

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 2009/2010ⁱ

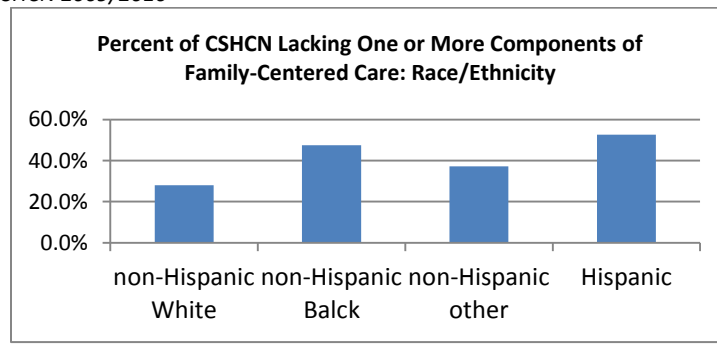
Receives family centered care

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 [^]	55.0
Nationwide	72.5	55.7 ^{**}	61.0

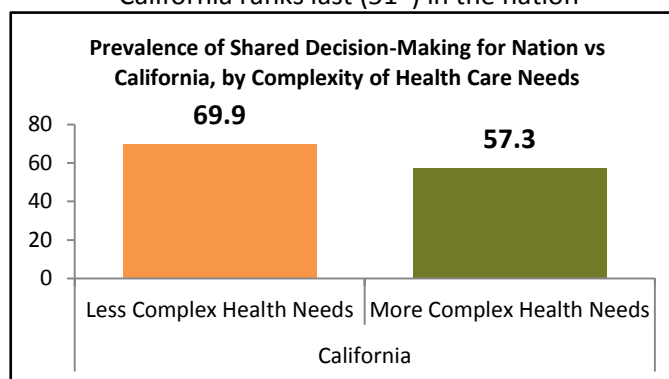
From National Survey of CSHCN 2009/2010



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 (51st) 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 $p < .05$

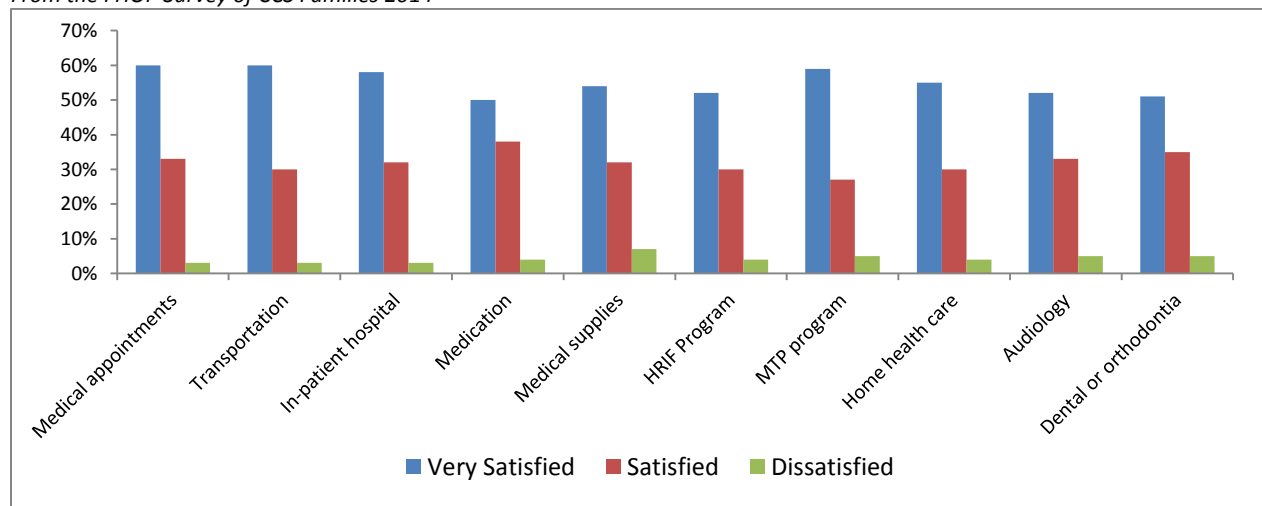
[^] Difference within the State significant at $p < .05$

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

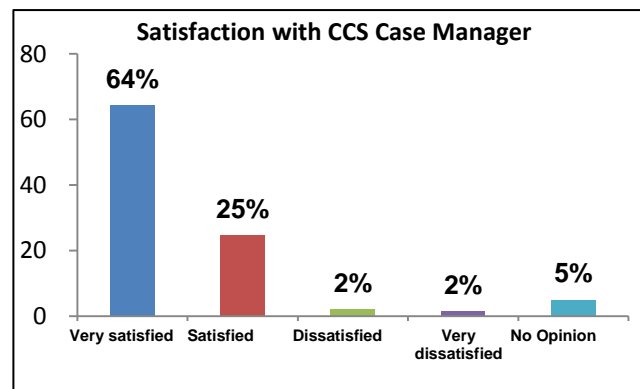
From the FHOP Survey of CCS Families 2014



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.*

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Challenges Raised by Families

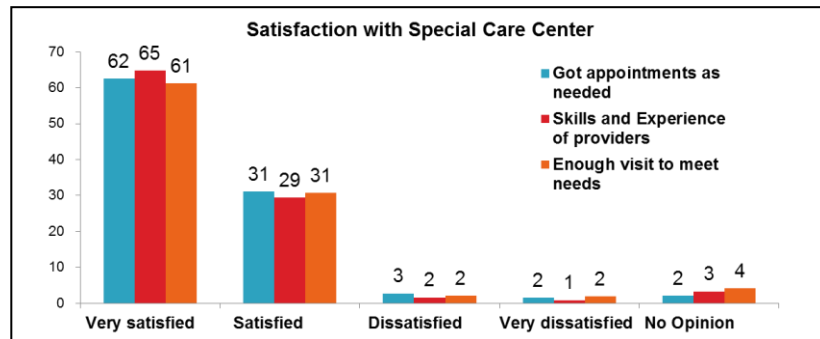
- Many parents don't know what this program is really about.
- Local case managers don't really engage with parents other than for compliances and travel/med/supplies, which they do very well.
- I am unsure what to expect from CCS what services CCS provides...not sure how this program actually works.
- 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

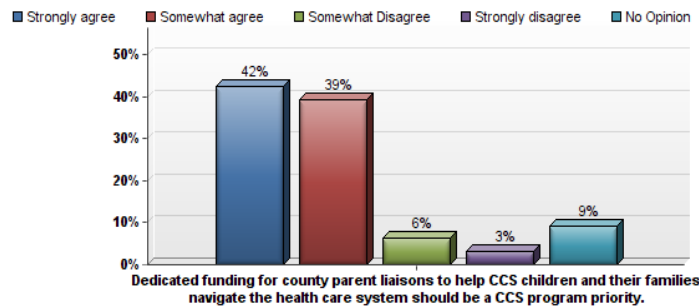
Been provided with a health care plan for child from doctor/nurse/clinic?

	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

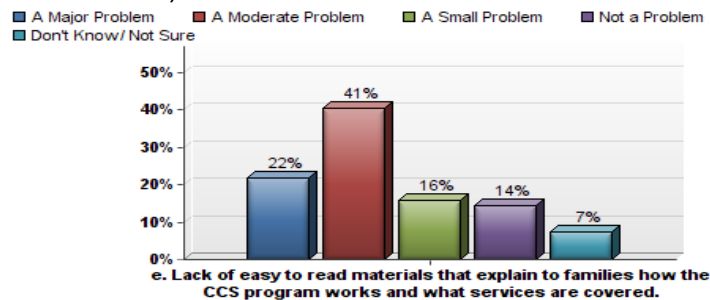
Parent Liaisons

From the FHOP Survey of Physicians 2014



Communication

From the FHOP Survey of CCS Administrators/Medical Consultants 2014



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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

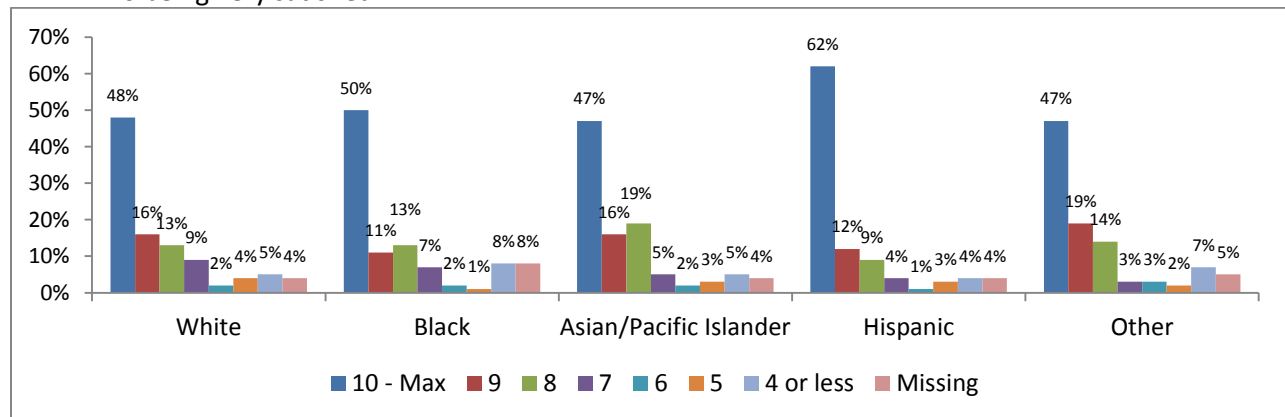
FHOP CCS Family Focus Groups & Survey

- *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



ⁱ 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.

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