems are organized so they can use them easily.
- **NPM 6** - YSHCN who received the services necessary to make transition to all aspects of adult life.

Priority 2: Expand the number of qualified providers of all types in the CCS program:

- **SPM 2 (new)** - The percent of primary care physicians, approved to participate in the CCS program, who are receiving authorizations for care.
- **NPM 3** - CYSHCN who receive coordinated, ongoing, comprehensive care within a medical home.
- **NPM 4** - CYSHCN age 0 to 18 whose families have adequate private and/or public insurance.

- **NPM 5** - CYSHCN whose families report the community-based service systems are organized so they can use them easily.
- **NPM 6** - YSHCN who received the services necessary to make transition to all aspects of adult life.

Priority 3: CCS will work with appropriate partners to define and create and implement standards for CCS children:

- **SPM 3 (new)** - The percentage of families of children, birth to 21 years enrolled in the CCS program, randomly selected by region who complete an annual satisfaction survey.
- **NPM 2** - CYSHCN whose families partner in decision making at all levels and are satisfied with the services they receive.
- **NPM 3** - CYSHCN who receive coordinated, ongoing, comprehensive care within a medical home.

While the CCS Title V NA Report produced by the Family Health Outcomes Project at UCSF, contained action plan recommendations and tools, it is unclear if CMS developed an action plan to address NA priorities in the following year. The Title V Annual Reports requested and received from CDPH for the years in this cycle did not include an action plan and no specific objectives were listed for the priorities above.

Progress Addressing Priorities from the 2010 NA

Priority 1: Provide a whole-child approach to services

In 2010, CCS Title V Stakeholders selected modifying the CCS program, with appropriate funding, to cover the whole child as one of their top three priorities. During the five-year NA, one of the key issues repeatedly identified was fragmentation of care for children enrolled in CCS. This fragmentation is due to the fact that services provided for a medical condition that qualifies a child for CCS (if they also meet financial and residential eligibility requirements) are 'carved' out of their other health care coverage (e.g., Medi-Cal or private insurance), and instead is handled through the CCS program. The CCS program authorizes services to care for the child's CCS-eligible medical condition and provides case management related to the eligible condition. CCS does not cover a child's primary care or care for non-CCS eligible conditions (e.g., autism, developmental delays), which can lead to a lack of communication and coordination between the child's various medical providers and case managers.

To address this fragmentation, NA stakeholders encouraged DHCS to take a whole child approach. This could have been done by either (1) carving all health care for a CCS child out of their health care coverage (e.g., Medi-Cal or private insurance) or by (2) ending the carve-out for care for the CCS-eligible condition, and instead have the child's health plan cover all the health care needs of the child, including care for the CCS-eligible condition.

Many stakeholders preferred that covering the whole child be accomplished by expanding from having CCS only cover the child's CCS-eligible medical condition to having CCS cover all the CCS child's health care needs, including primary and preventative care. With the expiration of California's Medicaid Section 1115 Waiver for hospital financing and uninsured care, DHCS took this opportunity and approached this priority by including CCS in the "Bridge to Reform" 1115 Waiver that was approved by the federal government in November 2010. There were two policy goals for California's 1115 Waiver, "restructuring the organization and delivery of services to be more responsive to the health care needs of enrollees to improve their health care outcomes and slowing the long-term rate of Medi-Cal program expenditures" (pg. 15)^x. Specific to CCS, DHCS stated that the waiver would allow services to be provided in a "more efficient manner that improves coordination and quality of care through integration of delivery services, uses and supports medical homes and provides incentives for specialty and non-specialty care" (pg. 15).^{xi}

As mandated by statute, a Stakeholder Advisory Committee for the 1115 waiver was made up of 39 people representing the populations whose delivery of care would be restricted through the waiver design, including seniors and persons with disabilities; CYSHCN; individuals eligible for both Medi-Cal and Medicare, and people in need of behavioral health services. Technical advisory workgroups (TWG), which reported to the Stakeholder Advisory Committee, also were constructed to discuss each of the populations listed above and to make recommendations to DHCS regarding what would be included in the waiver. The CCS TWG recommended that several delivery models for CCS be piloted to determine if any of them could more effectively provide care to CCS clients. The CCS TWG also advised that CCS keep the parts of the CCS program that were viewed as successful including quality standards and the network of providers.

The Request for Proposals (RFP) to implement the CCS portion of the 1115 Waiver to develop and administer the Demonstration Projects was released in April of 2011. The four possible models included in the RFP were 1) an Enhanced Primary Care Case Management Plan, 2) an Accountable Care Organization, 3) a Specialty Health Care Plan, or 4) a Medi-Cal Managed Care Plan. State Performance Measure 1, the percent of children 0-21 years enrolled in the CCS program who have all their health care provided and coordinated by one health care system, would be used to track progress. The goal for this SPM was to increase over time the number of CCS children enrolled in these pilot programs.

Plans and activities for addressing this priority included:

- convening a stakeholder group to help determine components on the pilot program models in the RFP;
- reviewing proposals, selecting pilot programs, and developing contracts;
- developing education materials for parents and care coordination tools with stakeholders;
- educating CCS program staff and Medi-Cal Managed Care Plan staff;
- a readiness review of pilot programs with the goal of enrolling some CCS children into the pilots by Jan. 1, 2012; later revised to starting enrollment from late 2012 through 2013;
- a rate analysis by the actuary Mercer;

- pilots being implemented and monitored;
- working with UCLA Center for Health Policy Research and UCSF Philip R. Lee Institute for Health Policy Studies to develop and implement the evaluation, including a dashboard that would allow for the rapid determination of any areas that required more attention;
- assessing family and provider satisfaction regarding access, integration of care, and the identification of barriers to the reforms in pilot and non-pilot counties.

Progress was made in addressing this priority, but not as much progress as anticipated. Five demonstration sites were selected to implement one of the four models of care, and the rate analysis by Mercer was completed. On April 1, 2013, the initial 1115 Waiver CCS Pilot Project began with the Health Plan of San Mateo (HPSM) which is a County Organized Health System (COHS) Medi-Cal Managed Care (MCMC) Plan. The Annual Report submitted in 2014 noted that initial steps to evaluate this program had begun but provided no further details regarding the evaluation. Of the five demonstration sites selected for the pilots, HPSM was the only one that started by the end of this cycle. SPM 1 was used to track progress (see Table 4.) and the goal of 40% of CCS clients having their health care provided by one health care system was not achieved during this five-year cycle.

Table 4. SPM 1: Percent of children birth to 21 years enrolled in the CCS program who have all their health care provided by and coordinated by one health care system

Measure	Notes
2012 = 0%	• Prior to pilot implementation
2013 = 0%	• Prior to pilot implementation
2014 = 2.9%	• Reflects HPSM pilot
2015 = 0.6%	• It is unclear why there was a decrease from the prior year

The 2014 Annual Report stated that initial steps to evaluate the HPSM 1115 Waiver pilot had begun, but no other details were provided. California’s Title V 2015 Annual Report/2017 Application³ submitted in 2016 stated that:

DHCS administered a family satisfaction phone survey to assess families’ knowledge and satisfaction with the demonstration project, knowledge and satisfaction with their care coordinator, access, and satisfaction with providers, satisfaction with the medical services provided, and to establish a baseline to compare against future surveys (pg. 95).^{xii}

That survey was the CCS Title V NA Family Satisfaction survey done as part of the NA and not as part of the evaluation of the 1115 Waiver CCS Pilot Projects. There was also no progress reported regarding the evaluation by the UCLA Center for Health Policy Research or the

³ In the 2015-20 cycle, HRSA changed the name of the annual Title V reports submitted by state from “Narrative Reports” to “Title V Annual Reports and Applications.”

development of the data dashboard that was supposed to be used to rapidly identify areas where attention was needed. No baseline data were collected prior to the HPSM pilot launch, effectively making a pre-post evaluation impossible.

Priority 2: Expand the number of qualified providers of all types in the CCS program.

The second priority for this NA cycle was to expand the number of qualified providers participating in the CCS program. The new performance measure developed to monitor progress was SPM 2, the percent of primary care physicians approved to participate in the CCS program who are receiving authorizations for care. As noted in the 2011 Annual Report, expanding the number of providers in CCS was mostly out of the scope of CCS, but whether CCS-approved PCPs were receiving authorization for care could be measured.

Initial plans and activities to address this priority included:

- improving the database to provide the most accurate results for this measure
- as staffing permitted, working with CCS Regional Office staff and local programs to authorize a PCP in conjunction with authorizations for the SCC or specialists
- work with the groups listed above as well as stakeholder groups to recruit non-specialist physician to become CCS-approved providers for CCS clients and promote medical homes for CCS children
- developing and issuing a policy letter to address the importance of and need for providing directions for authorizing PCPs
- focus on local programs/Regional Offices that are most deficient in authorizing PCPs to increase their PCP authorizations.

The 2012 Annual Report noted that CCS was addressing the shortage of both pediatric sub-specialty physicians and facilities approved to care for CCS clients, and that “there were significant compromises in maintaining the provider network for CCS patients which is barely adequate to meet the needs” (pg. 9).^{xiii} Despite the challenges, the Annual Report stated there was almost a 10% increase in designated tertiary hospitals and intensive care units and that the Telehealth Legislation enacted in 2012 would help to increase the availability of CCS services in more rural areas.

The 2012 Annual Report also explained that the Systems of Care Division, which oversees CMS, had reinvested in efforts to increase the processing of applications from facilities that wanted to become CCS-approved providers.^{xi} The Annual Report also mentioned that the passage of the Affordable Care Act (ACA) led to a significant increase in physician reimbursements for pediatric primary and sub-specialty care, which the state anticipated would increase access to health care for all CYSHCN, including CCS clients. Examining the potential integration of nurse practitioners into CCS and working to develop policies to implement the provision of Assembly Bill 415 which was designed to reduce barriers and expand access to Telehealth was noted as well. The 2015 report at the end of this cycle stated that CCS had improved the provider paneling process by developing systems to receive and process provider applications electronically.^x Not noted in the report is that the increase in Medicaid rates for physician reimbursements expired in 2015 and California did not maintain the increase, resulting in a 58.8% drop in payments to doctors.

The performance measure created to track progress on this priority was SPM 2: the percent of primary care physicians, approved to participate in the CCS program, who are receiving authorizations for care. Per the 2011 Annual Report, the annual indicator for SPM 2 was 23.7% and the performance objective to be reached by the end of the cycle in 2015 was 27%. The 2012 Annual Report stated that SPM 2 was inactivated and replaced by SPM 10: the percent of CCS clients who have a designated primary care physician and/or a specialist physician who provides a medical home. As a result, no performance measure could be used to assess progress addressing the priority of expanding the number of qualified providers in CCS.

Priority 3: CCS will work with appropriate partners to define and create and implement standards for medical homes for CCS children.

This priority was essentially the extension of Priority 8 from the previous NA cycle and reflected one of the challenges CCS faced: how to measure medical homes. In the previous cycle, CCS used data from a field in CMS Net that captured the name of a CCS child's primary care provider as a proxy for a medical, while recognizing that this did not actually measure whether a CCS child had a true medical home. The 2010 Annual Report explained that the Title V CCS NA stakeholder group had identified several priority objectives that CCS determined could be assessed through a family satisfaction survey, including implementing medical homes, thus the creation of SPM 3.^v SPM 3 measured the percentage of families of children 0-21 years enrolled in the CCS program (randomly selected by region) who complete an *annual* [emphasis added] satisfaction survey. The report went on to explain that the CCS program could not directly measure whether CCS children are receiving their primary care in a medical home, but through utilizing a family satisfaction survey, they could use specific questions to assess if children were receiving care in a medical home. The goal of SPM 3 was to create an annual CCS family satisfaction survey and over time increase the number of families completing the survey which would measure their satisfaction with the program, the services received, and families' perceptions regarding their participation in decision making and linkages provided to access support.

Plans and activities included:

- using the 1115 Waiver's CCS Pilots Projects' Evaluation Oversight Group and their work on a family survey for families participating in the pilot and a control group of families not participating;
- expanding the potential base of surveys (from 1115 Waiver's CCS Pilot Projects);
- utilizing translation services to translate surveys into most frequently used languages in the region;
- working with Regional Office staff and local programs to administer the surveys.

The 2014 Annual Report mentioned that family surveys have been implemented in the MTP program as part of the alternative therapy model, but the Annual Report did not provide any details about the percentage of families that completed the survey.^{xv} The Report also stated that a statewide family satisfaction survey was being developed with Title V stakeholder input,

based on a survey done by counties, most likely referring to the Title V CCS Family Survey that was done as part of the five-year NA (see Table 5).

Table 5. SPM 3: The percent of families of children, birth to 21 years enrolled in the CCS program, randomly selected by region who complete an annual satisfaction survey

Measure	Notes
2011 = 0%	<ul style="list-style-type: none"> No survey launched
2012 = 0%	<ul style="list-style-type: none"> No survey launched
2013 = 0%	<ul style="list-style-type: none"> No survey launched
2014 = 41.5%	<ul style="list-style-type: none"> Data from Title V survey
2015 = 41.5%	<ul style="list-style-type: none"> Data from Title V survey done in 2014

The 2012 Annual Report introduced a new state performance measure, SPM 10: the percent of CCS clients who have a designated primary care physician and/or specialist physician who provides a medical home.^{xi} Plans and activities to address this measure mirrored many of the activities for SMP 2, discussed earlier under priority 2.

Additional plans for activities to address SPM 10 included:^{xi,xii,vi}

- obtaining detailed reports from counties on the number and percent of CCS clients with a ‘medical home’ provided by a PCP vs. a specialist, and by an individual medical provider vs. a clinic;
- meeting with county CCS administrators to review the medical homes definitions and discuss how to consistently apply the definition in CMS (later changed to Systems of Care Division or SCD) performance measure reporting;
- developing and issuing a policy letter requesting that County CCS offices only identify physicians as providers of medical homes and not clinics;
- continued implementation of the 1115 Waiver Pilot Projects⁴ and analysis of initial and interval data from the Pilots, which included several measures of medical home function (e.g., being family centered);
- collaborating with CRISS on the development of a CCS medical home policy and having a CCS medical home Workgroup to assess how the medical home concept was being applied differently across regions and counties with different systems of care.

Regarding accomplishments to address the medical homes priority, the state CCS staff developed case management procedures to identify each CCS client’s primary medical home provider and enter that information into CMS Net, but it is unclear if a policy letter regarding this was issued. No accomplishments were reported regarding completing the medical homes policy letter that was supposed to be developed with CRISS.

⁴ The medical home was the foundation for each of the four integrated and coordinated health care delivery system models to be implemented in the Pilot Projects.

The percentage of CCS clients who have a designated primary care physician and/or specialty physician who provides a medical home (SPM 10) varied over this cycle (see Table 6.) and the annual objective of 90% established in 2012 was not achieved.

Table 6. SPM 10: Percent of CCS clients who have a designated primary care physician and/or specialist physician who provides a medical home. (Note: actual measure used is having a PCP listed in CMS Net)

Measure	Notes
2011 = 84%%	<ul style="list-style-type: none"> • Represents having a PCP
2012 = 62%	<ul style="list-style-type: none"> • Drop likely reflected impact of new guidance to not use the name of a clinic in the medical home field in CMS
2013 = 74.6%	<ul style="list-style-type: none"> • Improvement likely resulted from county CCS efforts to better report on measure
2014 = 78.4%	<ul style="list-style-type: none"> • Improvement likely resulted from county CCS efforts to better report on measure
2015 = 81.8%	<ul style="list-style-type: none"> • Improvement likely resulted from county CCS efforts to better report on measure

Additional information on medical home related activities and accomplishments was reported under NPM 03: the percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. The data source for this measure was the National Survey – Children with Special Health Care Needs (NS-CSHCN) and the California data represented this broader group of CYSHCN, including those CYSHCN without CCS. Annual indicator data for this measure showed a slight increase from 38.3% of CYSHCN having a medical home in 2011 to 41.5% having one in 2014. (The data source for this was the NS-CYSHCN and the field notes for this measure indicate that the 2009-2010 data were used for 2011-2015, so the data shouldn’t have changed in 2014 and 2015.)

Most of the plans and activities related to NPM 03 reflected plans and work done by CRISS and FVCA and built upon the medical homes work reported in the previous NA cycle. Key plans and activities included:

- the Sonoma FQHC, which was part of the Project Access grant that ended in 2009, continuing to promote medical homes for children with epilepsy;
- providing a “Hospital Discharge Questionnaire” developed by FVCA and translated into multiple languages for families to gather information to improve coordination of care when their child comes home from the hospital;
- CRISS, which expanded to an additional 11 rural counties in Northern California, compiling materials for pediatric practices, clinics, and child-serving agencies, and distributing these materials and Child Health Notebooks for family use to organize health care information and medical records in all 25 CRISS counties;

- FVCA providing training for families and professionals on medical homes and distributing “resource referral pads” to physicians with local listings for resources for families;
- CRISS continuing to expand and improve the Alameda County Medical Home project, including targeting clinics in Alameda with high numbers of CSS children;
- with a grant from the San Francisco Foundation, CRISS working to expand medical homes activities to San Francisco, San Mateo, and Contra Costa Counties.

Regarding the plans and activities that involved state CCS that were not previously mentioned, the 2013 Annual Report noted that state CCS would work with counties to develop new medical home performance measures and that the measures would include definitions of a medical home from the American Academy of Pediatrics, HRSA, and the National Center of Medical Home Implementation’s evolving standards. Under accomplishments, the 2014 Annual Report noted that the state had completed the expansion of MCMC services to all counties in the state, and that CYSHCN in CCS would have a primary care physician and a medical case manager to coordinate all their special health care. Given the lackluster performance of MCMC plans on child quality measures in subsequent years, it is unclear if the plans did provide this care coordination.

Contextual Factors

For this cycle, four factors were identified as potentially affecting progress addressing the priorities identified in the 2010 NA. First, there were the **lingering effects of budget cuts and staffing cuts brought on by the Great Recession**. It would take the state several years to start recovering financially. On a local level, counties continued to deal with the loss of CCS staff, many of whom had deep expertise in the program. With staffing cuts at both the state and local levels, it is likely that program sustainability was prioritized over program improvement.

The second factor was a change in leadership at CMS with the departure of Dr. Marion Dalsey and the elimination of CMS as a Branch. Dr. Dalsey was a pediatrician who had a long tenure with CCS and a deep understanding of the program, the needs of CCS children and their families, and the importance of meaningful collaboration with key partners (e.g., CRISS, FVCA) to meet those needs. She was also the last physician who held the position of branch chief, and the people who have filled this position since her departure have been health care administrators. Physicians and health care administrators have different approaches and knowledge bases.^{xvii} Physicians are trained to focus on delivering patient centered care, while administrators are focused on managing resources and creating system-level change. With the state eliminating CMS as a branch, CCS was folded into ISCD with Long-Term Care and other adult-serving programs.

Another factor was the national push to transfer Medicaid beneficiaries into managed care plans that was mirrored by a similar push in California. A big focus of CMS for this cycle was the 1115 Demonstration waiver project. Initially anticipated to involve five CCS Pilot Projects that would provide opportunities to evaluate which models of care — or which components of

the models — worked best for more effectively providing care for CCS children, many of whom have medically complex conditions, only one model was launched in this cycle. It appears that negotiating contracts and the other steps needed to launch these pilots were more time-consuming and complicated than anticipated, likely diverting attention and resources from meeting other NA priorities.

The passage of the ACA and the resulting tremendous growth and expansion of Medi-Cal was also a factor. From December 2012 through December 2015, 4.5 million people were added to the program, which has continued to grow (DHCS, 2015).^{xvii} Approximately 75% of this growth was attributed to the ACA and to the transition of children from the Healthy Families Program in Medi-Cal in 2013. This expansion also required extensive time, resources, and attention from DHCS.

2015 – 2020 Cycle

Starting in 2015, the structure and organization of the Title V Reports changed with new guidance from HRSA/MCHB. Particularly notable was the requirement that states submit an action plan and update the plan as needed across the cycle. In the Title V Reports from the previous two cycles, the most relevant content for information on progress addressing NA priorities was found under the state performance measures, from 2015 forward most of this information is found under the State Action Plan and Strategies by MCAH Population Domain (e.g., CYSHCN). Also new in this cycle was the requirement for states to include evidence-based (or informed) strategy measures (ESM) in their Annual Reports. The rationale given for this requirement is that it would hold states accountable for improving quality and performance related to the NPMs and related public health issues and help states’ efforts to more directly measure the impact of specific strategies on NPM.^{xix}

The top priorities from the 2015 NA selected by stakeholders were shared with SCD and revised into two priorities with several specific objectives. The first priority addressed the fragmentation of services experienced by CCS clients and their families, and the need for services to be organized in a way that makes them easier for families to use. It also addressed the medical homes, specifically, the lack of medical homes for CCS clients and the need for improved transition services, care plans, and increased family participation. The second priority addressed the need for improved access to care with objectives to increase the number of providers and expand approaches to accessing care.

Priority 1: Provide a whole-child approach to services

To address Priority 1, objectives for this cycle included:

1. Increase the percentage of CCS children who receive their primary and specialty care within one system of care;
2. Increase the number of CCS clients with a patient-centered medical home;
3. Implement at least two strategies to increase family involvement at all levels;

4. Increase the number of clients with an Individualized CCS Plan;
5. Explore methods to increase the number of CCS clients, ages 19 and 20 years, who receive at least one visit with an adult subspecialist.

Priority 2: Improve access to health care

To address Priority 2, objectives for this cycle included:

1. Increase the number of CCS paneled medical providers;
2. Increase the number of telehealth services provided to CCS clients living in rural areas or far from SCCs;
3. By June 30, 2020, all county programs will make medical eligibility determination based on a statewide CCS medical eligibility guide.

The two priorities above that came from the 2015 NA were further refined for inclusion in California's Title V Action Plan submitted to HRSA in 2015. In the Action Plan, they were Priority 4, "to provide high quality care to all CYSHCN within an organized care delivery system," and Priority 5, "to increase access to CCS paneled providers such that each child has timely access to a qualified provider of medically necessary care." Objectives to address the priorities also changed over the cycle, as detailed below, and the objective related to increasing the number of clients with an individualized CCS plan was dropped.

Progress addressing Priorities from the 2015 NA

Priority 4, Objective 1: Whole Child Approach

In the Action Plan submitted in 2015,^{xii} Priority 4 was "to provide high quality care to all CYSHCN within an organized delivery system," and the related objective for FY 2015-2016 was "by June 30, 2020, increase the children in CCS who receive primary and specialty care through a single system of care by 20%." The three strategies listed for this objective were:

1. Through the CCS redesign stakeholder process, refine the selected whole child approach to optimize access to qualified providers
2. Develop ability to track organization of care in CMS Net
3. Conduct surveys of CCS families and providers to assess satisfaction with organized care delivery system.

The stated goal for delivering primary and secondary care through a single system was to improve care coordination for primary, specialty, and behavioral health services for children's CCS covered condition(s) and their non-CCS conditions. DHCS worked to achieve this goal by moving a portion of the state's CCS-children covered by Medi-Cal for their primary care into MCMC plans that would cover all their health care needs through a program that is currently called the "Whole Child Model" (WCM). This was essentially an extension of plans that started in the last NA cycle with the 1115 Waiver CCS Pilot Projects, which were to have been implemented and evaluated to inform future reforms, such as the WCM.

Between 2015 and 2020, the objectives, strategies, and activities related to covering the whole child evolved and progress implementing the strategies varied. For FY 2016-2017,^{xx} the objective was adjusted to “by June 30, 2020, increase the children in CCS who received primary and specialty care through a single system of care by 10% from 7104 currently to 7814.” For FY 2017-2018,^{xxii} the objective was modified by dropping the reference to the numbers or percentage, and the strategies and activities focused on 1) refining the selected whole child approach to optimize access to qualified providers; and 2) conducting surveys of CCS families and providers to assess satisfaction with organized care delivery system. At the end of the cycle in FY 2019-2020,^{xxii} the objective evolved to: “By June 30, 2020, increase child and youth enrollment in the CCS program”, while the strategies to achieve the objective remained unchanged from those submitted in FY 2017-2018. No SPM was associated with this objective and no data was reported regarding increasing CCS enrollment, so it is unclear if enrollment increased.

Progress to move CCS children into the MCMC plans implementing the WCM was made in three phases, with six Phase 1 counties implementing the move starting in July 2018. Phase 2 implementation began in January 2019 and included 14 more counties. In Phase 3, one additional county implemented the move in July 2019. Using counts of CCS cases in calendar year 2018 as the basis for this estimate, it appears that approximately 17% of CCS children, from 21 counties, were moved into MCMC. This suggests that CCS basically met their objective of increasing the number of children in CCS who receive their primary and specialty care through a single system, although the process was slower and more complex than initially anticipated.

Regarding the implementation of different strategies to achieve the objective of increasing the CCS children who received all their health care through a single system, assessing progress by reviewing the Title V annual report was challenging. For the first strategy, “refine the selected whole child approach to optimize access to qualified providers,” DHCS:

- developed plans to implement the WCM;
- held meetings with health plans and counties to finalize the allocation methodology;
- issued Memorandum of Understanding guidance to health plans and counties
- updated provider notices, the All-Plan Letter, and CCS Numbered Letters (a CCS policy letter);
- worked closely with the Managed Care Quality and Monitoring Division that provides oversight over MCMC plan to ensure CYSHCN received appropriate referrals to CCS, tracked data, and made adjustments to facilitate the process;
- held daily and weekly teleconferences after each phase of WCM implementation with MCMC plans and counties to discuss implementation success and identify issues and concerns;
- worked with a CCS Advisory Group (which evolved from the Redesign Stakeholder Advisory Board) that provided expertise in caring for CYSHCN in the WCM.

The second strategy, “develop ability to track organization of care in CMS Net (the CCS case management system),” only appeared in the 2016 and 2017 Title V Applications.^{x,xvi} No information on progress for this strategy was found in the Title V Annual Reports.

For the strategy “conducting surveys of CCS families and providers to assess satisfaction with organized care delivery systems,” there is little evidence of progress during most of the cycle. Several of the Annual Reports mention the family satisfaction survey conducted by DHCS of CCS families enrolled in the Health Plan of San Mateo 1115 Waiver demonstration project initiated in 2013. As explained in the 2017 Title V Annual Report, the survey was conducted one year after implementation of the demonstration project, which would be 2014. This is again likely a reference to the CCS Title V Family Survey conducted during the NA and it was not designed to assess the 1115 Waiver Pilots. The 2016 Title V Application also mentioned that DHCS had developed and was preparing to administer a family satisfaction survey in conjunction with another 1115 Waiver demonstration project with Rady Children’s Hospital.^x However, in the Annual Title V Report for 2016, there was no discussion regarding whether this survey was conducted. In both the 2019 and 2020 Title V Applications, there was a discussion of the plans to conduct family and provider satisfaction surveys as part of the 2020 NA.^{xxii, xviii} Additionally, The Title V Annual report for 2020 did provide a short summary of the NA survey findings and mentioned the evaluation of the WCM being conducted by researchers at the University of California, San Francisco and the WCM evaluation report that they will submit to DHCS in December 2022.^{xxiv}

Priority 4, Objective 2: Medical Home

The second objective under Priority 4, “To provide high quality care to all CYSHCN within an organized care delivery system” in California’s 2015 Action Plan was: “By June 30, 2020, increase the number of CCS clients who receive coordinated ongoing comprehensive care within a family centered medical home by 20%, as measured by the National Survey of Children’s Health (NSCH).”^x The strategies to achieve this objective were:

1. With CCS redesign stakeholder workgroup, review existing national, state, and local medical home models and tools and identify best method(s) for CCS to promote for CYSHCN;
2. explore integration of the Affordable Care Act ACA health home concept with the medical home concept;
3. develop and disseminate materials to facilitate implementation of tools that promote medical homes, including binders and standards;
4. identify the number of counties with a family advisory council, parent health liaisons, family-centered care workgroup, or another role supporting CYSHCN, including CCS;
5. develop and implement policies to increase the number of counties with individuals or workgroup serving in an advisory capacity to CCS.

The Title V Annual Report for FY 2016 reported that DHCS and the CCS Redesign members selected medical homes as an area of improvement in the CCS redesign process.^{xvii} Progress on implementing the strategies in the Action Plan included DHCS reviewing medical homes definitions, models, and best practices, with input by the CCS Advisory Group through a topic-specific workgroup. The Annual Report stated that no definitive conclusions were reached, and the outcome of the review and discussions were inconclusive. There was no reported progress

on exploring the integration of the ACA health home concept with the medical home concept, and that strategy was dropped from the updated Title V Action Plan submitted in 2017. There also was no reported progress on developing and disseminating materials to facilitate medical homes implementation, so it is unclear if this ever happened. Annual Reports in subsequent years state that this objective was completed in FY 2015-2016 and that no further action was needed.

For Strategies 4 and 5 from the 2015 Action Plan, reported progress in the 2016 Annual Report includes examples of family participation in CCS county programs, such as advisory committees, task forces, family and agency advocacy, and providing feedback through surveys, group discussions, individual consultations, participating in Special Care Center team meetings and/or transition planning. In 2016, the Action Plan was updated, and the strategies 4 and 5 were replaced with the following strategy: “Increase the number of counties with a family advisory council, parent health liaison, family-centered care workgroup or other role supporting CYSHCN including CCS”.^{xvi} The accompanying ESM 11.1 was: “Number of county CCS programs with family members providing input into CCS policies.” No data was ever reported for this measure, and it was revised again in the Action Plan submitted in 2018 to ESM 11.2: “Number of completed informational trainings to increase awareness and participation in activities that engage families into partnership with systems and services.” No data for this measure was reported in 2018.

In 2019, the family engagement measure was revised and narrowed by adding “in Whole Child Model Counties” at the end to become the “number of county CCS programs with family members providing input into CCS medical homes policies in Whole Child Model Counties”.^{xviii} That year, DHCS/ISCD contracted with FVCA to provide outreach materials to CCS families enrolled in the WCM and to assist in navigating services and benefits. The contract also called for holding workshops/trainings on the WCM for families and included stipends for families to address barriers to participation. A total of 14 trainings were conducted that year, and an additional seven were conducted the following so that each of the 21 WCM counties had a training before the contract ended in June 2021.

In the updated Action Plan submitted in 2016, revisions were made to the medical home objective. The objective was rewritten to read “By June 30, 2020, increase the number of CYSHCN who receive care within a medical home by 10%, as measured by the medical home CCS performance measure.” There are important differences in how the NSCH measures medical homes compared to the CCS medical homes performance measure. The NSCH measure is based on a composite measure composed of five medical home subcomponents (usual source of care, personal doctor or nurse, referral access, receipt of care coordination, and receipt of family-centered care), while the CCS medical homes performance measure is defined as having the name of a primary care provider in the primary care provider field in CMS Net. In yearly Title V reports for this cycle, data on the NPM 11: “Percent of children with and without special health care needs having medical homes” is reported, but no data is reported for the CCS measure.

In the Title V report submitted in 2019, the objective in the Action Plan again was revised, this time to drop reference to the CCS performance measure.^{xviii} In that same report, data on NPM 11 is reported. It includes a field note explaining that the annual objective of 41.4% for the percentage of children with and without special health care needs, ages 0-17, who have a medical home was reached, and a new annual objective was set based on a 10% improvement over the most recent two-year average rate. The new objective was to increase the percentage of children with and without special health care needs, ages 0-17, who have a medical home to 44.8% or greater. The Title V report submitted in 2020 reports a drop in NPM 11, down to 40.4% having a medical home. However, one of the challenges in relying on data from the NSCH to measure progress is the very wide confidence intervals for most measures, changes in the measures, such as is the case with NPM 11, are typically within the confidence intervals thus calling into question whether significant changes have occurred.

Priority 4, Objective 3: Transition

The third and final objective submitted in California’s 2015 Title V Action Plan under Priority 4 was: “By June 30, 2020, increase by 20% the number of CCS clients with selected conditions who report having an identified adult subspecialist to assume specialty care.”^x The selected conditions specified were congenital heart disease, cystic fibrosis, respiratory failure, Type 1 diabetes, hemophilia, acute lymphocytic leukemia, sickle cell disease, cerebral palsy, and status post organ transplant. The strategies to achieve this objective were:

1. Explore current CCS transition practices, including transition fairs, parent liaisons, et al. and Redesign Stakeholder Advisory Board (RSAB) Transition Workgroup findings;
2. Increase parent liaisons providing input into local transition practices;
3. With RSAB Transition Workgroup, review options for CCS clients to have a visit with adult physicians through managed care.

In 2016, the object was revised to: “By June 30, 2020, increase by 20% the number of 20-year-old CCS clients with a transition planning plan of care documented by CCS county staff.” The strategies were also revised to the following:

1. Explore current CCS transition practices including transition fair, parent liaisons, and the CCS Advisory Group⁵ transition workgroup findings;
2. Increase the number of family members providing input into state and local transition practices;
3. With CCS Advisory Group, review options for CCS clients to have a visit with an adult physician through managed care.

Progress implementing these strategies included:

- SCD collaborating with the MCMC Quality and Monitoring Division on developing facilitation of transition services for CYSHCN with health plans;
- The RSAB Transitions Workgroup reviewing and providing feedback on the CCS transition performance measure for local CCS programs;

⁵ During the 2015-2020 cycle, the Redesign Stakeholder Advisory Board was renamed the CCS Advisory Group.

- County CCS programs providing more details about their county-specific transition efforts and sharing their promising practices, which included county-based transition fairs, CCS parent liaisons, and navigators that work with families to identify community resources;
- Some county CCS programs implementing transition planning, including identification of transition eligible clients, readiness assessment, and providing guidance on conservatorship;
- Some county CCS programs holding regular meetings with health plans and community-based resource providers to identify appropriate physicians and services for CCS clients transitioning to adulthood;
- DHCS meeting with MCMC plans to identify and resolve issues related to transition and to develop a statewide transition policy for CCS clients;
- SCD⁶ piloting and conducting a survey of county CCS administrators on transition successes and service gaps, the results of which provided baseline information for ESM 12.1 – “Number of county CCS programs with family members providing input into transition policies”;
- Administering the transition survey annually in FY 2017-18 and 2018-19, with survey results indicating an increase in the number of CCS programs with family members providing input.

County CCS programs have indicated there are barriers to transitioning CCS clients to managed care physicians as they age out of CCS, including a limited number of adult providers willing to accept clients with complex medical needs; adult providers not accepting new clients; lack of MCMC contracts with adult providers; long waiting lists for specialists; and a lack of local specialists for specific conditions. This led to CCS deciding that tracking a completed visit by CCS clients to managed care physicians should be part of transition planning.

In 2019, DHCS’ Integrated Systems of Care Division (ISCD) convened a Transition to Adulthood workgroup with members representing advocates, counties, families, health plans and providers. The purpose of the workgroup was to assist in answering three policy questions:

1. What age should transition services begin?
2. What transition activities should be required?
3. And for what populations?

By the end of FY 2019-2020, the DHCS/ISCD had held 14 web meetings and the workgroup decided to work on elements 5 (transfer of care) and 6 (transfer completed) of Got Transition’s elements for a successful transition. This work resulted in the development of a Risk Assessment Tool to identify youth who will need intensive case management to assist with continuity of needed services during their transitions to adulthood, and a list of recommendations that can assist transitioning youth to continue to embrace healthy lifestyles and receive needed services.

Regarding CCS’ decision to track a completed visit with a managed care adult physician as a part of transition planning, there were several options for tracking. These options included

⁶ During the 2015-20 cycle, the Systems of Care Division was renamed the Integrated Systems of Care Division

working with adult providers in MCMC to document a completed visit, following up with parents to collect this data, and using data from electronic health records. With variations in county CCS program capacity and resources, each program has implemented the tracking option(s) that are feasible for them. Overall, some good progress was made on transition during this cycle.

Priority 5: To increase access to CCS paneled providers such that each child has timely access to a qualified provider of medically necessary care.

Priority 5, Objective 1: Access to Care

The first objective listed under Priority 5 in the 2015 Title V Action Plan was: "By June 30, increase the percent of CCS families reporting that their child always saw a specialist when needed from 72% to 90% based on the CCS/FHOP survey." ^x The key strategies listed in 2015 to achieve this objective included:

1. with the Redesign Stakeholder Advisory Board, explore strategies to increase access to CCS paneled providers, with focus on rural areas, including streamlining processes and developing reports of shortage areas;
2. based on the findings of the NA, define issues associated with non-participation in CCS of durable medical equipment (DME), pharmacy, home health, and behavioral health providers, and explore methods to increase their participation in CCS;
3. review the criteria for providers to be CCS paneled with the goal of increasing numbers of paneled providers while maintaining quality standards.

In 2016, the third strategy was dropped with no reported progress on implementation. The first strategy was revised in 2016 to read: "With the CCS advisory group, explore strategies to increase access to CCS-paneled providers, with a focus on rural areas." ^{xvi} Both strategies were revised in 2017, ^{xvii} remained the same until the end of this NA cycle, and are as follows:

1. identify barriers to access to CCS-paneled providers;
2. define and identify issues associated with access to durable medical equipment, pharmacy, home health and behavioral health providers.

The objective for this priority was revised in 2019 to read: "By June 30, 2020, ensure CCS clients receive appropriate care from a subspecialist in a timely manner," The Annual Report for 2019 states that there is no data available to report on the prior objective, and that the objectives and strategies have been rewritten for the next cycle to ensure that they rely on available data and process measures to support monitoring and accountability. ^{xx}

Progress in addressing Objective 1 included:

- DHCS, responding to stakeholder requests, developed a new SPM for access to subspecialty care, which was the number of CYSHCN with select conditions who have a special care center team report documenting a visit within 90 days of CCS eligibility determination;
- redesigning the High-risk Infant Follow-up Program;

- starting a quality of care initiative with the California Perinatal Quality Care Collaborative with the goal of identifying quality improvement opportunities for NICUs to reduce long-term morbidity;
- the CCS Executive Committee, the state, and county MTPs working together to create the MTP Advisory Committee to establish a consistent forum for statewide MTP therapists with administrative and/or supervisory responsibilities at the county level to collaborate with one another and the State Therapy Consultant through regular meetings and electronic communication.

For home health services, broader access issues have affected the availability of these services for CCS clients and Medi-Cal beneficiaries. These access issues include geographic variation in provider participation and lower provider participation related to low provider reimbursement rates. To address these issues, local CCS Programs and the State’s CCS Program nurses worked to identify active service providers willing to accept CCS authorizations. The State worked on increasing Home Health Nursing rates, which took effect on July 1, 2018, and should help improve the state’s ability to recruit Home Health Independent registered nurses (RNs) and licensed vocational nurses (LVNs), Pediatric Day Health Care Centers, and Home Health Agencies to serve California.

CCS clients access DME and pharmacy services through the Medi-Cal Program’s enrolled durable medical equipment and pharmacy providers. The Medi-Cal Provider Enrollment Division (PED) is responsible for enrollment and re-enrollment of eligible fee-for-service providers into the Medi-Cal Program. One major activity performed by PED is determining accessibility of providers to Medi-Cal beneficiaries, including CCS beneficiaries. PED instituted the Provider Application and Validation for Enrollment (PAVE) Portal, a web-based application system, which has accelerated the provider enrollment process. There was no data provided on the number of CCS paneled providers and whether the number of providers increased.

The Medi-Cal Program’s Pharmacy Benefits Division is the principal source of DME and the pharmacy reimbursement policy, which extends to the CCS Program. The CCS Program provided additional policy and information directives to CCS county offices and to fee-for-service providers through publication of the CCS Numbered Letters and Information Notices.

While there has been some progress toward increasing access to subspecialists and implementing the strategies associated with this objective, one of the key issues that affect the availability of CCS paneled providers, including subspecialist, and DME and Home Health Service providers, is Medi-Cal’s reimbursement policies. Changing Medi-Cal reimbursement policies is beyond the scope of CCS and would likely require legislation.

Priority 5, Objective 2: Telehealth

The second objective for Priority 5 from the 2015 Title V Action Plan was: “By June 30, 2020, 100% of CCS Counties will report on the use of telehealth services”.^x The objective was revised to 99% in 2016, and in 2017 was changed to: “By June 30 2020, CCS county programs will demonstrate increased knowledge on billing processes for telehealth services”.^{xvi, xvii}

The strategies to achieve this priority from the 2015 Action Plan are:

1. Develop a system within CMS Net to track use of telehealth services for CCS clients.
2. Establish CCS telehealth workgroup with stakeholders including families, to build upon previous work assisting DHCS in telehealth implementation
3. Develop a telehealth survey of CCS providers.
4. Promote telehealth use through CCS provider and Special Care Center trainings on telehealth including e-consultation, consistent with the triple aim, CCS Redesign, and CCS infrastructure.

These strategies also evolved over the next five years, and strategies that involved surveying CCS providers and families to assess perceived access to medically necessary care were dropped after FY 2017 with no mention of any progress being completed. Areas where progress was made are discussed below.

Prior to the start of this five-year cycle, SCD had collaborated with the Center for Connected Health Policy (CCHP) to conduct a survey of CCS Administrators. Key recommendations from the CCHP's August 2015 report on survey findings included continuing collaboration of CCS, community-based providers, and family advocates; the expansion of the list of eligible billing codes for telehealth; and the inclusion of the patient's home in the locations eligible for telehealth payment.^x

In response, in FY 2015-16, ISCD submitted a request to Medi-Cal claims processing to update and add additional billing codes to payable claims for inclusion in the Medi-Cal claims system. Due to administrative delays, the revised billing codes for telehealth services were not implemented until the following year. As further guidance also needed to be issued regarding authorization and claiming of telehealth services, ISCD developed a Numbered Letter on Telehealth Services that was finally released in December of 2017 after unanticipated delays. Updated resources and FAQ were posted on the DHCS website.

ISCD engaged in teleconferences with selected CCS facilities on telehealth and NICU care, Pediatric Intensive Care Unit care, genetics counseling and others. The Telehealth Medical Consultant held discussions with UC Davis Center for Health and Technology on the use of telehealth for tele-audiology, CCS Medical Therapy Units, and rehabilitation medicine. ISCD also provided technical assistance to various local health agencies and CCS providers on billing for telehealth services, including problem solving with CCS programs and billing units in the state's Medi-Cal Management Information System, and the claims contractor.

ISCD also worked on developing and implementing trainings for providers on the billing guidelines for telehealth services. The Annual Report from FY 2018 indicates that trainings for CCS and Genetically Handicapped Persons Program providers were developed, but the FY 2019 Annual Report noted that funding sources were not determined for trainings or for telehealth stakeholder workgroup meetings. The Annual Report for FY 2020 states that all the strategies for this objective were completed and that no further action is needed. As no details are provided about the trainings (e.g., number of trainings conducted, results of pretest and post test evaluations, etc.), what exactly occurred is unclear.

With the emergence of the COVID-19 pandemic in the state in March of 2020, the resulting declaration of a public health emergency, and the statewide shelter-in-place order, there was a rapid shift to providing telehealth services throughout California and many telehealth trainings were conducted by multiple entities. Telehealth visits temporarily became the norm for outpatient visits, including CCS Outpatient Special Care Centers.

Overall, there were many changes made to the action plan objectives and strategies during this NA cycle. While understandable, these frequent changes made assessing progress challenging.

Contextual Factors

There were several factors identified that might have affected progress during this cycle. One factor was the continued push to shift Medi-Cal enrollees, including those CCS children with Medi-Cal, into MCMC through the implementation of the WCM. Preparing for the implementation of the WCM was a time-consuming and complicated process that involved developing contracts with MCMC plans and determining the rates that the plans would be paid for taking on CCS children. As happened with the 1115 Waiver CCS Pilots, DHCS may have underestimated the complexity of this task and the amount of time it would take for the MCMC plans to get ready to implement the WCM. Contracting for, developing, and implementing an evaluation of the WCM has also taken longer than anticipated, and the evaluation as currently planned is narrower in scope and won’t involve assessing outcomes. This is likely because evaluating outcomes would be complex, take longer, and be more expensive.

Another factor potentially influencing progress was the frequent changes in leadership at several levels in DHCS. CCS is a complicated program with many components and nuances at both the state and local level, and it takes time to learn about the program. Much of the work to address NA priorities involves working in partnership with many different entities and stakeholders. Developing the relationship and trust needed for effective partnerships also takes time. Frequent changes in leadership slows down this process. New leaders can also bring with them different skills, styles, visions, and priorities, which, depending on the leader, may enhance or detract from progress.

Compared to the programs that are part of DHCS and the vast number of people enrolled in or covered by these programs, the number of children in CCS is relatively small. This is another factor that may lead to less progress on addressing priorities, as priorities of other programs affecting larger populations (e.g., older adults with chronic conditions or numerous conditions) may be seen as fiscally more important or may have larger constituencies pushing for progress.

Issues related to Medi-Cal have impacted progress across all three cycles. Many of the priorities identified during the NAs are directly impacted by Medi-Cal policies, and in particular, Medi-Cal rates. Although CCS providers get a ‘bump’ above the Medi-Cal rate, the base rate paid to Medi-Cal providers is one of the lowest Medicaid rates in the country. These rates impact the ability to recruit more pediatric specialists to come to California and become CCS providers. They also impact CCS youth being successfully transitioned to adult providers. These providers are reluctant to take on these often time-consuming and complex patients as

caring for them costs more than the reimbursements received. Medi-Cal rates also impact the number of durable DME providers that are willing to work with CCS, thereby impacting access to DME for CCS clients.

The ability of PCPs to provide CCS clients with medical homes is also profoundly affected by Medi-Cal rates. Repeated NA surveys of providers have identified the additional cost of care coordination services for CCS children as an important barrier to providing medical homes for CCS children.^{i,v,x} Until some entity (such as HRSA, DHCS, or MCMC) incentivizes or in some way pays for or requires medical homes, CCS will continue to face ongoing challenges with ensuring that CCS children have true medical homes.

The COVID-19 pandemic and associated public health emergency had many negative impacts on the CCS program, including the diversion of CCS staff to pandemic response work. However, one way in which the pandemic was a positive factor affecting progress in relation to NA priorities is the rapid advancement of telehealth. Access to CCS paneled providers has been an ongoing challenge for CCS children in rural communities, and even for CCS families with transportation challenges in urban areas. With the onset of the pandemic, many of the barriers to providing telehealth services at the national, state, and local level were rapidly resolved, in many cases more rapidly than could ever have been imagined.

Conclusions and Recommendations

As the evaluation of progress in addressing the priorities identified over the three NA cycles is based on reviewing the NA, Title V Applications and Annual Reports, caution is advised in interpreting the findings. It is possible that some of the planned activities and strategies outlined in the Reports were in fact implemented, but the implementation was not discussed in subsequent Reports. As the Reports are typically hundreds of pages long, it is also possible that accomplishments addressing the priorities were noted in the report but overlooked during the reviews.

The priorities identified over the three NAs cycles represent broad, long-term goals and, as such, achieving meaningful progress to address these priorities may take many years and span across several NA cycles. Given this, it is not surprising that the same or similar priorities have been identified in the different NA cycles. Priorities that have been repeatedly identified, such as ensuring that CCS children have true medical homes, increasing the pool of qualified pediatric subspecialists, and providing a whole child approach are hard to achieve. Like the complex and nuanced needs that many CCS children have, the priorities for program improvement encompass many complex and nuanced issues. Some issues, such as increasing Medi-Cal rates, are beyond the purview of CCS and require champions at the high levels of state and national government.

There have been multiple specific objectives and strategies developed to address NA priorities, and many changes to these objectives and strategies. Progress achieving the objectives and implementing the various strategies has indeed been decidedly mixed.

Key challenges affecting progress across the cycles included internal program factors, such as the availability of existing data to track progress and CCS' ability to develop new methods to regularly collect data for SPMs. In many instances, the objectives and strategies developed to address the objectives appear to be more ambitious than the ability and capacity of CCS to implement the strategies. A prime example is the repeated plans to develop and administer an annual family satisfaction survey, which was never achieved. Another example is the progress in both the implementation and evaluation of the 1115 Waiver CCS Pilot Projects, which again fell short of the ambitious plans. As a result, there were no significant findings from the 1115 Waiver CCS Pilot Projects that could be drawn on to inform the implementation of other efforts to reform the delivery of health care to CCS children, namely the WCM. Similarly, the implementation and evaluation of the WCM has also been more complex and taken longer than initially anticipated.

External factors beyond the control of CCS also had a significant impact on progress addressing priorities. Factors such as Medi-Cal rates, California's high cost of living, and the Great Recession profoundly impact the ability of CCS to provide medical homes for CCS children, to recruit qualified pediatric subspecialists, and to ensure smooth transitions to adult providers as CCS youth age out of the program. While these challenges may be worse in California due to the high cost of living and low Medi-Cal rates, they are not unique. They reflect national health care policies that undervalue and underfund primary care and specialists caring for Medicaid beneficiaries as these providers receive lower salaries compared to providers in other specialties. In turn, fewer medical students choose these areas of practice, affecting provider availability over time. Action at national and state levels, including advocacy and legislation, is needed to address these important issues.

CYSHCN enrolled in CCS are some of the most fragile and vulnerable children in our state. We can and we must do better when it comes to addressing priorities to improve the systems of care these children and the broader group of CYSHCN not enrolled in CCS depend on. With this goal in mind, the following recommendations are offered.

Recommendations

- Begin each NA cycle with a convening of NA stakeholders to recap the findings from the previous NA, review what was/wasn't accomplished in the preceding five years. Explore and explain why objectives weren't met and/or plans weren't implemented (e.g., funding, beyond the scope and capacity of CCS, legislation required, etc.). This will enable stakeholders to use the lessons learned from the preceding cycles to advance progress in the new cycle.
- Prior to developing an action plan(s), work with NA stakeholders to conduct a problem analysis for each of the NA priorities. This will increase understanding of the factors affecting the issue at different levels (e.g., individual, institutional, policy) and facilitate the identification of areas where CCS can effectively intervene.
- Involve the NA stakeholders not only in the development of action plans to address NA priorities, but also in the revision of plans over the cycle. This will enhance stakeholder knowledge and awareness about what CCS/DHCS can accomplish, what is beyond their capacity, and what NA stakeholders can do to further progress addressing priorities.

- Enlist stakeholders and others to take on key roles and activities to achieve action plan objectives. CCS has limited funding and capacity to address priority issues. Coordinated partnerships can help advance progress. This is particularly true for issues that impact the CCS program but that CCS has little control over (e.g., Medi-Cal rates or funding for medical homes). These issues require strong advocacy efforts and likely legislative action.
- Increase strategic partnerships and leverage the resources other partners have or may be able to secure such as grant funds that could be used for specific activities that would advance progress addressing NA priorities (e.g., thoroughly exploring how other states provide medical homes to CYSHCN). The Title V resources that are provided to CCS are limited and alone are insufficient to adequately and effectively address all the priorities identified in the NAs.
- Have an ongoing CCS advisory group that includes NA stakeholders and provide the group with regular updates on progress and challenges addressing NA priorities. This would allow key stakeholders to continue providing input into strategies and activities between NAs while promoting increased transparency and accountability.
- Give careful consideration to selecting the measures used to track progress and address objectives. Invest in building state and local data infrastructure to ensure that the necessary resources will be available to collect the data needed to be able to regularly and reliably report on measures.⁷ Some of the ESMs are not related to or only tangentially related to the objectives and strategies developed to achieve the objectives. It would be beneficial to develop additional related and relevant strategy measures that can be used to monitor progress and to share with stakeholders (e.g., through data dashboards) but do not have to be included in the Title V plans.
 - Increase State CCS’s partnership with local CCS programs and partnerships among local programs to implement strategies to achieve objectives. Solicit promising practices from and provide more opportunities (e.g., fund meetings) for local CCS programs to share these practices and related materials amongst themselves. Develop a scope of work for local CCS programs that contains activities that can be implemented locally to help achieve statewide objectives.
 - Be more realistic and less ambitious when developing plans and strategies to address NA priorities. Take into consideration other DHCS priorities (e.g., shifting Medi-Cal enrollees into MCMC plans). Use prior experience and lessons learned to make realistic appraisals of CCS’ ability, capacity and the political will to make changes. Be transparent about this with CCS stakeholders and set appropriate expectations.

CCS has been helping CYSHCN receive needed medical care for almost 100 years, and millions of CYSHCN and their families have benefitted from these services. An ongoing focus on program improvements within CCS, combined with strong advocacy on issues beyond CCS’s control, will help ensure that the program continues to benefit CYSHCN and their families for years to come.

⁷ CCS funds cannot be used by county CCS programs to develop systems to collect and manage critical programs data.

References

- i HealthTubeAC. (2019, March 15). Alameda County California Children's Services (3 minutes) [Video]. YouTube. Available at https://www.youtube.com/watch?v=-lcc_xka-io
- ii Children's Medical Services Branch, California Department of Health Services. (2006). California Statewide Strategic Plan for Children with Special Health Care Needs 2006-2010.
- iii California Department of Health Services. (2005). California Five Year Needs Assessment for the Maternal and Child Health Services Title V Block Grant Program.
- iv Maternal and Child Health Services. (2006). Maternal and Child Health Services Title V Block Grant State Narrative for California Application for 2007 Annual Report for 2005.
- v Maternal and Child Health Services. (2009). Maternal and Child Health Services Title V Block Grant State Narrative for California Application for 2010 Annual Report for 2008. Maternal and Child Health Services. (2008).
- vi Maternal and Child Health Services Title V Block Grant State Narrative for California Application for 2009 Annual Report for 2007.
- vii California Department of Public Health. (2010). California Grant Application And Annual Report For The Maternal And Child Health Services Title V Block Grant Program.
- viii Maternal and Child Health Services. (2008). Maternal and Child Health Services Title V Block Grant State Narrative for California Application for 2009 Annual Report for 2007
- ix Bohn, S., Schiff, E. The Great Recession and Distribution of Income in California. Public Policy Institute of California (2011). Available at https://www.ppic.org/wp-content/uploads/content/pubs/rb/RB_1211SBRB.pdf.
- x California Department of Public Health. (2011). California Grant Application and Annual Report For The Maternal And Child Health Services Title V Block Grant Program.
- xii California Department of Public Health. (2011). California Grant Application and Annual Report For The Maternal And Child Health Services Title V Block Grant Program.
- xiii California Department of Public Health. (2015). Maternal and Child Health Services Title V Block Grant State Narrative for California Application for 2016/Annual Report for 2014.
- xiii California Department of Public Health. (2012). California Grant Application and Annual Report for the Maternal and Child Health Services Title V Block Grant Program.
- xiv (2015) California has no plans to Maintain Rate Increase for Medi-Cal Physician. Journal of Medicine, ISSN 1940-6967. Available at <https://www.namd.org/journal-of-medicine/1494-california-has-no-plans-to-maintain-rate-increase-for-medi-cal-physicians.html>
- xv California Department of Public Health. (2014). Maternal and Child Health Services Title V Block Grant State Narrative for California Application for 2015/Annual Report for 2013.
- xvi California Department of Public Health. (2013). California Grant Application and Annual Report for the Maternal and Child Health Services Title V Block Grant Program.

- xvii Chandrashekar, P., Jain, S.H. Understanding and Fixing the Growing Divide Between Physicians and Healthcare Administrators. Practice Management (March – April, 2019). Available at https://scholar.harvard.edu/files/poojachandrashekar/files/mar_apr_2019_264-268.pdf
- xviii Department of Healthcare Services, Research and Analytic Studies Division. (August 2015). Medi-Cal Statistical Brief.
- xix Title V information system: Guidance portal. Title V Information System | Guidance Portal. (2020, June 25). Available at <https://www.hhs.gov/guidance/document/title-v-information-system>.
- xx Maternal and Child Health Services. (2016). Maternal and Child Health Services Title V Block Grant State Narrative for California Application for 2017/Annual Report for 2015.
- xxi Maternal and Child Health Services. (2017). Maternal and Child Health Services Title V Block Grant State Narrative for California Application for 2018 Annual Report for 2016.
- xxii Maternal and Child Health Services. (2019). Maternal and Child Health Services Title V Block Grant State Narrative for California Application for 2020 Annual Report for 2018.
- xxiii Maternal and Child Health Services. (2018). Maternal and Child Health Services Title V Block Grant State Narrative for California Application for 2019/Annual Report for 2017.
- xxiv Maternal and Child Health Services. (2020). Maternal and Child Health Services Title V Block Grant State Narrative for California Application for 2021/Annual Report for 2019.
- xxv California State Auditor Report 2018-111 (March 2019). Department of Health Care Services – Millions of Children in Medi-Cal are not Receiving Preventive Health Services. Available at: <https://www.auditor.ca.gov/pdfs/reports/2018-111.pdf>.

Acknowledgements:

The Family Health Outcomes Project would like to thank the members of the Advisory Group for this project for their helpful input on refining the project's design and sharing their perspectives on the contextual factors that may have impacted progress addressing Title V CCS needs assessment priorities. We are also grateful for their review of and feedback on the synthesis and dissemination of project findings.

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Support for this work was provided by the Lucile Packard Foundation for Children's Health. The views presented here are those of the authors and do not reflect those of the Foundation or its staff. The Foundation's Program for Children with Special Health Care Needs invests in creating a more efficient and equitable system that ensures high-quality, coordinated, family-centered care to improve health outcomes for children and enhance quality of life for families.

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