



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

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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

FHOP Mission

- 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)**

What is the Title V MCH Program?

- 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

Goals of Title V Funding (cont.)

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)

Source: <https://mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-block-grant-program>

Federal MCH Pyramid



DIRECT HEALTH CARE SERVICES

(gap filling)

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.

CSHCN Background

1989
CSHCN-
specific
Amendments
to Title V
Legislation

- 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

CSHCN Background

2001 MCHB National Agenda

- 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

CSHCN Six Core Outcomes

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**

CSHCN Six Core Outcomes

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

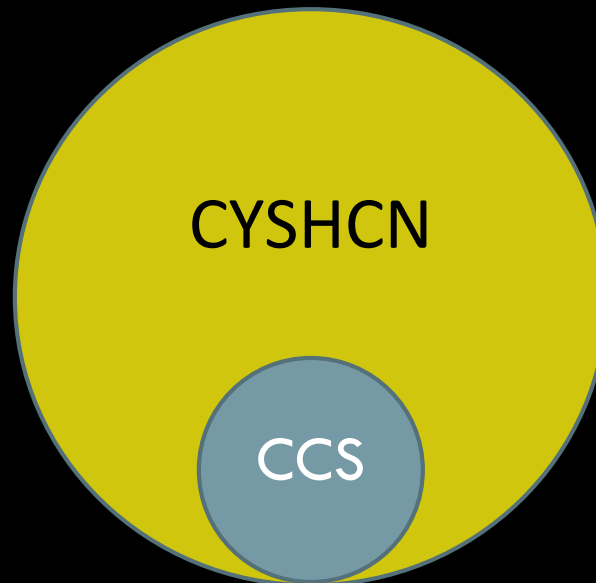
**Condition
Specific**

**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 broader group of CYSHCN



TITLE V NEEDS ASSESSMENT

Title V Assessment Background

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

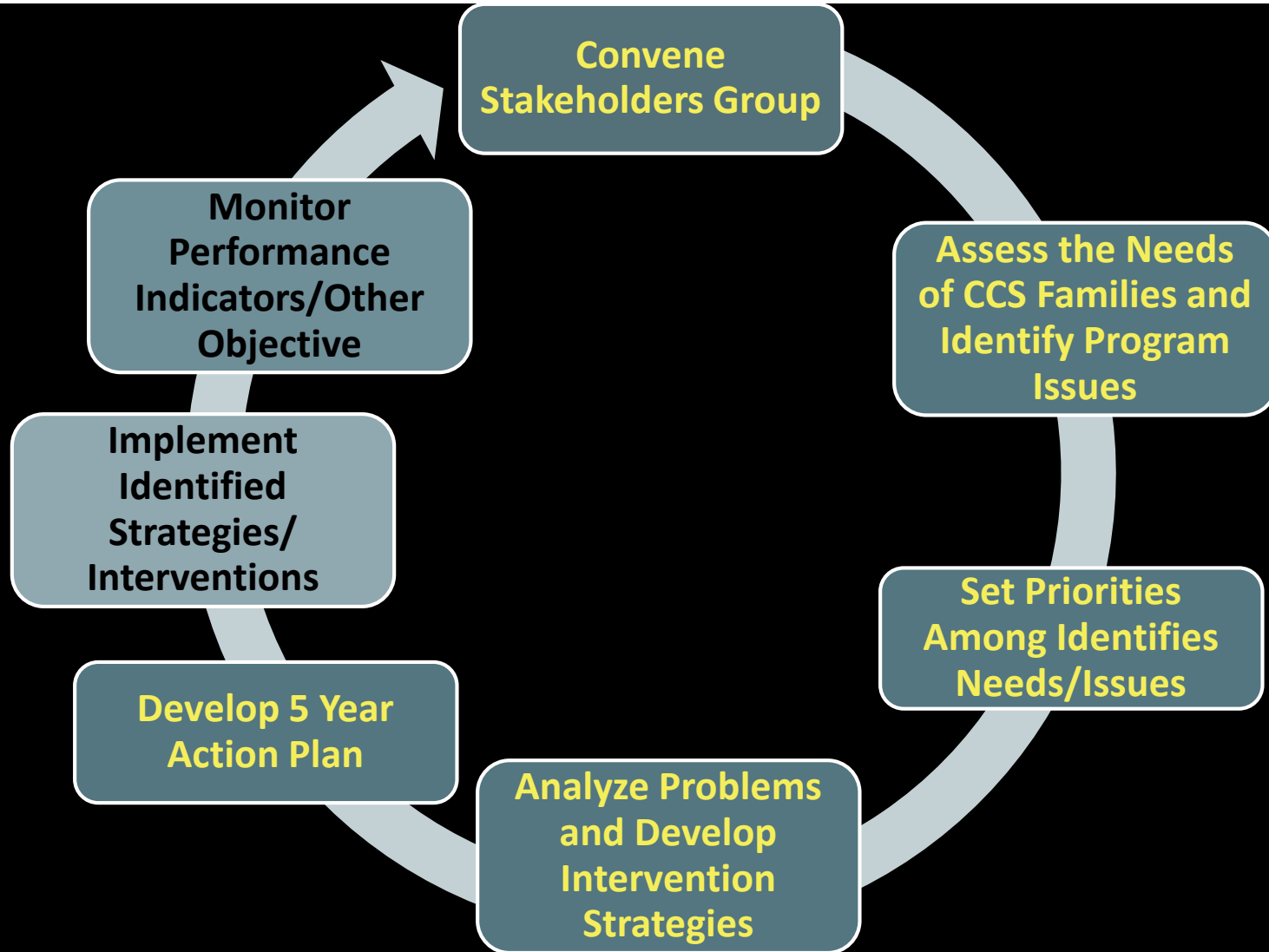
Historical Context

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



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 Health
- 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

Needs Assessment Timeline – 2019-2020



- 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

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**

**Commit to
using the
results (where
budget and
legislation
permits)**

**Available for
questions**

**Provide best
data within
resources/
time frame**

**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

MCH Bureau Needs Assessment Goals

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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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