PREPARING FOR THE TITLE V NEEDS ASSESSMENT OF THE INTEGRATED SYSTEMS OF CARE DIVISION’S CALIFORNIA CHILDREN’S SERVICES PROGRAM

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UCSF Family Health Outcomes Project
Meeting Objectives

- Orient stakeholders to the structure and functions of CCS and to the processes that will be used for the Title V Needs Assessment (NA)
- Update stakeholders about the status of services for Children and Youth with Special Health Care Needs (CYSHCN) in California and nationally
- Discuss criteria to evaluate potential priorities for CCS/CYSHCN
- Provide input on key issues to focus on in the NA process
- Discuss potential sources of CYSHCN data
To improve the health of children and their families and communities by supporting the development and implementation of comprehensive community planning, data-driven policies, evidence-based interventions, and effective evaluation strategies.
About FHOP

- Located in the Department of Family and Community Medicine at the University of California, San Francisco
- Contracted since 1992 with California Maternal, Child, and Adolescent Health (MCAH) Program in the Department of Public Health to provide training and data summaries to California’s local MCAH programs
- Have done numerous community-based research projects and evaluations of programs
- Conducted the three previous Title V Needs Assessments for the California Children’s Services Program
About FHOP

Public Health Core Functions
- Assessment, Policy Development, Assurance

6-Prong Strategy to build MCH capacity
- Trainings
- On-site and telephone technical assistance
- Guidelines/data methods
- Data and trends for maternal & child health
- Automated tools
- Web accessible resources
TITLE V AND SERVING CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN)
Enacted in 1935 as a part of the Social Security Act, the Title V Maternal and Child Health (MCH) Program is a Federal-State partnership.

The Federal Title V Maternal and Child Health Program has provided a foundation for ensuring the health of the Nation’s mothers, women, children, and youth, including children and youth with special health care needs, and their families.

Title V converted to a Block Grant Program in 1981.
Goals of Title V Funding

1. Access to quality health care for mothers and children, especially for people with low incomes and/or limited availability of care

2. Health promotion efforts to reduce infant mortality and the incidence of preventable diseases, and to increase the number of children appropriately immunized

3. Access to comprehensive prenatal and postnatal care for women, especially low-income and/or at-risk pregnant women
4. An increase in health assessments and follow-up diagnostic and treatment services, especially for low-income children

5. Access to preventive and child care services as well as rehabilitative services for children in need of specialized medical services

6. Family-centered, community-based systems of coordinated care for CSHCN

7. Toll-free hotlines and assistance in applying for services to pregnant women with infants and children who are eligible for Title XIX (Medicaid)

Federal MCH Pyramid

- **DIRECT HEALTH CARE SERVICES**
  - Basic health services and health services for Children with Special Health Care Needs (CSHCN).

- **ENABLING SERVICES**
  - Transportation, translations, outreach, respite care, health education, family support services, purchase of health insurance, case management coordination with Medicaid, WIC, and Education.

- **POPULATION-BASED SERVICES**
  - Newborn screening, lead screening, immunization, sudden infant death syndrome counseling, oral health, injury prevention, nutrition, and outreach/public education.

- **INFRASTRUCTURE-BUILDING SERVICES**
  - Needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, systems of care, and information systems.
State programs must “facilitate the development of community-based systems of services for CSHCN and their families”

State mandates:
- Annual applications for MCH Block Grant Funding
- Conduct state-wide needs assessment every five years
- Minimum 30% funding to CSHCN

1989 CSHCN-specific Amendments to Title V Legislation
10 year action plan for community-based service systems
Part of Healthy People 2010
Incorporated in to President Bush’s 2001 Freedom Initiative
Six core outcomes for assessing achievement and performance
1. All children will be screened early and continuously for special health care needs

2. Families of CSHCN will participate in decision making and will be satisfied with the services they receive

3. All CSHCN will receive coordinated comprehensive care in a medical home
4. All CSHCN will be adequately insured for the services they need.

5. Services for CHSCN will be organized so families can use them easily.

6. All youth with special needs will receive services needed to support the transition to adulthood.
Federal Definition

CSHCN are those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who require health and related services of a type or amount beyond that required by children generally.
Varying Definitions of CSHCN in States

- Condition Specific
- Categorical or Program Specific
- Consequences-based definitions
Expanding the Focus

- Past Title V CCS needs assessments have generally focused on CCS specifically.
- In addition to focusing on CCS, needs assessment will also focus on boarder group of CYSHCN.
1988 Institute of Medicine releases Future of Public Health report

- Emphasis on core functions of public health:
  - Assessment
  - Planning and Policy Development
  - Assurance
- Counting numbers served is no longer sufficient
1989 Omnibus Budget Reconciliation Act

- Required Title V Agency (MCHB) to use indicators and performance measures to assess state agencies

1992 MCHB developed a conceptual model for state programs
Title V Assessment and Planning Cycle

1. Convene Stakeholders Group
2. Assess the Needs of CCS Families and Identify Program Issues
3. Set Priorities Among Identifies Needs/Issues
4. Analyze Problems and Develop Intervention Strategies
5. Develop 5 Year Action Plan
6. Implement Identified Strategies/Interventions
7. Monitor Performance Indicators/Other Objective
8. Convene Stakeholders Group

The cycle repeats indefinitely.
Step 1: Convene Stakeholders Group

- Stakeholders representative of key interest groups:
  - Families
  - CCS County Programs
  - Professional and Advocacy Organizations
  - Managed Care Plans
  - Other State Departments
  - Academic Researchers
Stakeholder Group Activities

- Provide input on all aspects of needs assessment and decide priorities including:
  - Instruments
  - Respondents to recruit
  - Data analyses
  - Interpretation of data

- Establish subcommittees for:
  - Interviews
  - Focus groups
  - Surveys
  - Program/secondary data
Step 2: Assess the Needs of CCS Families and Identify Program Issues

- **Identify key issues** and existing data sources
- **Report findings from other projects** looking at CCS and CSHCN
  - i.e. Lucile Packard Foundation for Children’s Heath
- **Collect data** from iterative process via:
  - Key informant interviews
  - On-line surveys
  - Focus groups
- **Review** all data and findings with stakeholders
Step 3: Set Priorities Among Identified Needs/Issues

1. Select criteria for setting priorities
2. Develop criterion weights
3. Use criteria to prioritize issues
Step 4: Analyze Problems and Develop Intervention Strategies

- Review data on identified priorities
- Research literature and consult experts
- Get recommendations from stakeholders
- Identify evidence based intervention strategies
Step 5: Develop 5 Year Action Plan

- Solicit stakeholders’ recommendations
- Work with CCS state staff to develop goals and SMART objectives
  - Specific
  - Measurable
  - Achievable
  - Realistic
  - Time-bound
Needs Assessment Timeline – 2018

- Convene initial meeting with stakeholder group – Oct. 3
- Convene Advisory Workgroups to review data collection instruments
- Collect primary data and review secondary data
- Analyze, synthesize, and integrate data finds and share with Stakeholders
- Convene meeting with Stakeholders to prioritize identified problems/issues – SEPTEMBER 2019
Needs Assessment Timeline – Key Informant Interviews

- Identify participants for key informant interviews
- Convene Key Informant Interview Subcommittee to review interview guides
- Conduct key informant interviews
- Compile and summarize data from interviews
Needs Assessment Timeline – Focus Groups

- Convene Focus Group Subcommittee to review and finalize focus group discussion guides based on findings from key informant interview
- Identify participants for focus groups
- Conduct focus groups with providers and parents
- Compile and summarize data from focus groups
Needs Assessment Timeline - Surveys

- Convene Survey Advisory Subcommittee to review and finalize surveys
- Translate surveys into Spanish
- Invite providers and families to participate in survey
- Conduct web-based survey of providers and parents
- Summarize findings from surveys and share with stakeholders

Jan. 2019

May 2019
Needs Assessment Timeline – 2019-2020

Sept. 2019
- Create written report on process and results of assessment and review with stakeholders
- Work with state and local CCS staff and interested stakeholders to create Action plan based on identified priorities
- Prepare final Action Plan for adoption

Oct. - April 2020

May 2020
WHAT IS YOUR ROLE?
CCS Needs Assessment Stakeholders

- Be open to the process
- Commit time
- Agree to honor group outcome
- Provide expertise
- Use data and expert for decision-making
FHOP’s Part

- Assist communication and provide opportunities to be heard
- Provide framework & facilitation for a rational inclusive process and data for decision-making
- Manage time and keep the process on track
FHOP’s Role

- Facilitate process – we are not the experts on CCS and CSHCN, you are!
- Communicate with stakeholders and others
- Collect primary and secondary data and other relevant research findings
- Analyze, synthesize, and summarize data
- Share data summaries with stakeholders
- Prepare written summary of process, priorities, and action plans
State CCS’s Role

- Assure appropriate stakeholders are invited
- Provide best data within resources/time frame
- Available for questions
- Commit to using the results (where budget and legislation permits)
- Recognize and explain limitations
Process Guidelines

- Diverse group of stakeholders with varying experience with and knowledge of CCS
- Avoid acronyms and jargon where possible – keep it simple
- Allow space and opportunities for all to be heard, including participants attending via webinar and conference call
- If you are unsure, ask questions
Expectation of the Maternal and Child Health Bureau (MCHB) that the Needs Assessments conducted by the 59 States and jurisdictions will result in two ultimate goals:

1. Improved outcomes for maternal and child health populations
2. Strengthened partnerships
Questions?
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415-476-5283
California Children’s Services (CCS) Overview

Maria A.L. Jocson, MD, MPH
CCS Title V Needs Assessment Stakeholders’ Meeting
October 3, 2018
Created in 1927, CCS provides:

- Diagnostic and treatment services
- Medical case management
- PT/OT services

These services are provided to clients under age 21 with CCS-eligible medical conditions who also meet residential and financial eligibility requirements.
CCS Eligibility Requirements

Financial

• Family income of $40,000 or less
• Eligible for Medi-Cal
• Out-of-pocket medical expense more than 20 percent of family’s adjusted gross income (AGI)

Residential

• Services coordinated by county of residence

Medical

• CCS-eligible condition
• Need the Medical Therapy Program (MTP)* for PT/OT/MTU

* No income requirement for MTP eligibility
Medical Eligibility – Title XXII

- Infectious Disease
- Neoplasms
- Endocrine, Nutritional, Metabolic Diseases and Immune Disorders
- Mental Disorders and Mental Retardation*
- Diseases of the Nervous System
- Medical Therapy Program
- Diseases of the Eye
- Disease of the Ear and Mastoid Process

- Conditions of this nature are not eligible except when the disorder is associated with or complicates an existing CCS-eligible condition.
Medical Eligibility – Title XXII (cont.)

- Diseases of the Circulatory System
- Diseases of the Respiratory System
- Diseases of the Digestive System
- Diseases of the Genitourinary System
- Diseases of the Skin and Subcutaneous Tissues
- Diseases of the Musculoskeletal System and Connective Tissues
- Congenital Anomalies
- Accidents, Poisonings, Violence, and Immunization Reactions
Referrals to CCS

- Referrals to CCS can be made by anyone, including:
  - Hospital
  - Physician
  - School nurse
  - Family

- Referrals are sent to the appropriate county office where the child resides
CCS Service Providers

- Hospitals
- Specialty Care Centers
- Pediatric Specialists
- Pharmacies
- DME Providers
- Other Provider Types
Provider Standards

CCS Provider Paneling

Hospitals

Neonatal and Pediatric Intensive Care Units

Outpatient Special Care Centers
Healthcare Delivery Systems
Healthcare Delivery Systems

Improving Care Coordination Through an Organized Care Delivery System

- California Children’s Services (CCS) Redesign: Whole-Child Model (WCM)
- 1115 Waiver CCS Demonstration Project
CCS Redesign: WCM

**Bifurcated delivery system results in lack of coordination and integration when accessing care from both systems:**

| Specialty care is received from the CCS Fee for Service (FFS) system for the CCS condition | Primary care and behavioral health services are received from the managed care health plan (MCP) |

**Integrates Medi-Cal managed care and CCS FFS delivery systems, resulting in:**

| Improved care coordination for primary, specialty, and behavioral health services for CCS and non-CCS conditions | Care that is consistent with CCS program standards by CCS-paneled providers, specialty care centers, and pediatric acute care hospitals | Increased consumer protections, such as continuity of care, oversight of network adequacy standards and quality performance |
CCS Redesign: WCM

Goals

- Implement patient- and family-centered approach
- Improve care coordination
- Maintain quality
- Streamline care delivery
- Build on lessons learned
- Be cost-effective

Implementation Date

- Phase 1 - July 2018, 6 counties
- Phase 2 - Jan. 2019, 15 counties
WCM Transition by Numbers

- 2 phases
- 21 counties
- 30,000 children and youth
- 5 plans
1115 Waiver
CCS Demonstration Project

Goals

• Improve care coordination and remove delivery of fragmented health care
• Improve health outcomes
• Improve patient and provider satisfaction
• Establish clear provider and State accountability
• Maintain a family-centered delivery system
• Preserve existing CCS Regional Provider Network
Health Plan San Mateo - started April 2013; now part of WCM

• Medi-Cal Managed Care Plan model

• Comprehensive health care to about 1400 CCS-eligible clients; all health conditions covered

• Manages and coordinates a full range of health care services for the "whole" child, including periodic health assessments, immunizations, primary health care services, and specialty health care services
Rady Children’s Hospital, San Diego

- Operational date - July 2018
- Accountable Care Organization (ACO) model
- Includes 5 CCS health conditions: Hemophilia, Cystic Fibrosis, Sickle Cell, Leukemia, Diabetes
- Population size: about 400
Evaluation

WCM

• Will be conducted by an independent entity
• Data will be collected on standardized performance measures - comparing WCM MCPs to CCS Program prior to implementation; WCM vs. non-WCM counties
• Evaluation results due to state legislature on Jan. 1, 2021

1115 Waiver Demonstration Project

• Evaluation design approved by CMS
Performance Measures
2017 Performance Measures Technical Workgroup

Goal
To align and standardize performance measures across programs for Children and Youth with Special Health Care Needs (CYSHCN)

Programs
- CCS
- 1115 Waiver CCS Demonstration Project
- Title V Federal Block Grant
- WCM
Product

- High-level summary document of the proposed performance measures in the categories of
  - Access to Care
  - Care Coordination
  - Family Participation
  - Quality of Care
  - Transition Services
2018 Performance Measures Quality Subcommittee

Goals

- To discuss the set of performance measures for the 1115 Waiver, Title V, WCM, and the CCS Statewide Plan Fiscal Guidelines
- To discuss consistent data pull for the established performance measures

Objectives

- To standardize data collections for the performance measures associated with the 1115 Waiver, Title V, WCM (in conformance with SB 586), and the CCS Statewide Plan and Fiscal Guidelines
Product

- Technical specifications document for performance measures is being finalized
Current Title V Report
Main Topics

1. Organized care delivery system: WCM

2. Medical Home

3. Transition

4. Timely access to a qualified provider of medically necessary care

5. Telehealth
Example: State Performance Measure

Percentage of CYSHCN with select conditions who have a documented special care center (SCC) visit within 90 days of referral

- **Numerator**: Number of unique CCS children with select conditions who have an initial visit with the SCC within 90 days of CCS Program (state or county) receiving a service authorization request (SAR) to the SCC

- **Denominator**: Number of unique CCS children with an initial SAR to the SCC

- **Data Source**: CMS Net, FFS claims and encounter data
Example: Evidence-Based Strategy Measure

Number of county CCS programs with family members providing input into transition policies

**Numerator**: Number of county CCS programs with family members providing input into transition policies

**Denominator**: 58 CCS county programs

**Data Source**: Survey of CCS County Administrators
DEVELOPING CRITERIA FOR PROBLEM/ISSUE PRIORITIZATION

Gerry Oliva M.D., MPH
UCSF Family Health Outcomes Project

2015-2020 Title V CCS Needs Assessment
October 3 “Kick-Off” Meeting – Sacramento, CA
Benefits of the Formal Prioritization Process

- Facilitates a systematic, rational and transparent decision-making process
- Assures a fair and inclusive decision-making process that generates priorities reflecting values and opinions of all stakeholders
- Assures that recommended actions impact a greater number of CSHCNs and have the greatest impact on child and family function
- Identifies a manageable number of priorities
Utility of Prioritization Process in Targeting CSHCN System Goals

Designed to streamline priority setting process with multiple problems and diversity among participants.
To set priorities stakeholders will…

- Select and define criteria
- Engage in a thorough discussion of criteria
- Select manageable number of criteria
- “Buy into” the process of criteria selection
Example Criteria

- Problem results in great cost (disability or expense)
- Effective intervention available
- Unacceptable disparities among population subgroups
- Problem is significantly worse than benchmark or worsening
- There is impetus for change
- Large # of CCS Families affected
A numeric scale is developed for each criterion with an explicit definition for each value.

**Sample Criterion:** Problem results in great cost to child/ family/program

0 = Problem does **NOT** result in significant cost

1 = **Some cost** to child/family **OR** program

2 = **High cost** to child/family **OR** program

3 = **High cost** to BOTH child/family **AND** program
Weigh the Criteria

Level of Importance
How important are the criteria relative to each other? Are some criteria more important than others?

Weighted Criterion
1 = important
2 = very important
3 = extremely important
Individuals Rate Problems/Issues

- Individually stakeholders apply the criteria using agreed upon scoring and weighting values
- Apply the criteria to the problem to determine the numeric “score” using a scale of 1 through 5
- Multiply the numeric score by the “weight” for that criterion
  1 = Important
  2 = Very important
  3 = Most important
### Example of Individual Scoring

<table>
<thead>
<tr>
<th>PROBLEM/ISSUE</th>
<th>CRITERIA (Score x Weight)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Severity of Consequences</strong> (2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of provider knowledge about eligibility</td>
<td>4 x 2 = 8</td>
<td>20</td>
</tr>
<tr>
<td>Lack of a medical home</td>
<td>5 x 2 = 10</td>
<td></td>
</tr>
<tr>
<td><strong>Problem is Increasing</strong> (3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of provider knowledge about eligibility</td>
<td>4 x 3 = 12</td>
<td></td>
</tr>
<tr>
<td>Lack of a medical home</td>
<td>2 x 3 = 6</td>
<td>16</td>
</tr>
</tbody>
</table>
Scores are Summed to Produce Group Ranking

<table>
<thead>
<tr>
<th>PROBLEM/ISSUE</th>
<th># of PARTICIPANTS</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of services for transition to adulthood</td>
<td>9 12 9 6</td>
<td>36</td>
</tr>
<tr>
<td>Lack of a medical home</td>
<td>16 12 6 12</td>
<td>46</td>
</tr>
<tr>
<td>Access to medical equipment</td>
<td>4 6 12 6</td>
<td>30</td>
</tr>
<tr>
<td>Providers lack knowledge about eligibility</td>
<td>20 15 15 6</td>
<td>66</td>
</tr>
</tbody>
</table>
### Highest Score = Top Ranked Issue

<table>
<thead>
<tr>
<th>Issue</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providers lack of knowledge about eligibility</td>
<td>66</td>
</tr>
<tr>
<td>Lack of medical home</td>
<td>46</td>
</tr>
<tr>
<td>Lack of services for transition to adulthood</td>
<td>36</td>
</tr>
<tr>
<td>Family access to medical equipment</td>
<td>30</td>
</tr>
</tbody>
</table>

From previous example
1. Does addressing the issue positively affect families, providers, and the program?
2. Does addressing the issue reduce disparities in health outcomes?
3. Does addressing the issue enhance the continuity and coordination of care?
4. Does addressing the issue increase the administrative timeliness and efficiency of providing care to CCS families to promote the quality of care and adherence to CCS standards?

5. Does addressing the issue enhance family-centered care?

6. Are there evidence-based/best practices to address the issue that will improve the health outcomes of the child enrolled in CCS?
Prioritization Criteria #1

**Does addressing the issue positively affect families, providers and the program?**

**Weight: 3**

**Definition/Concepts:** Addressing the issue would increase satisfaction for one or more of these groups – families, providers, and programs. For example, improving access to specialists would increase satisfaction for families; reducing paper work burdens would improve providers work satisfaction; improving wrap-around services would increase program satisfaction.
Prioritization Criteria #1 Rating Scale

0 = Addressing the issue **WOULD NOT** positively affect any group (families, providers or the program)
1 = Addressing the issue **would** positively affect **ONE** group (families OR providers OR the program)
2 = Addressing the issue **would** positively affect providers **AND** the program
3 = Addressing the issue **would** positively affect families **AND** one other group (providers OR the program)
4 = Addressing the issue would positively affect **ALL** THREE groups
Prioritization Criteria #2

Does addressing the issue reduce disparities?

Weight: 2

Definition/Concepts: One or more population subgroups as defined by race/ethnicity, income, insurance status, gender, geography, or diagnosis are more impacted than the general group and that addressing the problem would reduce unequal impacts.
Prioritization Criteria #2 Rating Scale

0 = No group is disproportionately affected by the issue
1 = One or more groups is disproportionately affected by the problem, but the differences are not statistically different.
2 = Statistically significant differences exist in one group
3 = Statistically significant differences exist in more than one group
4 = Statistically significant differences exist in one or more groups and impacts a large portion of the affected population
Prioritization Criteria #3

Does addressing the issue enhance the continuity and coordination of care?

Weight: 3

Definition/Concepts: Enhancing continuity and coordination of care could mean making it easier for CCS children to regularly see the same provider, better coordinating of referrals among needed providers, making it easier for different providers to access and share a child’s health record, facilitating authorization and reauthorization of services; providing resources to help coordinate care and referrals.
Prioritization Criteria #3 Rating Scale

0 = Addressing the issue does **NOT** enhance continuity and coordination of care

1 = Addressing the issue provides **SOME** enhancement to continuity and coordination of care

2 = Addressing the issue **enhances** continuity and coordination of care for a **small part** of the population

3 = Addressing the issue **enhances** continuity and coordination of care for **more than half** of the population

4 = Addressing the issues **assures** continuity and coordination of care for **ALL** CCS clients
Does addressing the issue increase the administrative timeliness and efficiency of providing care to CCS families to promote the quality of care and adherence to CCS standards?

**Weight:** 1

**Definition/Concepts:** Increasing timeliness and efficiency can mean many things, including reducing the cost of care, more effectively deploying staff and other resources to save money and/or increase productivity, making it easier for families to navigate the system across counties and payers; and making it easier to administer the program.
Prioritization Criteria #4 Rating Scale

0 = Addressing the issue will NOT improve the timeliness and efficiency of providing care

1 = Addressing the issue improves the timeliness and/or efficiency of providing care for **ONE group** (families OR providers OR the program)

2 = Addressing the issue improves the timeliness and/or efficiency of providing care for providers **AND** the program

3 = Addressing the issue improves the timeliness and/or efficiency of providing care for families **AND** one other group (providers OR the program)

4 = Addressing the issue improves the timeliness and/or efficiency of providing care for **ALL THREE** groups (families, providers, and the program)
Does addressing the issue enhance family-centered care?

Weight: 3

Definition/Concepts: Family-centered care is a standard of practice in which families are respected as equal partners by health professionals. Families and providers work together to create a care plan and families’ needs are incorporated into the delivery of health care services. Families also receive timely, complete and accurate information in order to participate in shared decision-making.
Prioritization Criteria #5 Rating Scale

0 = Addressing the issue does **NOT** enhance family-centered care.

1 = Addressing the issue **partially** enhances family-centered care in

2 = Addressing the issue **enhances** family-centered care for **less than half** of the family population of the family population.

3 = Addressing the issue **enhances** family-centered care for **more than half** of the family population.

4 = Addressing the issue provides enhancements for the **entire population**.
Are there evidence-based/best practices to address the issue that will improve the health outcomes of the child enrolled in CCS?

Weight: 3

Definition/Concepts: Health outcomes include physical and mental health as well as the overall quality of life for the child, their family, and their community. Evidence based means support in research/evaluation literature. Best practices have not been formally validated but are recommended by experts or by informal evaluations of local, state or national programs. Additionally, expanding enrollment of CCS-eligible children may improve outcomes by providing access to needed care.
Prioritization Criteria #6 Rating Scale

0 = There are **NO** evidence-based/best practices available.

1 = There is/are **best practice(s)** that have been shown to have a **limited impact** on health outcomes of the CCS-enrolled child.

2 = There is/are **evidence-based intervention(s)** that has/have a **limited impact**

3 = There is/are **best practices** that has/have a **broad impact**

4 = There is/are **evidence-based intervention(s)** that have a **broad impact**
Background

- The Family Health Outcomes Project (FHOP), at UCSF

- Conduct CCS Title V Needs Assessments every 5 years

- Funded by Integrated Systems of Care (ISCD)-DHCS
California Children’s Services:

- Most CCS-eligible children are low-income, Medi-Cal eligible as well
- Diagnosis and Treatment services, medical case management, and physical and occupational therapy services to children under age 21 with CCS-eligible medical conditions; Medical therapy services delivered in public schools
  - County, State General and Federally funded
  - Administered as a partnership between county health departments and DHCS
CSHCN with CCS Enrollment in CA

Total number of CSHCN = 1,409,545

CSHCN in CCS = 238,033
NATIONAL SURVEY ON CHILDREN’S HEALTH – RESULTS IN CYSHCN

NSCH - 2016
Sponsored by United States Department of Health and Human Services (HHS), Health Resources and Services Administration’s (HRSA) Maternal and Child Health Bureau (MCHB)

- Conducted by the US Census Bureau on behalf of the above
- designed to provide national and state-level estimates on key indicators of the health and well-being of children, their families and their communities, as well as information about the prevalence and impact of special health care needs.
Sample = 364,150 households in the US

stratified by state and a child-presence indicator (to survey homes more likely to have children)

Screener questionnaires, respondent = a parent or guardian who knew about the child’s health and health care needs.

NOTE: Between 2012 and 2015, HRSA MCHB redesigned the surveys, combining content into a single survey, and shifting from a periodic interviewer-assisted telephone survey to an annual self-administered web/paper-based survey utilizing an address-based sampling frame.
NSCH 2016: Methods

1) Screener used to identify households with children

2) If children in household, respondent completed list with age + other demographics plus questions to identify SHCN

3) After screener completed, one child randomly selected to be subject of age-specific topical survey

- Web-survey invitations mailed – *cannot be compared to previous year data because methods have changed*
- 138,009 Screener questionnaires completed
- 67,047 topical-eligible
  - 50,212 completed the topical questionnaire
CSHCN ages 0-17: CA vs. Nation (2016)

US - Nationwide: 19.4%
California: 15.5%
CCHCN Prevalence by Age: CA vs. Nation (2016)

* Please interpret with caution: estimate has a 95% confidence interval width exceeding 20 percentage points or 1.2 times the estimate and may not be reliable.
* All of these data have very wide confidence intervals, which can result in a less precise estimate, but specifically the Other, non-Hispanic data for California is (10.4 - 35.8). Please view this data with caution!
Discussion of prevalence within CA vs. Nation

- Higher prevalence in the US than CA overall and across all age groups
- Race/ethnicity data unclear
- We want to be able to interpret these data, but wide confidence intervals don’t allow for conclusive interpretation
- What might some of the reasons be that California has a lower (15.5%) prevalence than the US as a whole (19.8%)?
MCHB Goals for CSHCN

- **Community-Based Services** - ensure community services are organized for easy use by families

- **Early Continuous Screening** - Ensure children are screened early and continuously for special health care needs

- **Access to Medical Home/Access to Care*/Unmet Needs** - increase the number of CSHCN who have a medical home that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective

*Not mentioned in MCHB goals, but may be implicit
MCHB Goals for CSHCN

- **Transition to Adulthood** - increase the percentage of adolescents with SHCN who have received the services necessary to transition to all aspects of adult life, including adult health care, work, and independence.

- **Adequate Insurance** - increase number of children who are adequately insured.

- **Families as Partners** - Ensure families are partners in decision making.
Goal: Adequate insurance for CSHCN

Inadequate Insurance for CSHCN in CA

- CSHCN: 24.5%
- Non-CSHCN: 27.8%
Goal: Adequate insurance for CSHCN

Percent of Inadequate health insurance by complexity of need in CA

- CSHCN more complex health needs: 31%*
- CSHCN less complex health needs: 22.2%
- Non-CSHCN: 27.8%

• Please interpret with caution: estimate has a 95% confidence interval width exceeding 20 percentage points or 1.2 times the estimate and may not be reliable.
Goal: Adequate Insurance for CSHCN AND Community-Based Services

Private vs. Public Insurance for CSHCN in CA and the US

- Nationwide
  - Public Insurance: 24.8%
  - Private Insurance: 16.0%
  - Both public and private: 33.9%
  - Uninsured: 12.3%

- California
  - Public Insurance: 20.1%
  - Private Insurance: 13.6%
  - Both public and private: 1.6%
  - Uninsured: 0%

- No data on both for CA: 1.6%
Goal: Adequate Insurance for CSHCN AND community-based services

Percent of children with special health care needs (CSHCN), ages 0 through 17 with subgroup for consistency of health insurance coverage:

- Consistently insured throughout past year
- Currently uninsured or periods without coverage

<table>
<thead>
<tr>
<th></th>
<th>Nationwide</th>
<th>California</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consistently insured</td>
<td>19.8%</td>
<td>16.6%</td>
</tr>
<tr>
<td>Currently uninsured</td>
<td>16.1%</td>
<td>4.9%</td>
</tr>
</tbody>
</table>
### Goal: Access to Medical Home and Unmet Needs

#### National Performance Measure 11: Percent of children with special health care needs, ages 0 through 17, who have a medical home

<table>
<thead>
<tr>
<th></th>
<th>Care MEETS medical home criteria</th>
<th>Care does NOT meet medical home criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nationwide</strong></td>
<td>43.2</td>
<td>56.8</td>
</tr>
<tr>
<td><strong>Confidence Interval</strong></td>
<td>(41.2 - 45.1)</td>
<td>(54.9 - 58.8)</td>
</tr>
<tr>
<td><strong>Sample Count</strong></td>
<td>5,691</td>
<td>5,696</td>
</tr>
<tr>
<td><strong>Population Estimate</strong></td>
<td>6,121,436</td>
<td>8,062,553</td>
</tr>
</tbody>
</table>

| **California**         | 39.4                             | 60.6                                     |
| **Confidence Interval**| (29.2 - 50.5)                    | (49.5 - 70.8)                            |
| **Sample Count**       | 84                               | 96                                       |
| **Population Estimate**| 554,762                          | 854,784                                  |
Title V National Performance Measure #11: Percent of children with special health care needs, ages 0 through 17, who have a medical home

2016 National Survey of Children’s Health

Nationwide: 43.2% of children met indicator
Range Across States: 31.3% to 57.4%

CA is ↓ than U.S. but not significantly
Goal: Transition to Adult Care, CSHCN

- **US - Nation**: 16.5% received services necessary for transition to adult health care, 83.5% did not receive services.
- **California**: 18.7% received services, 81.3% did not receive services.

**Legend**:
- Blue: Received services necessary for transition to adult health care
- Yellow: Did not receive services necessary for transition to adult health care
Goal: Continuous Screening

- Nation:
  - Parent did not complete developmental screening: 30.4%
  - Parent completed developmental screening: 69.6%
  - C.I. = (12.8 – 36.3)

- CA:
  - Parent did not complete developmental screening: 22.4%
  - Parent completed developmental screening: 77.6%
  - C.I. = (63.7 – 87.2)
Goal: Community-Based Services for CSHCN (Special Education)

Is this child, age 1-17 years, currently receiving services under a special education or early intervention plan?

Nationwide: 27.5% Yes, 72.5% No
California: 28.5% Yes, 71.5% No
National Outcome Measure 17.2: Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system

- **Nationwide:**
  - Receive care in a well-functioning system: 16.5%
  - Do not receive care in a well-functioning system: 83.5%

- **California:**
  - Receive care in a well-functioning system: 20.9%
  - Do not receive care in a well-functioning system: 79.1%
Data Implications

- **Community-Based Services**
  - CSHCN not receiving care within well-functioning systems
  - Special ED and early intervention services utilization is low

- **Early Continuous Screening**
  - Goals not met for the US and CA

- **Access to Medical Home/Access to Care/Unmet Needs**
  - The data are unreliable, but less than 50% for needs met for Medical Home (both CA and US)

- **Transition to Adulthood for CSHCN**
  - The majority are not receiving appropriate transition services in CA and nationally
Data Implications

- **Adequate Insurance**
  - Barely $\frac{1}{4}$ of CSHCN are receiving adequate insurance in CA
  - Adequacy of insurance is worse for those with more complex needs
  - Most CSHCN in CA receive public insurance, but there are no data on uninsured

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