

Getting Ready for the Children's Medical Services Part of the Title V Needs Assessment

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UCSF Family Health Outcomes Project
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Sacramento, CA

Today's Objectives

- Understand the Title V Needs Assessment background and requirements
- Understand the goal of and the processes to be used in the CMS/CCS Title V needs assessment
- Be updated about what is going regarding services for children with special healthcare needs in CA and nationally
- Become familiar with the methods and available findings from other CA projects focused on CCS and CSHCN (State redesign/HMA, CHCF, and Lucile Packard Foundation)

Meeting Objectives (cont)

- Become knowledgeable about national and state level data from the survey of CSHCN
- Reach agreement on the criteria to be used for evaluating and deciding upon priorities
- Identify key issues to be focused on in the needs assessment process
- Identify associated data sources
- Have the opportunity to participate in subcommittees to review program data and to help develop methods, review instruments and data collected from key informant interview, focus groups, and web surveys

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

- Part of the Department of Family and Community Medicine, UC San Francisco
- Supports Public Health core functions: Assessment, Policy Development, Assurance
- 6 pronged strategy: trainings, on-site and telephone technical assistance, guidelines/data methods, automated tools, web accessible resources.
- Ongoing cooperative agreement with California DPH Maternal, Child and Adolescent Health Program since 1992

About FHOP

- Cooperative agreement with the CA Center for Health Statistics for consultation on data methods, data standards and data quality related projects since 2000
- Conducts community based participatory research projects with county and nonprofit agencies related to reductions in health risks and disparities

Title V Assessment: Background

- Institute of Medicine Future of Public Health Report 1988 - emphasis on the core functions of public health; focus on population based programs and essential public health services (counting numbers served is no longer sufficient)
 - Assessment
 - Planning and Policy Development
 - Assurance

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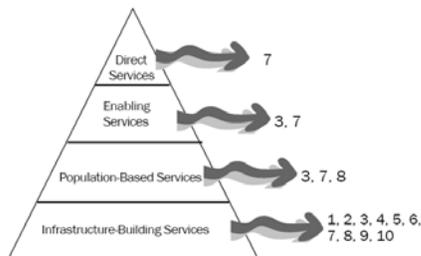
Historical Context

- 1989 - OBRA '89 required federal Title V agency, the MCH Bureau (MCHB), to use indicators and performance measures to assess state agencies
- 1992 MCHB developed a conceptual model for state MCAH programs

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Federal MCHB PYRAMID



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The Title V MCH Pyramid corresponds to the 10 MCH Essential Services.

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Background CSHCN

- 1989 – CSHCN-specific Amendments to Title V Legislation
 - State programs for CSHCN were to “facilitate the development of community-based systems of services for CSHCN and their families.”
 - Mandate for states to submit annual applications for MCH Block Grant Funding
 - Mandate for states to conduct MCH/CSHCN state-wide needs assessments every five years (last one conducted in California 2005)
 - Minimum 30% funding to CSHCN

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Background CSHCN

- 2001 MCHB released **The National Agenda***
 - 10 year action plan to achieve community-based service systems for CSHCN and their families
 - Companion document to Healthy People 2010
 - Action Plan incorporated into President Bush's New Freedom Initiative in 2001
 - Plan contained **six core outcomes** for assessing the achievement of the MCHB Action Plan and for assessing the performance of State Title V programs

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CSHCN Six Core Objectives

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

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CSHCN Six Core Objectives (cont.)

4. All CSHCN will be adequately insured for the services they need
5. Services for CSHCN 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

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Federal MCHB 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.”

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Varying Definitions of CSHCN at State Level

- Condition-specific (ICD-9 codes)
- Categorical or program-specific
- Consequences-based definitions
 - MCHB Definition
 - The Questionnaire for Identifying Children with Chronic Conditions (QUICCC)
 - The CSHCN Screener

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California's CCS Program and how it fits MCHB Pyramid

- Defines medical eligibility
- Neonatal care (HRIF, NICU, coop agreement QI)
- Provider/center certification
- Medical standards of care
- Newborn hearing screening
- Provider training
- County CCS (authorization, case management, reimbursement for services)

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Fiscal and Policy Changes Affecting State CCS in 2009

- National and state budget deficits are resulting in cuts for basic social and health services for poor families
- The state Title V Block Grant funds have been maintained at the same level for almost 10 years with no increase in sight
- Some of the local funds used to match state funding are being threatened by county deficits

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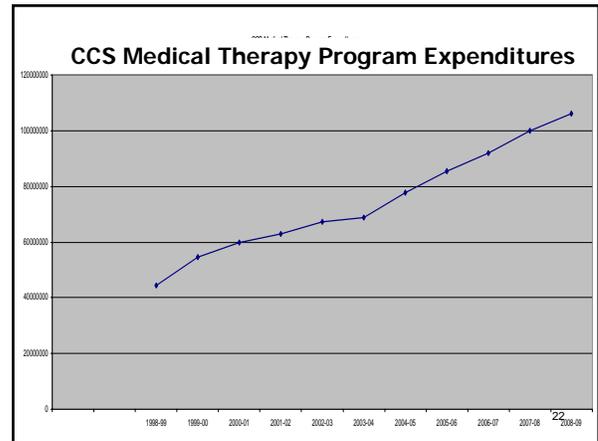
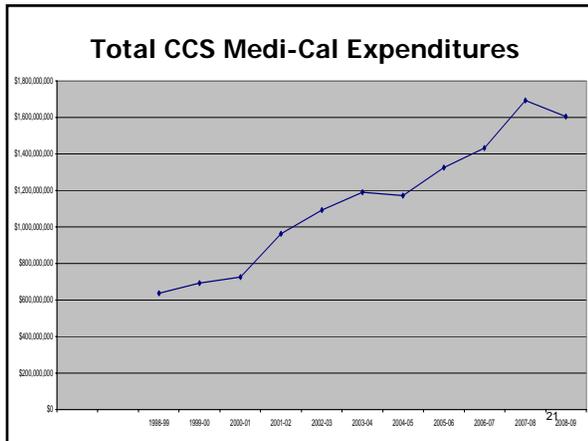
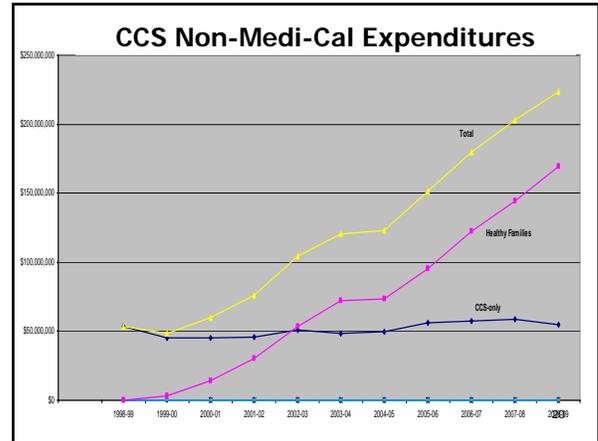
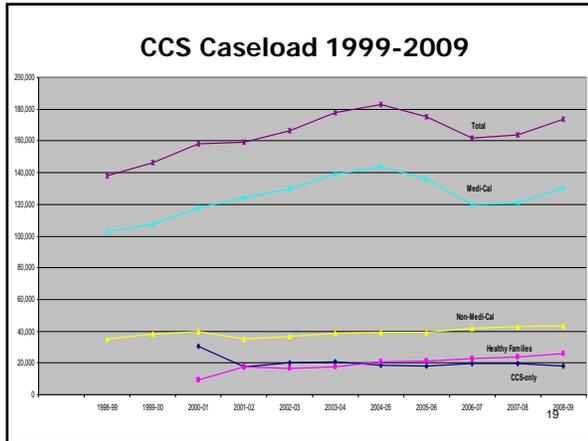
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Fiscal and Policy Changes Affecting County CCS

- State General Fund match for administrative support of program capped in FY 2008-09
- Paying for treatment services at twice the amount of MOE from Realignment Legislation
- Reduced real estate tax revenue

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CMS Use of Current Title V Funds

FY 2009-10

\$9,417,000 **CCS Case Management** (County program staff support)

\$2,511,800 **Contracts**

- HRIF Program Coordinators
- HRIF Quality Improvement Initiative
- Neonatal Quality Improvement Initiative
- FHOP

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Current Efforts to Influence Systems of Care for CSHCN

California Health Care Foundation

- Goal: Assess the current environment, identify program strengths and challenges, and look for research opportunities
- Deliverables: Stakeholder interviews; review of literature, legislation, and policy papers; Issue Brief

Lucile Packard Foundation for Children's Health

- Goal: Developing an ideal system of care for all CSHCN in California
- Deliverables: Stakeholders meeting, proposal

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Current Efforts to Influence Systems of Care for CSHCN

HMA Redesign Project:

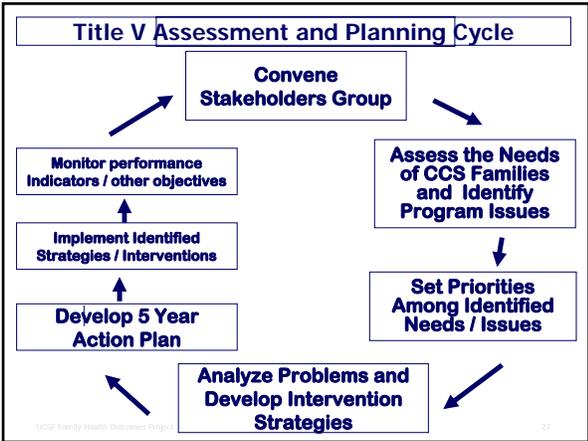
- How to ensure viability of CCS program and how to make a better CCS program
- HMA project goal: To identify and assess options for reforming the CCS program
- Deliverables: Interviews and written comments; review of Medi-Cal and CCS data; Final Report

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CCS Needs Assessment and Action Plan Goals

- Within budget and legislative constraints, determine *Action* priorities to be addressed during FY 2010-2014
- Identify the most important and potentially effective changes CCS can make to improve services for CCS-eligible children

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Convene Stakeholders Group

- Stakeholders representative of key interest groups: Families, CCS County Programs, Professional and Advocacy Organizations, Managed Care Plans, other State Departments, and Academic Researchers
- Stakeholders to provide input in all aspects of the needs assessment and decide priorities

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Convene Stakeholders

- Establish subcommittees for interviews, focus groups, surveys and program/secondary data
- Stakeholder subcommittees provide input on instruments, respondents to recruit, data analyses and interpretation of results

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Assess the Needs of CCS Families and Identify Program Issues

- Work with Stakeholders to identify key issues and existing data sources
- Report findings from other projects looking at CCS and CSHCN (California HealthCare Foundation, Lucile Packard Foundation for Children's Health, Health Management Associates)

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Assess the Needs of CCS Families and Identify Program Issues

- Collect additional data in an iterative process via
 - Key Informant Interviews
 - Focus Groups
 - On-line Surveys
- Review all data and findings with stakeholders

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Set Priorities Among Identified Needs / Issues

1. Select criteria for setting priorities
2. Develop criterion weights
3. Use criteria to prioritize issues

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Analyze Problems and Develop Intervention Strategies

- Review data on identified priorities
- Research literature and consult experts
- Get recommendations from stakeholders
- Identify evidence based interventions strategies

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Develop 5 Year Action Plan

- Solicit stakeholders' recommendations for action plan
- Work with CCS state staff to develop goals and SMART (Specific, Measurable, Achievable, Realistic, and Time-bound) objectives

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Needs Assessment Timeline

September – October 2009

- Convene initial meeting with stakeholders group
- Convene Advisory Subcommittee to review and finalize interview guide
- Identify participants for key informant interviews
- Conduct key informant interviews
- Compile and summarize data from interviews

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Needs Assessment Timeline

October – November 2009

- Convene Advisory Subcommittee to review and finalize focus group discussion guides
- Identify participants for focus groups

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Needs Assessment Timeline

November – December 2009

- Conduct focus groups with providers and parents
- Compile and summarize data from focus groups

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Needs Assessment Timeline

January – February 2010

- Convene 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

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Needs Assessment Timeline

March 2010

- Summarize findings from surveys
- Convene second meeting with stakeholders group to prioritize needs

April 2010

- Create written report on process and results of assessment and review with stakeholders

May – June 2010

- Prepare final Action Plan for adoption

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Success: State CCS Part



- Assure appropriate stakeholders are invited
- Provide best data within resources/timeframe
- Available for questions
- Commit to using the results (where budget and legislation permit)
- Be honest about and explain limitations

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Success: CCS Needs Assessment Stakeholders



- Be open to the process
- Commit time needed to review materials and actively participate
- Agree to honor group outcome
- Provide expertise during discussion
- Use data and expert knowledge for decision-making

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Success: Consultants Part

- Assist communication / provide opportunities to be heard
- Provide the framework, facilitation for a rational inclusive process and data for decision-making
- Manage time and keep the process on track

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Developing Criteria for Problem or Issue Prioritization

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September 9, 2009

Purposes of Formal Prioritization Process

- Direct resources to issues that have the greatest impact on child and family function
- Direct resources to areas that reflect the values and opinions of the stakeholders group
- Identify a manageable number of issues
- Assure a fair and inclusive process
- Facilitate a systematic, rational decision-making process

Utility of Prioritization Process

To assist when there are too many problems to address and diverse participants in the priority setting process



Select Criteria for Setting 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

Sample 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

Develop Criterion Scoring Scales

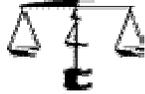
A numerical scale is developed for each criterion with an explicit definition for each value.

Criterion: Problem Results in Great Cost to Child/Family/Program:

1. Problem does not result in significant cost
2. Some cost to child/family OR program
3. Moderate cost to child/family OR program
4. High cost to child/family OR program
5. High cost to BOTH child/family & program

Weight the Criteria

- How important are the criteria relative to each other? Are some criteria more important than others?
- Each criterion is given a weight, for example:
 - 1 = important
 - 2 = very important
 - OR
 - 3 = extremely important



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Individuals Rate Problems/Issues

Individually apply the criteria using the agreed upon scoring and weighting values

Apply the criteria to the problem by:

Determining the numeric "score" (1 to 5) for the criterion

- Multiplying the numeric score by the "weight" for that criterion, that is:

- 1 = Important
- 2 = Very important
- 3 = Most important

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Example of Individual Scoring

PROBLEM / ISSUE	CRITERIA (Score x Weight)		TOTAL
	Severity of Consequences (2)	Problem is Increasing (Trend) (3)	
Lack of provider knowledge about elig.	4 x 2 = 8	4 x 3 = 12	20
Lack of medical home	5 x 2 = 10	2 x 3 = 6	16

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Scores are Summed to Produce a Group Ranking

PROBLEM / ISSUE	PARTICIPANTS				TOTAL
	1 +	2 +	3 +	4 =	
Lack of services for transition to adulthood	9	12	9	6	36
Lack of medical home	16	12	6	12	46
Access to medical equip	4	6	12	8	30
Providers lack knowledge about eligibility	20	15	15	6	66

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Rank Problems & Confirm Agreement

Highest Score = Top Ranked Issue

From previous example:

Providers lack knowledge about eligibility	66
Lack of medical home	46
Lack of services for transition to adulthood	36
Family access to medical equip	30

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Prioritization Criteria from 2005 Needs Assessment

- Criterion Name: Problem has great impact on families (quality of life, functionality)**

Definition/Concepts: This means that the child / family's quality of life and functionality are affected by the problem. Examples are a parent cannot work; a child cannot go to school.

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Prioritization Criteria from 2005 Needs Assessment

Criterion 1 Rating Scale:

1. Problem is not affecting the quality of life or functionality of the family
2. Problem is minimally or occasionally affecting the quality of life or functionality of the family
3. Problem is moderately and/or frequently affecting the quality of life or functionality of the family
4. Problem is negatively impacting the family's quality of life and functionality most of the time.
5. Problem is severely negatively impacting the family's quality of life and functionality most or all of the time

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Prioritization Criteria from 2005 Needs Assessment

2. Criterion Name: Addressing the problem is important to consumers

Definition/Concepts: Addressing the problem is important to the recipients or potential recipients of services: child, siblings, parents, extended family

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Prioritization Criteria from 2005 Needs Assessment

Criterion 2 Rating Scale:

1. Addressing the problem is not important to consumers
2. Addressing the problem is of some importance to consumers
3. Addressing the problem is of moderate importance to consumers
4. Addressing the problem is important to consumers
5. Addressing the problem is a very high priority for consumers

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Prioritization Criteria from 2005 Needs Assessment

3. Criterion Name: Problem results in great cost to program and/or society, there is a significant fiscal impact of not addressing it

Definition/Concepts: If problem is not addressed there will be increased monetary costs, e.g. health care and/or social services costs to the CCS program or to society and loss of education and productivity of individuals because of chronic illness, disability or premature death

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Prioritization Criteria from 2005 Needs Assessment

Criterion 3 Rating Scale:

1. Economic / societal cost is minimal
2. There is some potential increased costs
3. There is likely to be moderate increased costs
4. There is likely to be substantial increased costs
5. There will be great economic and societal cost C

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Prioritization Criteria from 2005 Needs Assessment

4. Criterion Name: Addressing the problem maximizes opportunity to leverage resources and relationships for effective system change.

Definition/Concepts: There is opportunity for existing partners to plan together or pool resources to address the problem or there is opportunity to build new relationships. Leverage resources and relationships to affect systems change

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Prioritization Criteria from 2005 Needs Assessment

Criterion 4 Rating Scale:

1. No known opportunity to collaborate
2. There may be opportunities to collaborate
3. There are opportunities to collaborate
4. There are opportunities to collaborate and some collaboration is already occurring
5. Major collaborative efforts are already underway

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Prioritization Criteria from 2005 Needs Assessment

5. **Criterion Name: Addressing the problem would increase equity and fairness**

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. Addressing the problem or issues would promote equity and reduce disparities.

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Prioritization Criteria from 2005 Needs Assessment

Criterion 5 Rating Scale:

1. No group is disproportionately affected by the problem
2. It appears that one or more groups is disproportionately affected by the problem, but differences are not statistically significant
3. Statistically significant differences exist in one group
4. Statistically significant differences exist in more than one group
5. Very large statistically significant differences exist in one or more groups

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Prioritization Criteria from 2005 Needs Assessment

6. **Criterion Name: There is likelihood of success. Problem is amenable to prevention or intervention, and/or there is political will to address it**

Definition/Concepts: There is a good chance that the strategies used to intervene will result in an improvement in outcomes. The intervention strategies are shown in research or practice to be effective or promising. Can also mean that the problem is a national or regional priority

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Prioritization Criteria from 2005 Needs Assessment

Criterion 6 Rating Scale

1. No known intervention available
2. Promising intervention with limited impact (not effecting a wider array of problems), little political will
3. Proven intervention with limited impact, moderate political will
4. Promising or proven intervention with broad impact and moderate political will
5. Proven intervention with broad impact and strong political will

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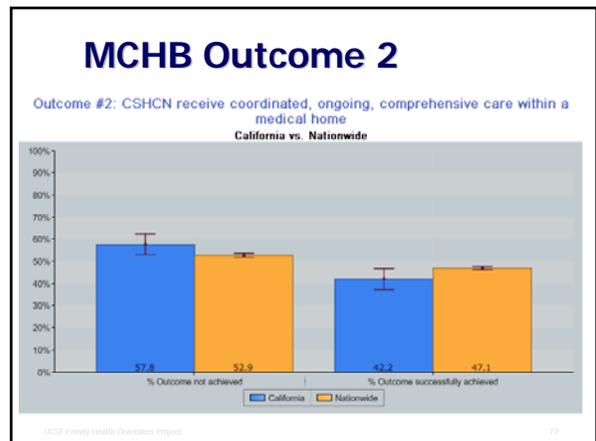
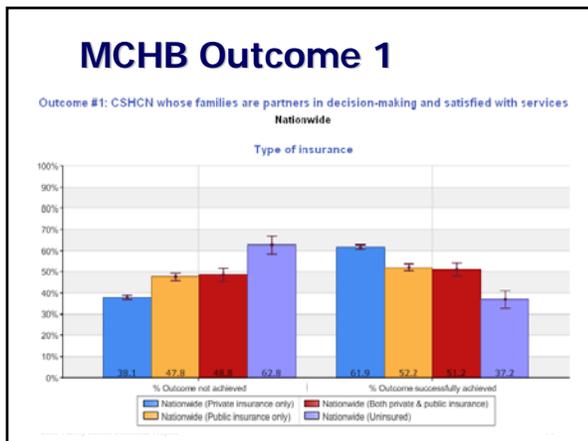
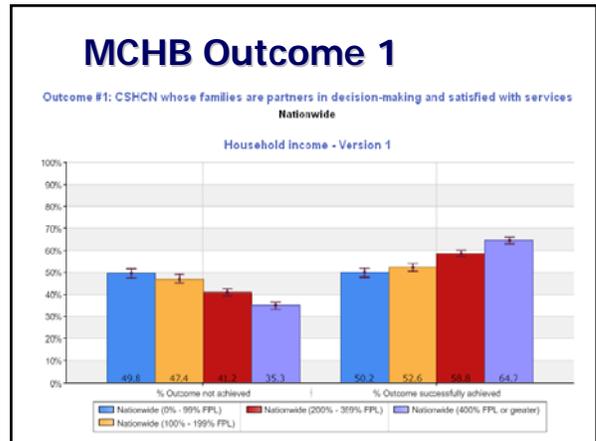
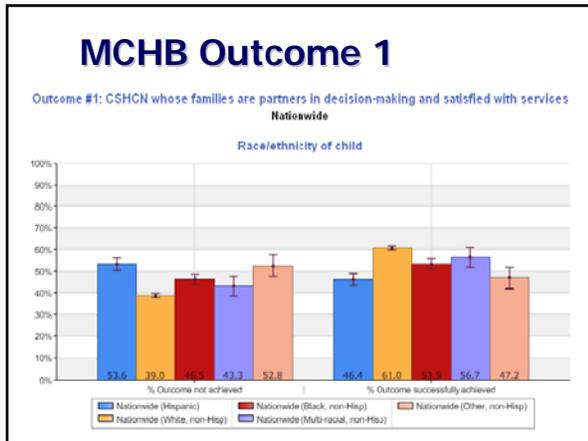
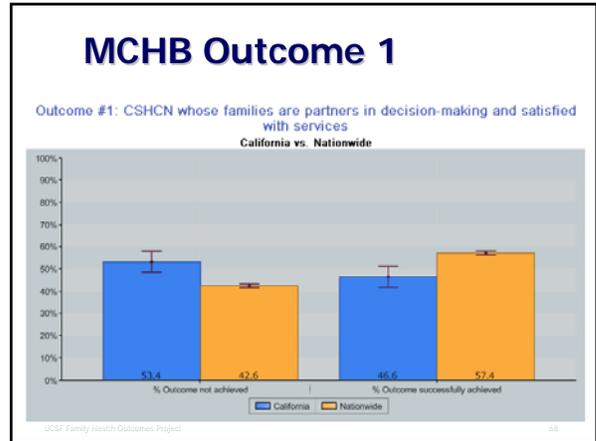
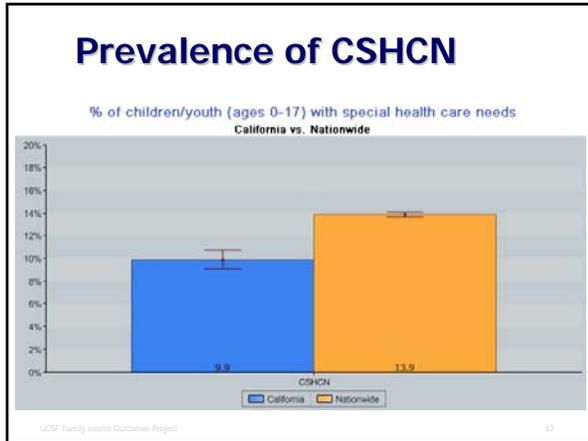
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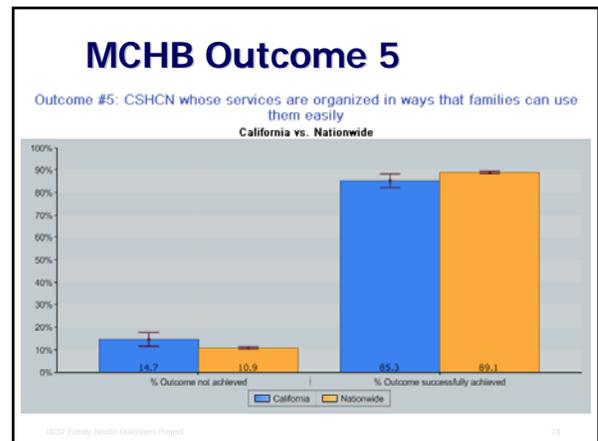
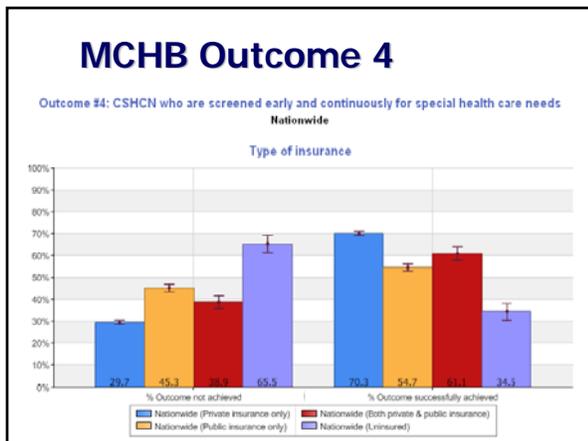
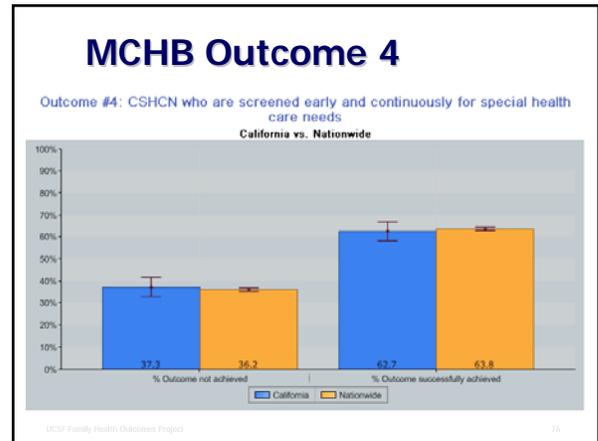
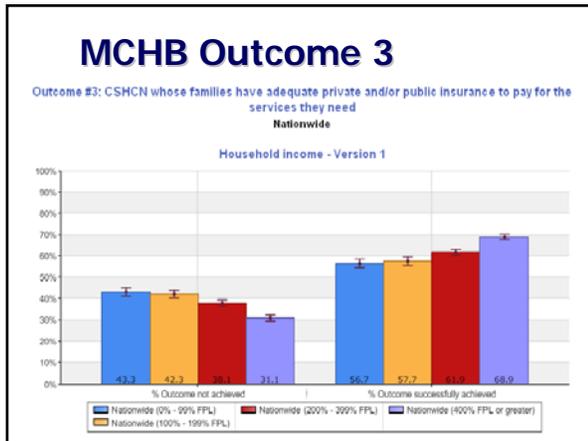
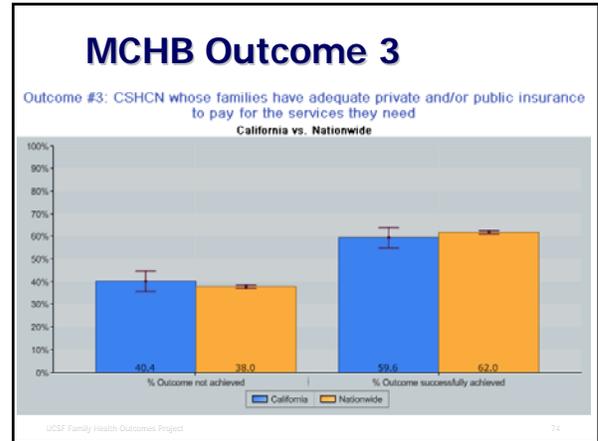
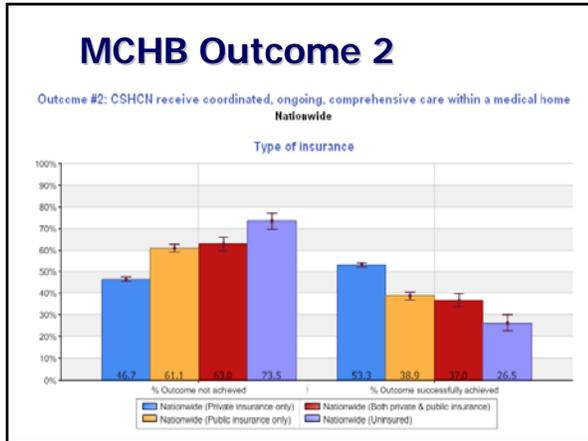
National Survey of CSHCN: Methods

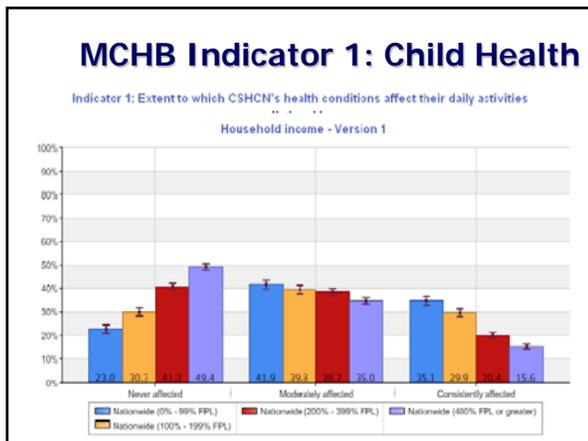
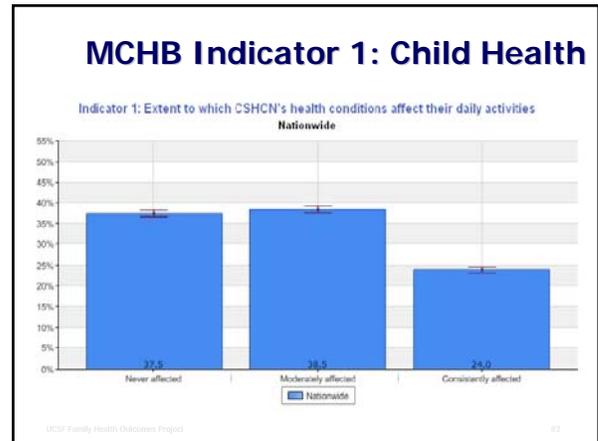
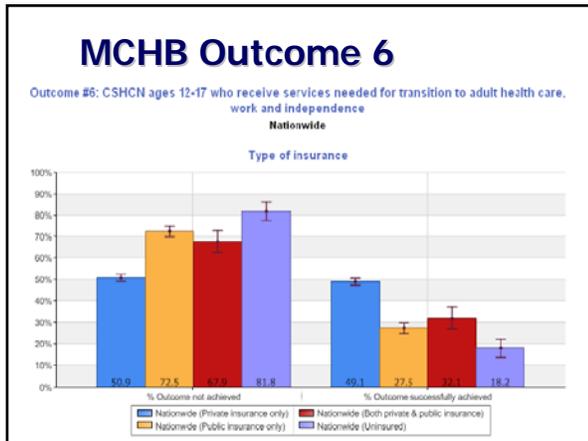
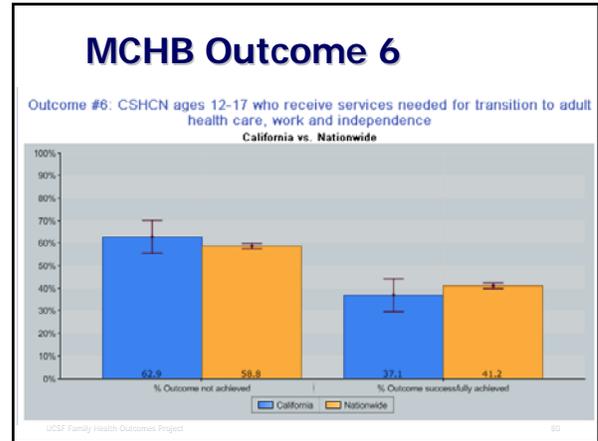
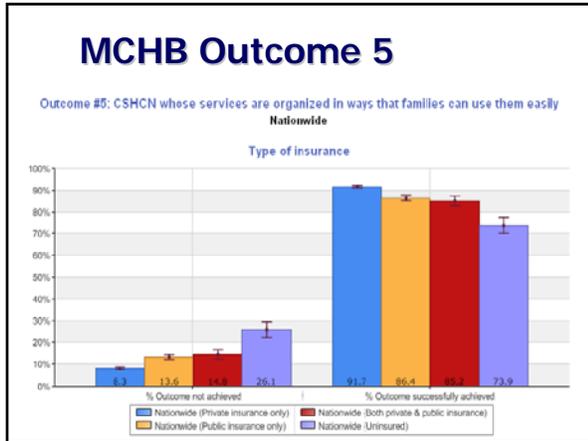
- A national telephone survey conducted in 2001 and 2005/2006
- In 05/06, 364,841 children under 18 were screened Nationwide
 - Number of CSHCN Identified in CA: **1,303**
 - Weighted estimate for CA: **964,167**
- Approx. 750 detailed CSHCN interviews were collected in each state and D.C.

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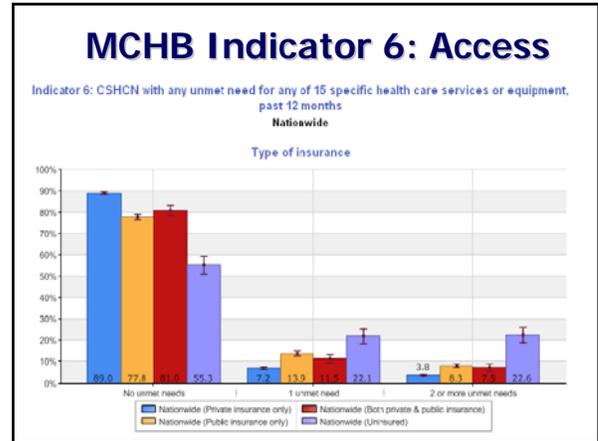
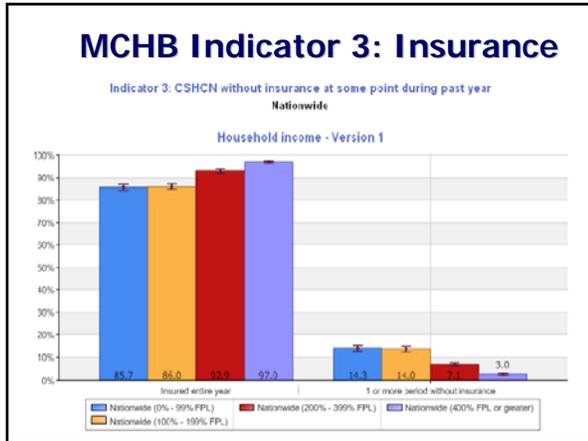






MCHB Indicator 3: Insurance

Indicator 3:	2001	2005/2006
Without insurance in prior year	11.6	8.8*
0-99% FPL	21.8	14.3*
100-199% FPL	20.3	14.0*
200-399% FPL	8.8	7.1
400% FPL or more	3.8	3.0

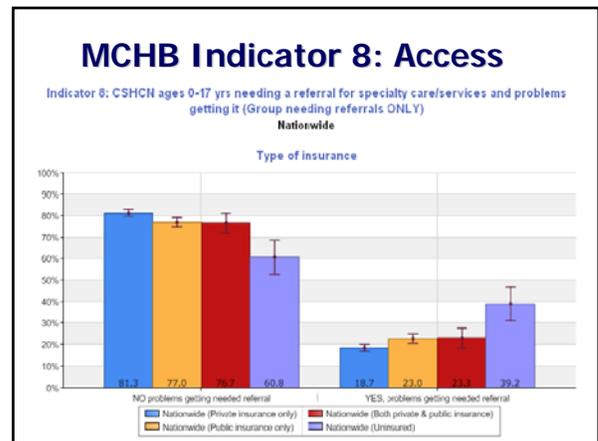
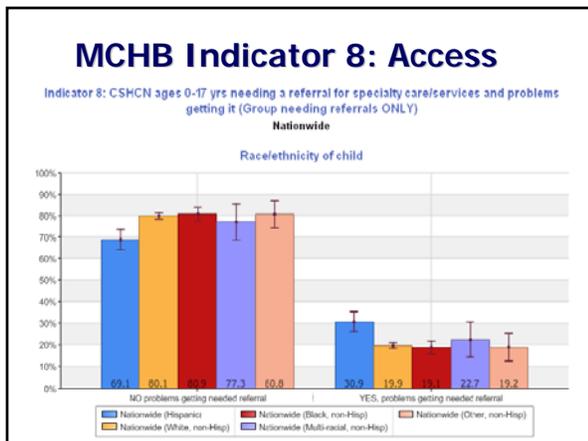
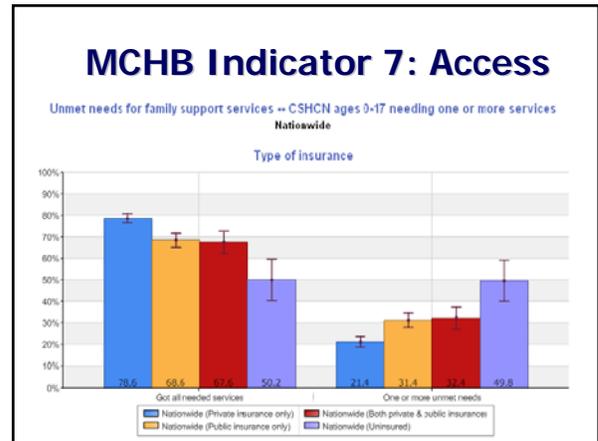


MCHB Indicator 7: Access

Indicator 7b:
Needed but did not get family support services

	2001	2005/2006
Needed but did not get family support services	23.1	27.9*
Private Insurance	18.7	21.4
Public Insurance	23.3	31.4*
Both types of insurance	28.4	32.4
No insurance	48.3	49.8

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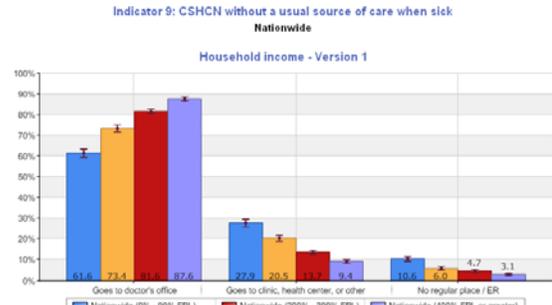
MCHB Indicator 9: Access

Indicator 9: No usual place or relies on ER	2001	2005/2006
	9.3	5.7*
0-99% FPL	12.2	10.6
100-199% FPL	10.7	6.0*
200-399% FPL	7.9	4.7*
400% FPL or more	7.3	3.1*

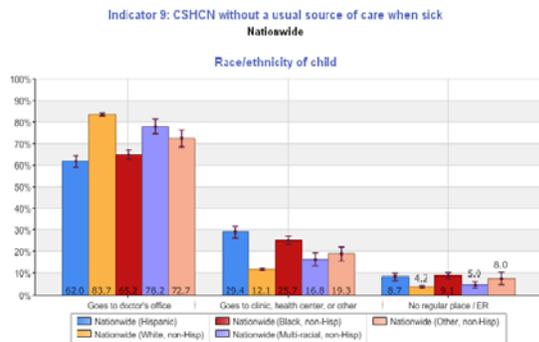
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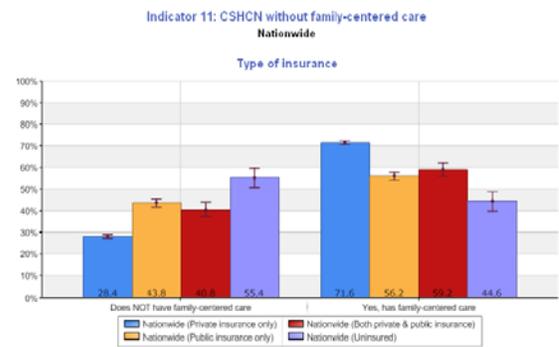
MCHB Indicator 9: Access



MCHB Indicator 9: Access



MCHB Indicator 11: Family-Center Care



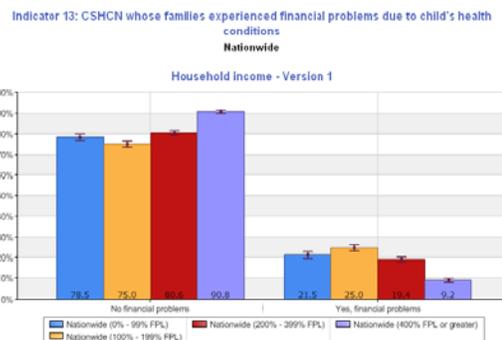
MCHB Indicator 13: Impact on Families

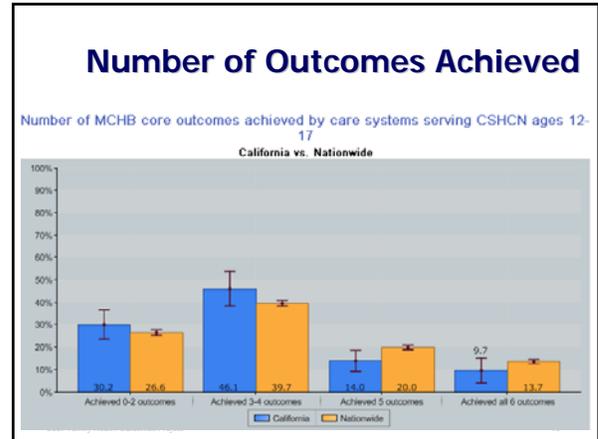
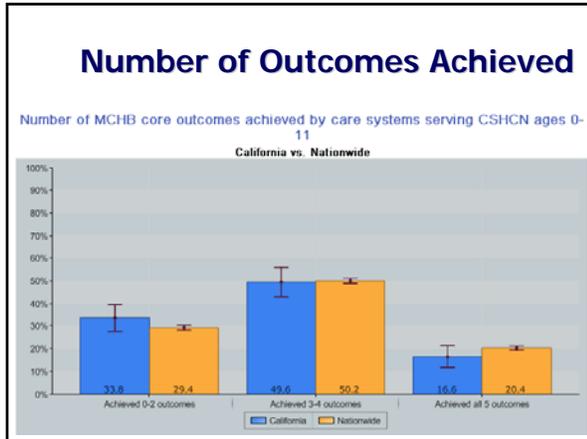
Indicator 13: Condition causes financial problems for family	2001	2005/2006
	20.9	18.1*
0-99% FPL	28.5	21.5*
100-199% FPL	29.4	25.0*
200-399% FPL	21.5	19.4
400% FPL or more	12.0	9.2*
Public Insurance	24.4	19.5*

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MCHB Indicator 13: Impact on Families





General Observations from the Nationwide Data (NS of CSHCN 05-06)

Significant Improvement

- MCHB Outcome 3: Adequate Insurance
- Indicator 3: Without insurance at some point in past year
- Indicator 4: Without insurance at time of survey
- Indicator 6: With any unmet need for specific health care services
- Indicator 9: Without a usual source of care when sick or who rely on the emergency room
- Indicator 13: Conditions cause financial problems for the family

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General Observations from the Nationwide Data (NS of CSHCN 05-06)

No Significant Change

- % of children who have special health care needs
- MCHB Outcome 1: Family Involvement
- Indicator 1: Health conditions consistently affect their daily activities
- Indicator 2: 11 or more days of school absences due to illness
- Indicator 5: Currently insured CSHCN whose insurance is inadequate
- Indicator 8: Needing a referral, have difficulty getting it
- Indicator 11: Without family-centered care

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General Observations from the Nationwide Data (NS of CSHCN 05-06)

Significantly Worse

- Percent of families or parents of CSHCN who needed and did not get support services.
 - 23.1% (2001) vs. 2005/2006 27.9%

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General Observations from the Nationwide Data (NS of CSHCN 05-06)

- Black and Hispanic populations tend to have worse outcomes compared to the White population.
- In general, outcomes improve as income level improves.
- Significant difference in outcomes between children with private insurance, public insurance, and no insurance.
- Outcomes for CSHCN with a medical home are significantly better compared to CSHCN without for every MCHB priority outcome and for every indicator.

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Instructions for Breakout Groups

Breakout Group –Assign Tasks Instructions

- Select recorder to enter info into the laptop
- Select recorder for butcher block
- Select presenter to report back for the group

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Breakout Group Instructions

Questions for Breakout Groups - Part 1 (See agenda for detailed questions)

- What works well in CCS?
- What data illustrates program successes?
- What are the important issues or problems accessing, providing or managing services?
- What data illustrates the issues or problems and how frequently it occurs?
- Do you have any information that you can share? Or do you have the capacity to produce data on this population?

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Breakout Group Instructions

Questions for Breakout Groups Part 2 *Key informant interviews*

- Who to include and why? Contact information?
- Types of questions (open vs. closed-end questions)?
- Specific topic areas/questions? (First review topics from Part 1)
- Challenges to anticipate?

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Breakout Group Instructions

Questions for Breakout groups Part 2 *Focus Groups*

- Who to include and why? Contact information?
- What regions/locations around the state?
- Agencies or organizations who can host/recruits /assist with groups?
- Topic area or questions? (First review topics from Part 1)
- Challenges might we encounter with recruitment and logistics? Suggested solutions?

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Breakout Group Instructions

Questions for Breakout groups Part 2 *Web Surveys*

- Who to include and why? Contact information?
- How best to recruit participants?
- How to provide access for families without computers?
- Challenges around recruitment and logistics? Suggested solutions?
- Can you suggest potential topics/questions (First review topics from Part 1)
- Questions from other surveys that we should use?

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Wrapping Up and Looking Forward

- Next Steps
- Closing
- Evaluation

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Issues Identified in preliminary Conversations with Stakeholders

Patient Care Related Concerns:

- Need to broaden definition of CSHCN to include prevention services eg, asthma, obesity
- CCS deals with conditions not whole child
- More funds for services, less bureaucracy
- Electronic alert system for providers and notification system for families when family falls off the grid
- Fragmented financial coverage causes gaps in services/ system should be seamless to families and providers
- County by county differences in eligibility, authorization and payment processes difficult for families and providers

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Issues Identified in preliminary Conversations with Stakeholders

County management issues:

- County unfunded mandates – loss of tax revenue, capped state funds
- MTU's have increasing numbers but capped funding from state and increasing unmatched county expenditures- no one looking at this
- Too much bureaucracy – too many different funding sources
- CCS kids are costing more, sicker?

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Issues Identified in preliminary Conversations with Stakeholders

Provider Concerns:

- Perverse incentives – overuse of transport, inpatient tests
- Fee for service results in inflated costs, should move to capitated system
- Concern about potential loss of CCS as certifier, standard setter and quality assurer
- Why can't case management be delegated to regional centers
- Conflicts over use of family physicians for CCS
- Excessive auditing for expenses wastes resources

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Issues Identified in preliminary Conversations with Stakeholders

Unique factors in California

- Size of state
- Hard to compare/evaluate programs in other states

Hopes for future

- Desire for electronic information flow
- Bottom line: desire to help children who need it

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