

## Children with Special Health Family Centered Care

**MCHB Outcome & AMCHP System Outcome #1: Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive.**

*From the National Survey of CSHCN 2009/2010<sup>i</sup>*

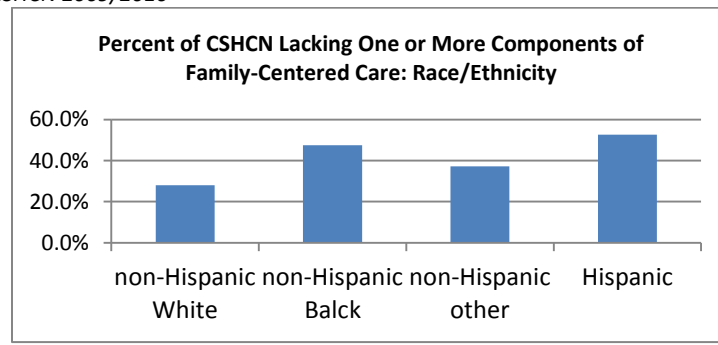
Receives family centered care

California %	61.2
Nationwide %	64.6

Family centered care outcome successfully achieved, by insurance type

	Private insurance only	Public insurance only	Both public & private insurance
California	68.4	49.8 <sup>^</sup>	55.0
Nationwide	72.5	55.7 <sup>**</sup>	61.0

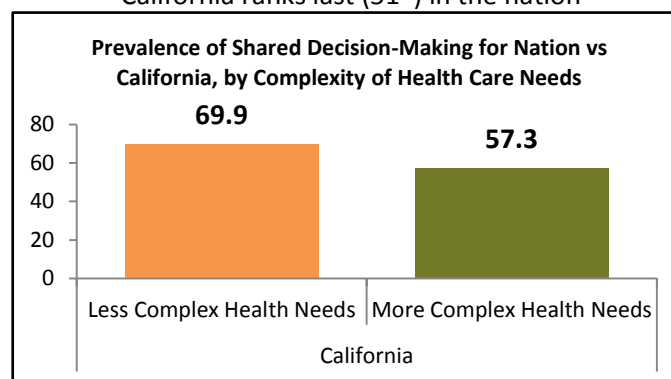
*From National Survey of CSHCN 2009/2010*



*From "Children with Special Health Care Needs: A Profile of Key Issues in California" (Bethell, 2014)*

*Data Source: 2011/12 National Survey of Children's Health*

**CSHCN whose families are partners in shared decision-making:**  
California ranks last (51<sup>st</sup>) in the nation



*From FHOP Key Information Interviews 2014*

Issued Raised Regarding Family-Centered Care:

- *If families don't understand the program, how can they participate?*
- *Need to get PCPs involved to provide family-centered care, can't expect specialists to do it all and families need local care.*

\* Difference between CA and Nation significant at  $p < .05$

\*\* Differences within the Nation significant at  $p < .05$

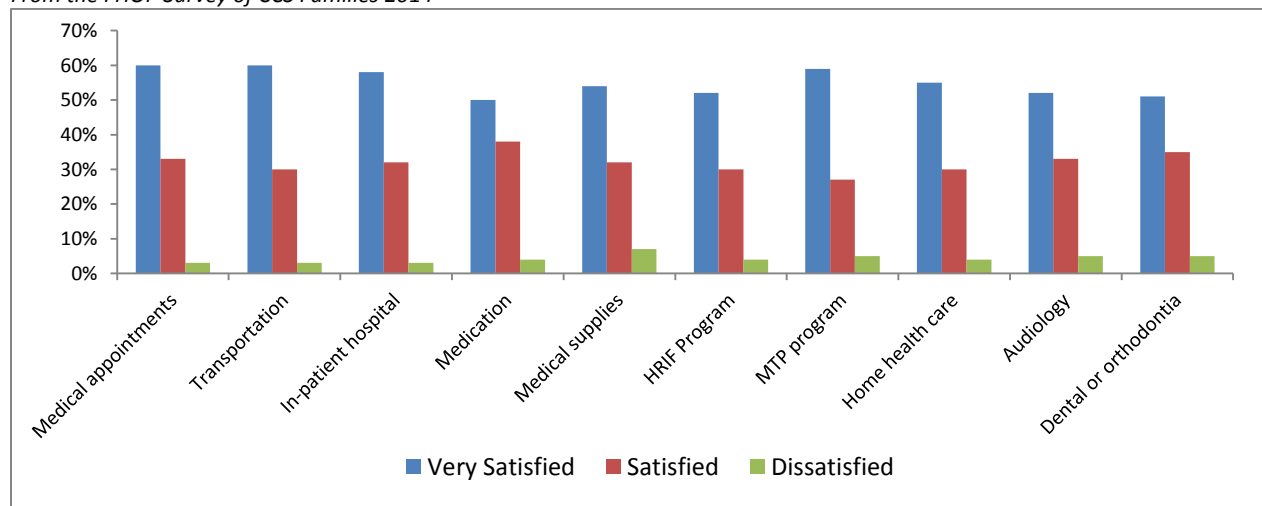
<sup>^</sup> Difference within the State significant at  $p < .05$

## Children with Special Health Family Centered Care

- Need a paradigm shift to more care coordination – meeting with families, doing home visits, etc...an increase of staff is needed to allow this to happen.
- Meaningful family representation on all of their committees, task force, etc. where decisions are made that affect the care of these children.
- Gap is getting the family to participate...[regional] centers could be more flexible with scheduling family time, better coordination of appointments.
- There is an unrealistic expectation about CCS can and cannot do [for families]. Need to try to help families to develop the skills to advocate for themselves.
- Families should be included in the discussion, sending something on paper doesn't work [they need an orientation] when [a family] first gets authorized.

### Parent Satisfaction with Services/Care

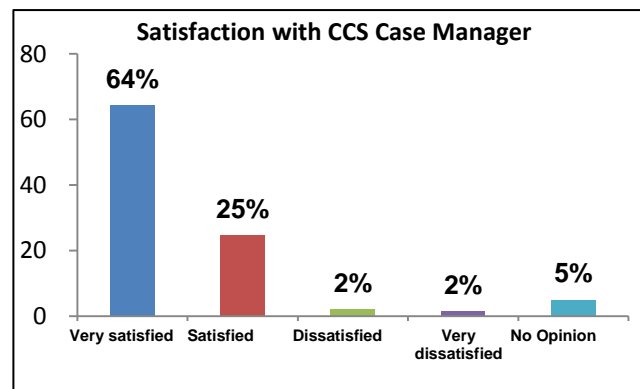
From the FHOP Survey of CCS Families 2014



No Services n=359

### CCS Case Management

Does your child have a case manager?		
	N	%
Yes	2,658	65
No	526	13
Don't Know	698	17
Missing	183	5



From the FHOP CCS Family Survey 2014

#### Positive Comments

- Thank you for telling me I have a case manager.
- I appreciate the mail I get...I appreciate receiving paperwork from you.
- Everyone is always helpful and understanding. I always feel as though my concerns are heard and concerned.

\* Difference between CA and Nation significant at  $p < .05$

\*\* Differences within the Nation significant at  $p < .05$

^ Difference within the State significant at  $p < .05$

## Children with Special Health Family Centered Care

### Challenges Raised by Families

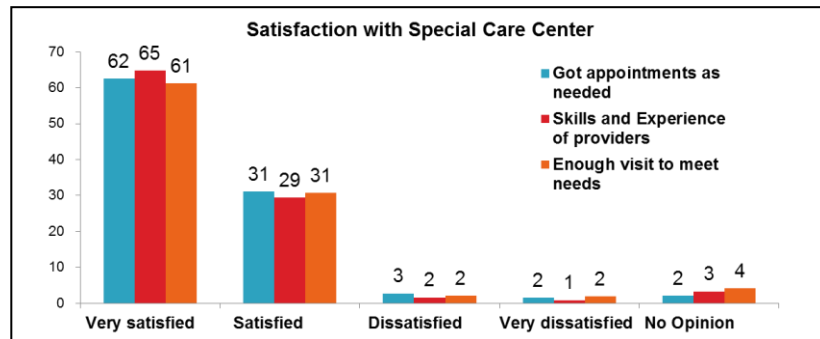
- Many parents don't know what this program is really about.
- Local case managers don't really engage with parents other than for compliances and travel/med/supplies, which they do very well.
- I am unsure what to expect from CCS what services CCS provides...not sure how this program actually works.
- I would like to know more about the program. My child came to me through foster care and I did not receive info about CCS.

### Specialty Care

From the FHOP CCS Family Survey 2014

Went to Special Care Center in the last 12 months?

	N	%
Yes	1956	49
No	1762	44
Do not know	295	7
Missing	52	1



### Health Care Plans

From the FHOP CCS Family Survey 2014

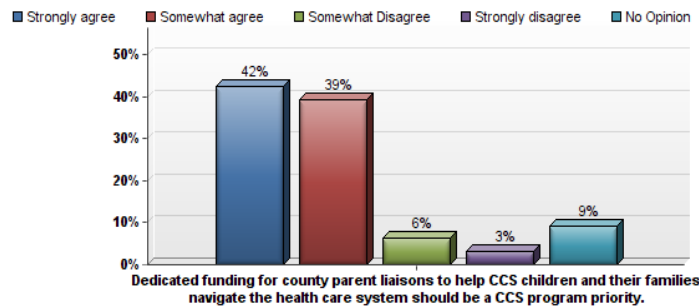
Been provided with a health care plan for child from doctor/nurse/clinic?

	N	%
Yes	1521	42
No	1462	41
Don't Know	611	17

- 61% of those without a health care plan would like to receive one

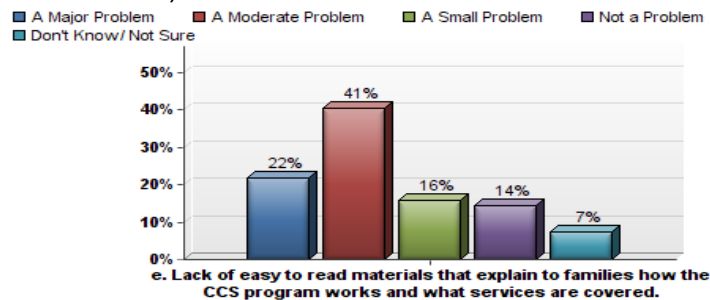
### Parent Liaisons

From the FHOP Survey of Physicians 2014



### Communication

From the FHOP Survey of CCS Administrators/Medical Consultants 2014



\* Difference between CA and Nation significant at  $p < .05$

\*\* Differences within the Nation significant at  $p < .05$

^ Difference within the State significant at  $p < .05$

## Children with Special Health Family Centered Care

From the FHOP CCS Family Survey 2014

- Very little/poor communication
- Difficult getting appointments as needed due to a lack of communication (e.g., 1-lb premie had to wait 10 months for a pulmonology appointment)
- No knowledge of a CCS-sponsored case manager, who they are, how to connect, what they are for
- Little to no knowledge of services covered (or not) by CCS; lack of information in the community
- Unsure of service status
- Unsure of how CCS could help their child
- CCS staff at the same facility provide different answers to the same question from the same family about the same child
- Unsure of who to contact and how depending upon what the issue is (e.g., care provider, case manager, care coordinator, nurse, administrator); may not know who to contact for an issue and if they know who to contact, they don't know how to do so.
- Service lapse when families do not receive renewal notices

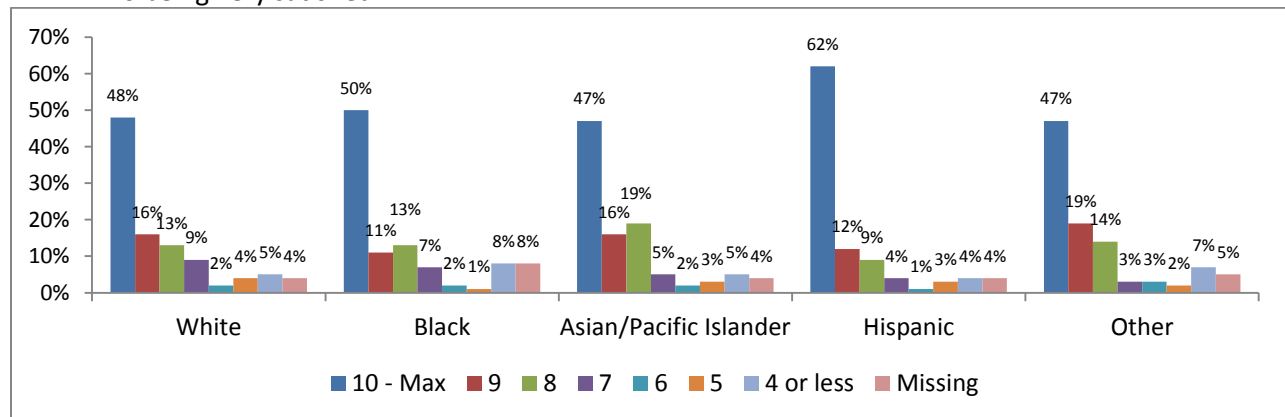
FHOP CCS Family Focus Groups & Survey

- *Not enough phone contact for follow-up regarding administration.*
- *I would like to have a case coordinator. I would like to learn more about CCS. What programs do they offer that can help with my daughter's condition?*
- *There is a communication breakdown among providers...no one runs the system...there's no communication between specialists.*
- *How would you [parents, families] know what questions and how to ask the questions?*

### Overall Satisfaction with CCS Services

From the FHOP CCS Family Survey 2014

- 0 being not at all satisfied
- 10 being very satisfied



<sup>i</sup> National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12/30/14 from [www.childhealthdata.org](http://www.childhealthdata.org).

\* Difference between CA and Nation significant at  $p < .05$

\*\* Differences within the Nation significant at  $p < .05$

^ Difference within the State significant at  $p < .05$

Title V CCS Needs Assessment 2015-2020 - 4 -  
Data Summary Sheet: Family Centered Care  
Family Health Outcomes Project UCSF