



Children with Special Health Care Needs Prevalence Information

Prevalence of CSHCN Population

From the National Survey of CSHCN 2005/2006ⁱ

Percent of children identified as having special health care needs

	2001	2005/2006
California %	10.3	9.9*
Nationwide %	12.8	13.9**

Prevalence by Race/Ethnicity, 2005/2006ⁱ

	Hispanic	White	Black	Multiracial	Other
California %:	6.2	13.9	15.1	17.1	6.3
Sample Size:	390	590	91	67	82
Est. Pop.:	271,166	444,961	98,192	53,266	64,931
Nationwide %:	8.3	15.5	15.0	17.9	8.2
Sample Size:	5,402	37,336	5,829	2,163	2,071
Est. Pop.:	1,175,345	6,509,153	1,607,185	369,120	299,111

- There are no significant differences between CA and the nation in terms of prevalence of CSHCN by race/ethnicity
- Nationally, the prevalence for White, Black, and Multiracial children increased since 2001 and this difference is statistically significant. There are no significant differences from 2001 to 2005/2006 in prevalence between Racial/Ethnic groups in California.

Prevalence by Age 2005/2006ⁱ

	0 – 3 yrs.	4 – 7 yrs.	8 – 11 yrs.	12 – 14 yrs.	15 – 17 yrs.
California %	4.9*	9.8*	11.0*	11.5*	13.2*
Nationwide %	7.2	13.2	16.5	16.7	16.9

- Compared to the nation, significantly fewer children at all ages are identified as CSHCN
- Nationally, the prevalence of CSHCN for children ages 0-3 years, 4-7 years, 8-11 years, and 15-17 years has increased from 2001 to 2005/2006 and this difference is statistically significant. There are no significant differences from 2001 to 2005/2006 in prevalence by age group in California.

Prevalence and Public Insurance

From the “Experiences with health care for California’s children with special health care needs”ⁱⁱ

- About 15% of California’s CSHCN receive specialty care through the CCS program. (150,000 annually).

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

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

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

- The prevalence is lower for Medi-Cal and Healthy Families

Percent of children enrolled with special health care needs, 2001

	%
Medi-Cal	7.4
Healthy Families	3.5

Prevalence of CSHCN Population by Household Income, 2005/2006ⁱ

	0 - 99% FPL	100 - 199% FPL	200 - 399% FPL	400% FPL or greater
California %	7.1* [^]	9.5*	10.9*	11.4*
Nationwide %	14.0	14.0	13.5	14.0

Note: FLP = Federal Poverty Level

- In 2001, the poorest children in CA (199% of the FPL or less) were significantly less likely than the poorest children in the nation to be identified as CSHCN. In 2005/2006, fewer children in California at all household income levels were identified as CSHCN compared to children nationwide.
- In California in 2005/2006, children in households earning 99% or less of the FPL are significantly less likely to be identified as a CSHCN than children in households earning 200% or greater than the FPL.

Prevalence of CSHCN by Criteria for Qualifying as a CSHCN for All Children 0-17, 2005/2006ⁱ

Screening Criteria	California %	Nationwide %
Use of prescription medication	7.2*	10.9
Elevated need/use of medical, mental health or educational services	3.8*	5.3
Functional limitation	2.1*	3.0
Need/use of specialized therapies	1.6*	2.4
Emotional, developmental or behavioral conditions	2.7*	3.9

- Nationally, the percent of children qualifying based on use of prescription medication has increased from 9.5% in 2001 and this difference is statistically significant.

Prevalence of CSHCN by Specific Types of Special Health Needs for All Children 0-17, 2005/2006ⁱ

Type of Health Need	California %	Nationwide %
Conditions that result in functional limitations	2.1*	3.0
Condition managed by prescription medication	4.1*	6.1
Condition requires above routine use of medical, mental health or other services	1.9	2.0
Condition required prescription medicine and above routine use of services	1.8*	2.9

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

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

Demographics of CSHCN Population in CA and Nationally

Race/Ethnicity

From the National Survey of CSHCN 2005/2006

	Hispanic	White	Black	Multiracial	Other
California %	29.1*	47.7*	10.5*	5.7	7.0
Nationwide %	11.8	65.4	16.1	3.7	3.0

- Significantly more of the CSHCN in CA are Hispanic, and significantly fewer are white or black, consistent with the racial/ethnic composition of CA compared to the nation,
- There are no significant differences from 2001 to 2005/2006 in distribution of CHSCN between Racial/Ethnic groups in California.

From the 2005 Los Angeles CCS Parent Surveyⁱⁱⁱ

	Hispanic	White	Black
Los Angeles %	80.2	5.8	8.3

Age of the CSHCN population

From the National Survey of CSHCN 2005/2006ⁱ

	0 – 3 yrs.	4 – 7 yrs.	8 – 11 yrs.	12 – 14 yrs.	15 – 17 yrs.
California %	10.5	22.2	25.0	20.1	22.3
Nationwide %	11.1	21.4	25.7	20.8	20.9

From the 2005 Los Angeles CCS Parent Surveyⁱⁱⁱ

	<5 years	6-11 years	12-17 years	18-21 years
Los Angeles %	34.8	25.7	30.0	9.2

Demographics and types of needs for CSHCN population

How Many CSHCN Qualified On Specific Types of Special Health Needs Screening Criteria

From the National Survey of CSHCN 2005/2006ⁱ

Screening Criteria	California %	Nationwide %
Elevated need/use of medical, mental health or educational services	19.6*	14.3
Conditions result in functional limitation	21.3	21.3
CSHCN whose conditions are managed w/ prescription medicines only	41.2	43.7
Conditions require prescription medicine AND above routine use of services	17.9	20.7

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Percent CSHCN by number of Criteria that apply
From the National Survey of CSHCN 2005/2006ⁱ

	One	Two	Three	Four or five
California %	56.7	23.1	10.6	9.6
Nationwide %	55.2	20.8	12.7	11.4

From the "Your Voice Counts!!" Survey^{iv}:

- Most children were affected by more than one condition. 37% had two or three conditions, 53% had four or more conditions. Fourteen percent of the children were technology dependent or assisted, needed things such as a feeding tube, shunt, or ventilator, etc.

Impact of Health Conditions

From the National Survey of CSHCN 2005/2006ⁱ

- 34.8% of CSHCN in CA never have their daily activities limited or affected by their health condition, 41.5% have their daily activities moderately affected and 23.6% have them consistently affected. These rates are similar to national rates and they do not differ significantly from 2001 rates.
- 53.5% of CSHCN in CA missed 0 – 3 days of school due to illness, 19.8% missed 4 to 6 days, 11.3% missed 7 to 10 days, and 16.2% missed 11 or more days. These rates are similar to national rates and they do not differ significantly from 2001 rates.

Diagnoses among CCS clients

From 2005 Los Angeles CCS Parent Survey

Medical Conditions of Children in CCS

Heart disease/defect	10.6%
Prematurity/low birth weight	9.4%
Deafness/hearing	7.0%
Mental retardation/dev't delay	6.5%
Asthma	5.9%
Cerebral palsy	5.4%
Diabetes	5.0%
Blindness/vision	5.0%
Seizures/epilepsy	4.0%
Injury	4.0%
Cleft lip/palate	3.3%
Physical malformation	2.9%
Kidney	2.8%
Cancer	2.0%
Spina bifida	1.6%
Scoliosis	1.4%

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Active Cases (including LA)through 4/12/2010 From CMS Net

Primary Diagnosis	N	%
Undiagnosed Condition	50	0.0
01 Infectious/parasitic (includes HIV, Hepatitis. Viral and other infections, immunizations and screening)	702	0.4
02 Neoplasms (cancers)	7,748	4.4
03 Endocr/nutrit/metab/immune (includes thyroid disorders, diabetes, other endocrine disorders, nutritional deficiencies, cystic fibrosis, sickle cell, anemia, and coagulation disorders)	21,117	12.1
05 Mental Illness (includes delirium, developmental disorders, mood disorders, alcohol and substance-related disorders, suicide and self-inflicted injury, and other mental disorders)	2,706	1.6
06 Nervous/Sensory (includes meningitis, encephalitis, paralysis, epilepsy, blindness and other eye problems, and hearing disorders)	46,455	26.6
07 Circulatory (includes heart valve problems, dysrhythmia, cardiac arrest, and acute cardiovascular disease)	6,641	3.8
08 Respiratory (Asthma and other respiratory problems)	2,194	1.3
09 Digestive (includes teeth and mouth problems, gastritis, stomach problems, appendicitis, hernia, ulcerative colitis and other digestive problems)	7,747	4.4
10 Genitourinary (include nephritis, renal failure, urinary tract infections, kidney and bladder problems)	5,321	3.1
11 Preg/Birth/Puerperium Cx (includes pregnancy complications, pelvic obstructions, other birth complication, and normal pregnancy and delivery)	59	0.0
12 Skin/subcutaneous (includes skin infections and ulcers on the skin)	395	0.2
13 Muscle/skeleton/connective (includes arthritis, other joint problems, connective tissue problems, bone problems, and other acquired deformities)	8,013	4.6
14 Congenital anomalies (including cleft lip, cleft palate, cardiac and other congenital anomalies)	39,723	22.8
15 Perinatal conditions (including low birth weight, respiratory distress, birth trauma and other perinatal diagnoses)	9,963	5.7
16 Injury/poison	13,338	7.6
17 Symptoms/signs/factors (includes exams, evaluations, and other screenings)	1,700	1.0
18 Injury Unclassified	549	0.3

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Deaths among CCS clients 2008 and 2009 *From CMS Net*

Deaths Primary Diagnosis	2008		2009	
	N	%	N	%
01 Infectious/parasitic (includes HIV, Hepatitis. Viral and other infections, immunizations and screening)	4	0.4	1	0.1
02 Neoplasms (cancers)	117	10.5	109	10.5
03 Endocr/nutrit/metab/immune (includes thyroid disorders, diabetes, other endocrine disorders, nutritional deficiencies, cystic fibrosis, sickle cell, anemia, and coagulation disorders)	51	4.6	37	3.6
05 Mental Illness (includes delirium, developmental disorders, mood disorders, alcohol and substance-related disorders, suicide and self-inflicted injury, and other mental disorders)	6	0.5	7	0.7
06 Nervous/Sensory (includes meningitis, encephalitis, paralysis, epilepsy, blindness and other eye problems, and hearing disorders)	166	14.9	189	18.2
07 Circulatory (includes heart valve problems, dysrhythmia, cardiac arrest, and acute cardiovascular disease)	57	5.1	70	6.7
08 Respiratory (Asthma and other respiratory problems)	58	5.2	53	5.1
09 Digestive (includes teeth and mouth problems, gastritis, stomach problems, appendicitis, hernia, ulcerative colitis and other digestive problems)	15	1.3	13	1.3
10 Genitourinary (include nephritis, renal failure, urinary tract infections, kidney and bladder problems)	9	0.8	7	0.7
11 Preg/Birth/Puerperium Cx (includes pregnancy complications, pelvic obstructions, other birth complication, and normal pregnancy and delivery)	0	0	1	0.1
12 Skin/subcutaneous (includes skin infections and ulcers on the skin)	4	0.4	13	1.3
13 Muscle/skeleton/connective (includes arthritis, other joint problems, connective tissue problems, bone problems, and other acquired deformities)	208	18.7	173	16.6
14 Congenital anomalies (including cleft lip, cleft palate, cardiac and other congenital anomalies)	307	27.5	275	26.4
15 Perinatal conditions (including low birth weight, respiratory distress, birth trauma and other perinatal diagnoses)	98	8.8	82	7.9
16 Injury/poison	11	1.0	5	0.5
17 Symptoms/signs/factors (includes exams, evaluations, and other screenings)	4	0.4	5	0.5
Total	1115	100.0	1040	100.0

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Birth Defects Data

Estimates from California Birth Defects Monitoring Program registry data 1999-2003

CALIFORNIA			
Estimated cases for 529,245 total livebirths			
	Estimated Cases	Rate per 1000	Frequency
All Structural Birth Defects	16,038	30.3	1 in 33
Specific Conditions			
Serious heart defects	1,348	2.55	1 in 390
- Conotruncal heart defects	389	0.73	1 in 1,360
Chromosome abnormalities	694	1.31	1 in 760
- Down syndrome	538	1.02	1 in 980
Oral clefts	720	1.36	1 in 730
- Cleft lip with/without cleft palate	497	0.94	1 in 1,060
- Cleft palate	232	0.44	1 in 2,280
Intestinal atresia/imperforate anus	275	0.52	1 in 1,930
Neural tube defects	262	0.49	1 in 2,020
- Anencephaly	138	0.26	1 in 3,800
- Spina bifida	189	0.36	1 in 2,800
Abdominal wall defects	236	0.45	1 in 2,250
- Gastroschisis	185	0.35	1 in 2,860
- Omphalocele	47	0.09	1 in 11,320
Limb defects	217	0.41	1 in 2,440
Infant deaths with birth defects	1588	~3.00	1 in 333
Mental retardation, school age	2646	5.00	1 in 200
Source: Estimates use registry data and California birth totals			

http://www.cbdmp.org/gd_california.htm

ⁱ Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved [04/08/10] from www.cshcndata.org

ⁱⁱ Inkelas M, Ahn P, Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

ⁱⁱⁱ Inkelas M, Samson K. Specialty Health Care for Children in the Los Angeles California Children's Services Program (CCS) Report. UCLA Center for Healthier Children, Families and Communities. 2005.

^{iv} Wells, N., Doksum, T., Martin, L., Cooper, J. (2000) *What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants*. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.

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Children with Special Health Care Needs Family-Centered Care

MCHB 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 2005/2006ⁱ

Family centered care outcome successfully achieved

California %	46.6*
Nationwide %	57.4

The numbers are not significantly difference from 2001.

Family centered care outcome successfully achieved, by insurance type in California

Public Insurance %	40.6
Private Insurance %	52.0

This pattern is seen in the national data and the difference is significant.

Family centered care outcome achieved, by race/ethnicity

	Hispanic	White	Black	Multiracial	Other
California %:	39.5	50.3	51.4	52.5	38.0
Nationwide %:	46.4**	60.1**	53.5	56.7	47.2

In 2001, similar patterns are seen. In 2001 compared to 2005/2006, fewer Hispanic CSHCN (28.6%) and more White CSHCN (62.3%) achieved the outcome; however, this difference is between the years is not significant for either group.

Parent Satisfaction with Services/Care

From the FHOP Survey of CCS Families 2010

All things considered, how satisfied are you overall with the CCS program?

	Response %	Count
Very satisfied	44%	126
Somewhat satisfied	39%	113
Somewhat dissatisfied	11%	31
Very dissatisfied	5%	14
Don't know/Not sure	1%	4
answered question		288

All things considered, how satisfied are you overall with the Medical Therapy Unit (MTU)?

	Response %	Count
Very satisfied	50%	121
Somewhat satisfied	28%	69
Somewhat dissatisfied	11%	27
Very dissatisfied	6%	14
Don't know/Not sure	5%	13
answered question		244

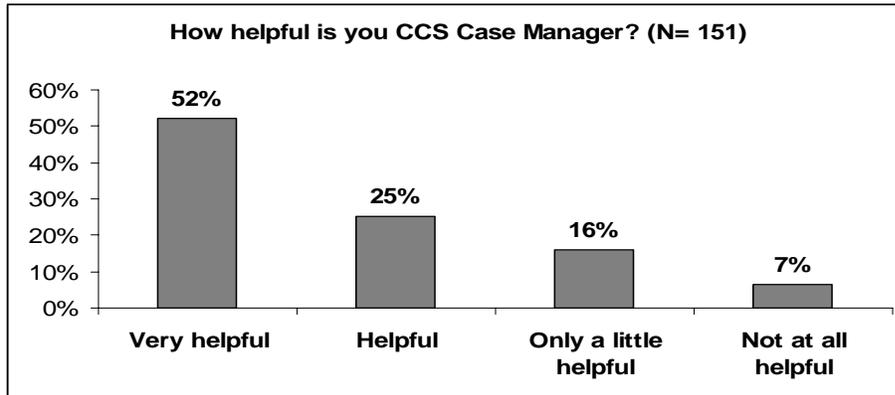
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CCS Case Management

From the FHOP Survey of CCS Families 2010



Overall, how satisfied are you with the help you have received in coordinating your child's care

	Response %	Count
Very satisfied	37%	100
Somewhat satisfied	33%	91
Somewhat dissatisfied	19%	52
Very dissatisfied	11%	29
answered question		272

Primary Care and Specialty Care

- 13% (44) respondents think that their primary care provider does not have the skills and experience necessary to care for their child
- 88% (257) of families say that it is very important to have ONE person who knows their child and can help them understand what their child needs and connect their child to the services he/she needs

What kind of doctor or other health care provider is most important to your child's care now

	Response %	Count
Primary care doctor (such as a pediatrician, or family medicine doctor)	34.7%	118
Specialist doctor	59.7%	203
Other health care provider	4.4%	15
Don't know/Not sure	1.2%	4
answered question		340

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Please tell us about your child's experience with THERAPY in the last 12 months. Please check all that apply.

Answer Options	PHYSICAL THERAPY					OCCUPATIONAL THERAPY					SPEECH THERAPY				
	Yes %	Yes total	No %	No Total	Total	Yes %	Yes total	No %	No Total	Total	Yes %	Yes total	No %	No Total	Total
a. My child needed this therapy	91%	191	9%	19	210	88%	175	13%	25	200	60%	110	40%	73	183
b. My child received this therapy.	84%	161	16%	30	191	90%	160	10%	18	178	75%	83	25%	28	111
c. My child needed but did not get this therapy.	27%	43	73%	116	159	18%	27	82%	125	152	34%	32	66%	63	95
d. I was satisfied with the therapy my child received.	70%	122	30%	53	175	74%	124	26%	43	167	54%	53	46%	45	98
e. Having therapy available at my child's school was helpful.	80%	91	20%	23	114	86%	96	14%	16	112	80%	67	20%	17	84
f. Having therapy appointment times from 7:00 AM to 6:30 PM was helpful.	94%	143	6%	9	152	88%	127	12%	17	144	72%	48	28%	19	67
g. Getting a referral for this therapy was a problem.	19%	30	81%	132	162	12%	18	88%	136	154	33%	27	67%	56	83
h. Getting an appointment was a problem.	17%	29	83%	139	168	14%	23	86%	137	160	27%	22	73%	60	82
i. Getting dropped from the therapy schedule because we missed too many appointments was a problem.	3%	5	97%	142	147	2%	3	98%	142	145	5%	4	95%	75	79
j. Finding a therapist with the skill and experience to care for my child was a problem.	25%	41	75%	124	165	23%	36	77%	121	157	45%	39	55%	47	86
k. It was a problem getting the number of visits my child needed.	44%	75	56%	95	170	33%	54	67%	110	164	47%	40	53%	45	85
l. It was problem getting transportation to the therapy appointment.	18%	29	82%	134	163	13%	21	87%	135	156	13%	10	88%	70	80
m. Coordination between my child's therapist and other providers was a problem.	20%	32	80%	128	160	16%	25	84%	128	153	24%	19	76%	61	80
n. The amount we had to pay was a problem.	8%	12	92%	145	157	6%	9	94%	143	152	16%	13	84%	67	80
o. My child's health care coverage would not pay.	21%	28	79%	108	136	20%	27	80%	107	134	32%	25	68%	52	77
p. Other problems	33%	29	67%	58	87	30%	24	70%	57	81	48%	22	52%	24	46

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Communication With and Between Providers

From the LA CCS Survey 2005

- 66.5% of parents said that the child's health care providers usually or always: provided information, listened carefully, sensitive to family customs and customs, treated the parent like a partner in care, and spent enough time with the child.

Parents' rating of Communication between Medical Providers

Excellent or very good %	63.4
Fair or poor %	13.7

Family Participation and Having a Personal Provider

Parents always receive information they need about managing condition

Child has multiple providers	73.7
Child has single provider	64.5
Child does not have a provider	47.6

Parents' rating communication as excellent or good

Child has multiple providers	84.8
Child has single provider	86.2
Child does not have a provider	73.8

Communication and Access to Interpretation Services

From 2010 FHOP Survey of CCS Families

- 8.1% (25) families reported needing interpretation services to communicate with their child's medical provider in the *last 12 months*
- Among the 30 families having needed interpretation services, 30% (9) only sometimes got this service and 13% (4) never got this service

From the LA CCS Survey 2005¹

- About three-quarters (75.4%) of parents always received interpreter services when needed.

Interpreter needed, by insurance type

Medi-Cal Only %	44
Healthy Families %	38
Private Insurance %	8

- 86% of parents said that they were always confident that translated information between the parent and the child's providers is accurate.
- 28.3% of parents report ever used a friend or relative to interpret for them and the child's providers. 13.8% report using a child under 18 to translate.

From the "Your Voice Counts!!" Survey

- Parents who responded in Spanish were less satisfied in terms of overall quality of care from their doctors, their doctor's overall communication with the family, and their waiting times. Spanish respondents were more satisfied with their doctor's respect for their child and the family than those responding in English

¹ In the LA CCS Survey sample, about 80.2% of children are reported as Hispanic, compared to 31.0% of CSHCN in California from the 2001 NS CSHCN.

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Quality of the Provider-Parent Relationship

From "Experiences with health care for California's children with special health care needs" 2003

Research generally shows that a good interpersonal relationship between the provider and parent/child improves adherence to medical advice, patient satisfaction, self-rated access to care, fewer unmet needs and fewer emergency department visits.

- Fewer children in Medi-Cal (62%) than with private insurance (82%) were reported to have enough time with their providers.

From the FHOP Survey of CCS Families 2010

How well is this doctor or other health care provider who is most important to your child's care doing on...

	Excellent		Good		Okay		Poor		Total
a. Overall, providing quality care?	58%	184	33%	106	9%	29	0%	1	320
b. Explaining about my child's health needs in a way that I can understand?	57%	184	34%	108	8%	26	1%	4	322
c. Being easy to contact by phone?	40%	125	32%	100	19%	60	8%	26	311
d. Being available to give medical care or advice at night and on weekends?	31%	72	26%	61	25%	58	19%	45	236
e. Giving me reassurance and support?	47%	144	27%	84	19%	60	7%	21	309
f. Being easy to reach in an emergency?	39%	98	26%	67	20%	52	15%	37	254
g. Including my family in decision making and Giving me updated information about medical research that might help my child?	47%	140	27%	82	16%	48	10%	31	301
h. Showing respect for my child?	68%	217	24%	77	7%	22	1%	4	320
i. Respecting our culture, ethnic identity, and religious beliefs?	63%	174	30%	84	6%	16	1%	4	278
j. Communicating with my child's other health care providers?	47%	139	33%	98	14%	41	7%	20	298
k. Communicating with my child's school or early intervention program?	37%	76	31%	64	15%	31	17%	35	206
l. Communicating with other systems that provide services to my child (not including school)?	38%	93	33%	81	14%	35	14%	35	244
m. Communicating with my child's health insurance plan staff?	44%	102	32%	73	14%	33	10%	22	230

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Family Participation *From State Performance Measures*ⁱⁱ

This summary performance measure is designed to assess the degree to which the CMS program demonstrates family participation.²

In 51 CA counties, the percentage of points counties received on this measure ranged from 0 to 100% with an average of 41% of possible points.

- 6% of counties scored 80% or more of possible points
- 18% of counties scored between 60 to 79% of possible points
- 22% of counties scored between 40 to 59% of possible points
- 29% of counties scored between 20 to 39% of possible points
- 26 of counties scored less than 20% of possible points

Understanding How Health Plans Work

From the “Experiences with health care for California’s children with special health care needs”ⁱⁱⁱ

- 73% of parents of CSHCN in Medi-Cal said that they have enough information about how their child’s health insurance plan works, compared to 92% of parents of privately insured children.
- Among parents of the children most severely affected by their condition, 56% of those in Medi-Cal reported having enough information about their health insurance plan compared to 92% of privately insured children.

From the “Your Voice Counts!!” Survey^{iv}:

- Nearly half (46%) of families surveyed did not know whether their child was in a managed care plan, though most (72%) were in fact in a plan with at least one managed care feature, such as a network of doctors or required primary care doctor

ⁱ Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved [04/08/10] from www.cshcndata.org

ⁱⁱ State performance measures

ⁱⁱⁱ Inkelas M, Ahn P, Larson K. 2003. “Experiences with health care for California’s children with special health care needs.” Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

^{iv} Wells, N., Doksum, T., Martin, L., Cooper, J. (2000) What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.

² The measure combines responses to 6 questions regarding family member participation on advisory committees or task forces, offering of financial support for parent activities or groups, providing opportunities for family members to provide feedback regarding their satisfaction with services received through CCS program, involving family members in in-service trainings of CCS staff and providers, hiring family advocates for their expertise as paid staff or consultants to the CCS program, and involving family members of diverse cultures in all the above activities.

* 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 Care Needs Medical Home and Access to Care

MCHB Outcome #2: Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home.

Medical Home

From the National CSHCN Survey 2005/2006ⁱ

The National Survey of CSHCN implements the America Academy of Pediatrics definition of a medical home – medical care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective and delivered or directed by a well-trained primary care or specialty physician who helps to manage and facilitate essentially all aspects of care for the child. The medical home variable is derived from responses to questions about having a usual source of care, having a personal doctor or nurse, having no problems receiving referrals when needed, and family centered care.

CSHCN lacking a medical homeⁱ

California %	58.0
Nationwide %	52.9

ⁱnot a significant difference

- In 2001, significantly more CSHCN in California were lacking a medical home compared to the national rate. Because of changes in the questions asked, the results are not comparable between years.

Percent of CSHCN in California lacking a medical home by race/ethnicityⁱ

White %	47.3 [^]
Hispanic %	71.3
Black %	71.7

Percent of CSHCN in California lacking a medical home by special health needsⁱ

Needs managed by prescription drugs %	46.0 [^]
Functional limitations %	68.5
Above routine needs and use of services %	69.4

- In CA, children with one of more emotional, behavioral, or developmental issue are more likely to lack a medical home than children without one of those issues [75.0% vs. 51.4%].

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

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

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

Having a Usual Source of Care and Personal Provider

From the FHOP Survey of CCS Families 2010

- 95% of families reported that their child has a primary care provider

From CMS Netⁱⁱ

In CMS Net, having a medical home is defined as having a primary care provider. CA Counties vary widely in 2005 in their percentages of CCS children with a medical home.

- In 35% of counties, 80% or more of their CCS children have medical homes
- In 24% of counties, between 60 to 79% of their CCS children have medical homes
- In 22% of counties, between 40 to 59% of their CCS children have medical homes
- In 5% of counties, between 20 and 39% of their CCS children have medical homes
- In 15% of counties, fewer than 20% of their CCS children have medical homes.

From the LA CCS Survey 2005ⁱⁱⁱ

- About 85% of children in LA CCS have personal providers.
- Nearly all children in CCS have a usual source of health care, irrespective of the type of health insurance coverage.
- 85.4% of children have a usual source of care and one personal provider.
- Among parents who consider the emergency room to be their child's usual source, 72.4% said the child has a personal provider.
- Lacking a personal provider increases among adolescents and young adults. 2.2% of children age 0-12 years lack a provider, 6.3% of those age 13-17 and 11.4% of those age 18-21 lack a personal provider.
- Among children with exclusively Medi-Cal coverage who have personal doctors, slightly more children in managed health plans than in fee-for-service Medi-Cal had one personal provider (92.3% vs. 88.6%).
- Among children in Medi-Cal, more children in CCS (85.2%) than in the general population of CSHCN (72.2%) have a personal doctor.

Unmet Medical Needs

Unmet need is a direct measure of access to health care services. Unmet service needs may affect severity of the disease, lead to more urgent care contacts and greater emergency department utilization, and ultimately reduce children's physical and mental well-being.

From the National Survey of CSHCN 2005/2006ⁱ

CSHCN with **no** unmet needs for health care servicesⁱ

	2001	2005/2006
California %	76.9	82.5
Nationwide %	82.3	83.9**

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

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

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

CSHCN with **no** unmet medical needs by race/ethnicityⁱ

	White	Black	Hispanic	Mutli-racial
California %	84.8	81.7	78.9	91.9
Nationwide %	86.1**	81.1	77.8**	80.0

- This pattern also was seen in the 2001 and the 2001 rates are not significantly different from 2005/2006 nationwide.

Percent of CSHCN in California with **no** unmet medical needs, by medical homeⁱ

With a medical home	91.2
Without a medical home	76.6*

CSHCN with **no** unmet medical needs, by insurance statusⁱ

	With Insurance	Without Insurance
California %	83.3	61.8
Nationwide %	85.0	55.3**

From “Experiences with health care for California’s children with special health care needs” 2003^{iv}

- Nearly half of children in Medi-Cal (43%) were reported having at least one unmet need. Rates of unmet need among those children in Medi-Cal requiring a particular service were high for mental health (42%) and specialty care (10%). Among all CSHCN in California, the highest reported rates of unmet need were for respite care (35%), family counseling or mental health services (23%) and mental health services for the child (22%)
- Most health services needed by CSHCN in Medi-Cal are covered benefits of the federal Medicaid program. Unlike adult services, children’s benefits in Medi-Cal come from the expansive federal Early and Periodic Screening Diagnosis and Treatment (EPSDT) requirements. The medical necessity definition in EPSDT requires the state Medicaid program to provide children with any federal Medicaid benefit that is needed to ameliorate a condition. Moreover, the CCS program covers specialty care for those children in Medi-Cal or Healthy Families with severe or disabling conditions. CCS also pays for some specialty services for commercially insured children whose health plans limit benefits:
 - Fewer parents of CSHCN in Medi-Cal (61%) compared to those with private insurance (86%) reported that their child’s needs are met by insurance benefits.
 - Parents of 18% of CSHCN in Medi-Cal said that the benefits “never” meet their child’s health care needs.

Unmet Need for Therapy Services

From the FHOP Survey of CCS Families 2010

- 27% (43) of families reported that their child needed physical therapy but did not receive physical therapy
- 18% (27) of families reported that their child needed occupational therapy but did not receive occupational therapy
- 34% (32) of families reported that their child needed speech therapy but did not receive speech therapy

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

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

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

Unmet Need for Family Support Services

From the FHOP Survey of CCS Families 2010

- 33% (95) families report attending family support groups to help them cope with their child's health condition
- Of the 239 families not currently attending family support groups, 39% (94) would like to attend family support groups
- Only 29% (85) of families report that anyone from the CCS program told them that CCS could help them find emotional support, community resources, and family/individual counseling for their child and family
- Only 20% (56) of families report that anyone from the CCS program referred them to any family to family support services

From the National Survey of CSHCN 2005/2006ⁱ

Percent of families or parents of CSHCN needing but not getting support servicesⁱ

	2001	2005/2006
California %	25.1	28.8
Nationwide %	23.1	27.9**

- In California and nationally, there were no statistically significant differences in unmet needs for family support services by race/ethnicity.

Access

From the FHOP Survey of CCS Families 2010

- 13% (40) families report going to the hospital emergency room in the last 12 months for a problem or illness that they think could have been taken care of by their child's health care provider if they had been able to talk to or see the provider earlier. 36 of these families reported a combined total of 82 of these ER visits in the last year, with one family reporting 7 visits.

How well is this doctor or other health care provider who is most important to your child's care doing on...

	Excellent		Good		Okay		Poor		Total
Being easy to contact by phone?	40%	125	32%	100	19%	60	8%	26	311
Being available to give medical care or advice at night and on weekends?	31%	72	26%	61	25%	58	19%	45	236
Being easy to reach in an emergency?	39%	98	26%	67	20%	52	15%	37	254

From "Experiences with health care for California's children with special health care needs" 2003^{iv}

- In general parents of CSHCN in Medi-Cal report experiencing more access problems than parents of CSHCN in other state Medicaid programs. (Nearly 80% of CCS children are Medi-Cal beneficiaries.)

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

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

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

Access to Primary Care

From the FHOP Survey of CCS Families 2010

- 95% (322) families report having a primary care provider
- 13% (44) reported some problems getting primary care services and 3% (20) reported a lot of problems. Types of problems most frequently reported include not being able to get an appointment, not being able to find a primary care provider with the necessary skills and experience, and coordination between primary and specialty care providers

Access to Specialty Care

From the FHOP Survey of CCS Families 2010

- 18.2% (62) reported some problems getting specialty care services and 7.6% (26) reported a lot of problems. The most frequently reported problem was getting an appointment. Other frequent problems included getting a referral, not being able to find specialist with the need skill and experience, and coordination between primary and specialty care providers, and refusal by the health plan to pay for the service
- When asked what type of doctor is most important to their child's care now, 60% (203) said a specialist doctor

From "Experiences with health care for California's children with special health care needs" 2003^{iv}

- Parents of CSHCN in Medi-Cal more frequently reported difficulty obtaining a referral (54%) if their child is significantly affected by their medical condition.
- Most children eventually got needed specialty care even when they had problems with referrals. Parents of 9% of the CSHCN who needed a specialist (about 44,000 children) said that the child did not receive the needed care, with no differences between children in Medi-Cal (10%) and children in private insurance (8%)

Specialist Shortages

From the Children's Specialty Care Coalition's survey of medical groups based at the regional pediatric tertiary centers and are members of the Coalition

Sub-specialty	# of Current Filled Positions	# Positions open/recruiting (%Total)	Length of time recruiting
Cardiologist	36	10 (28%)	1-2 yrs
Orthopedist	23	5 (22%)	1-3 yrs
Hematologist/ Oncologist	26	7 (27%)	1-2 yrs
Endocrinologist	43	7 (16%)	1m - 2 yrs
Neurologist	36	11 (31%)	1 - 3yr
Otolaryngologist	13	2 (15%)	1m-1 yr
Allergy	13	1 (8%)	1 yr
Behavioral/Developmental	7	2 (29%)	1 yr
Critical Care	46	6 (13%)	1m-1 yr
Gastroenterology	35	9 (26%)	1- 2.5 yrs
Geneticist	13	3 (23%)	1 yr
Infectious Disease	12	1 (8%)	1 yr
Nephrology	20	1 (5%)	2 yrs
Rheumatology	10	3 (33%)	3 yrs
Surgery	35	8 (23%)	1-2 yrs
Pulmonary Medicine	23	5 (22%)	6-12 ms
Rehabilitation Medicine	6	3 (50%)	2 yrs
Totals	397	84 (22%)	

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

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

Average Wait Time for Non-Urgent Specialty Care

From the Children's Specialty Care Coalition's survey

Condition	Sub-specialty	Wait Time for Non-Urgent Patient
Suspected Heart Condition	Pediatric Cardiologist	39 days
Hearing Loss	Otolaryngologist	53 days
Treatment for compound fx	Pediatric Orthopedist	16 days
New Bleeding disorder order	Pediatric Hematologist	18 days
Diabetes	Pediatric Endocrinologist	56 days
Seizure	Pediatric Neurologist	45 days
Concern for autism	Pediatric Neurologist	54 days
Asthma	Pediatric Pulmonologist	36 days
Cleft lip/palate	Otolaryngologist	95 days
	Orthodontist	114 days
	Plastic Surgeon	72 days

Barriers to Physician Participation in CCS

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010 and the FHOP Survey of Physicians 2010

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010 and the FHOP Survey of Physicians 2010	Physicians		Hospitals/Health Plans Staff	
	Percent	Count	Percent	Count
a. Lack of knowledge about the CCS Program and how to participate	30%	37	91%	144
b. Low Medi-Cal outpatient reimbursement rates for care of CCS children	60%	69	97%	154
c. Delays in payments for the services provided to CCS children	67%	78	97%	149
d. Time consuming and difficult paper work to complete to get reimbursed	78%	88	98%	145
e. Having to get a Medi-Cal number	32%	37	84%	118
f. Process and length of time to get a Medi-Cal number	49%	56	93%	128
g. Having to be CCS-paneled provider	33%	41	87%	136
h. Process and length of time to be a CCS-paneled provider	43%	49	92%	133
i. The complexity of care needed by CCS children and the increased time it takes to care for them	44%	55	81%	121
j. The need to coordinate services for CCS children and the lack of information on how to do it	59%	73	85%	126
k. Lack of knowledge about resources for CCS children	53%	65	85%	124
l. Lack of medical training or expertise on how to treat/or expertise for serving children with special health care needs	14%	17	73%	105
m. Lack of a specialist to easily consult for advice in caring for children with special health care needs	35%	42	77%	110
n. Medi-Cal Health plans do not pay enhanced rate for the primary care services for children in CCS	50%	53	93%	111

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

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

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

Strategies to increase Physician Participation in CCS

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010 and the FHOP Survey of Physicians 2010

	Hospitals/Health Plans/ CCS Program Survey				Physician Survey			
	Agree Strongly		Agree Somewhat		Agree Strongly		Agree Somewhat	
a. Increase the reimbursement rates paid to physicians to care for CCS clients.	80%	130	18%	29	88%	112	12%	15
b. Ensure that there are staff at the Medi-Cal fiscal intermediary that are familiar with CCS to process claims for providing services to CCS clients.	88%	138	11%	17	73%	91	27%	34
c. Primary care physicians should receive more training on how to handle common subspecialty problems such as diabetes.	38%	54	46%	65	16%	18	45%	52
d. Create training opportunities on CCS and caring for CSHCN in pediatric and family medicine residency programs and adolescent medicine fellowships.	64%	98	33%	50	29%	33	50%	57
e. Work with professional organization such as the CSCC, the California affiliate of the AAP, the CAFP and others to identify ways to further educate physicians about participating in the CCS program.	64%	99	34%	52	42%	49	47%	55
f. Work with professional medical associations to offer continuing education on caring for children with special health care needs	58%	89	38%	58	40%	49	49%	59
g. Streamline the process for CCS providers of having to re-apply for a Medi-Cal number when the provider moves.	77%	122	22%	34	54%	65	35%	42
h. The CCS paneling process should be done concurrently with the Medi-Cal approval process and should be completed in a reasonable timeframe, particularly if staff privileges have been granted at a CCS approved regional tertiary center.	82%	128	17%	27	72%	89	20%	25
i. Provide assistance to physicians to help with getting CCS paneled	72%	114	25%	39	63%	79	27%	34
j. Provide ongoing assistance with authorizations and billing for services once physicians are paneled.	78%	123	20%	32	79%	100	17%	21
k. Better align Codes and reimbursement rates to allow for outpatients tests and procedures where appropriate	68%	101	31%	46	78%	93	20%	24
l. Managed Care plans should provide enhanced rates for the primary care services for children with CCS eligible conditions.	70%	96	25%	34	75%	88	24%	28

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

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

Referrals

Problems Getting Referrals

From the National Survey of CSHCN 2005/2006ⁱ

CSHCN needing a referral for specialty care and having difficulty getting itⁱ

California %	27.6
Nationwide %	21.1

CSHCN needing a referral for specialty care and having difficulty getting, by race/ethnicityⁱ

	White	Black	Hispanic
California %	23.3	-	33.8
Nationwide %	19.9	19.1	30.9**

CSHCN needing a referral for specialty care and having difficulty getting, by type of health problemⁱ

	Functional limitations	Managed by Rx	Above routing need/ use of services	Rx meds and service use
California %	63.8	81.3	69.1	71.9
Nationwide %	73.9	85.5**	74.1	79.1

Waiting times from referral to first authorization for CCS services *from CMS Net*

- In 54 CA counties in 2005, average waiting times for referral to authorization varied from 55 to 227 days, with an average of 127 days.
- In CA counties in 2010 (all except LA), wait times range from 0 to 364 days, with an average of 32.5 days, a mode of 0 and a median of 17 days; in LA, wait times ranged from 0 to 381 days with an average of 12 days
- Relative risk statistics were computed comparing dependent counties with independent counties (excluding LA). For CCS children in the dependent counties, they are 6.2 times more likely to have to wait for longer than a month from referral to first authorization than are CCS children in independent counties (CI 5.6-6.8)

Access to Ancillary Services/Durable Medical Equipment and Medical Supplies

From the FHOP Survey of CCS Families 2010

	% and # who report needing the Service		Of those needing the service, % and # who did NOT get service		Of those who got service, % and # who were satisfied		Of those who got service, % and # who were NOT satisfied	
Dental care	81%	237	16%	38	92%	183	8%	16
Disposable medical supplies	53%	152	13%	19	92%	122	8%	11
Durable medical equipment and medical technology	71%	209	6%	13	85%	167	15%	29
In home support services (IHSS)	51%	142	23%	32	93%	102	7%	8
Respite care	56%	152	22%	34	79%	93	21%	25

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

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

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

Wait time between request for in-home support services and authorization

From CMS Net

- In 2005, wait time between request for and authorization for in-home support services ranges from 0 to 1469 days in 2005, with average being 24 days, the mode (most frequent value) being 0 days and the median (middle value) being 5 days.
- In 2009, wait time for request until authorization of in-home support improved with a range of 0 to 303 days and an average of 18.2 days and a mode of 0 days.

Access to Medical Supplies/Durable Medical Equipment/Mobility Aides

From the FHOP Survey of CCS Families 2010

- 31% (61) of the 191 families needing medical supplies for their CCS child in the last 24 months report delays in receiving needed medical supplies
- Among the 190 CCS families who report their CCS child ever being hospitalized and needing durable medical equipment on discharge, 12% (22) report delays in discharge because DME was not available when needed.
- 42% (84) of the 201 families needing mobility aides or devices, such as canes, crutches, wheelchairs, or scooters in the last 24 month report delays in getting these items
- 32% (42) of the 136 families who have ever experienced delays in getting mobility aides or devices report that when the equipment did arrive, it was no longer the correct size

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010 and the FHOP Survey of Physicians 2010

- Hospital/health plan staff and physicians responded to the following regarding durable medical equipment (DME)

	Hospital/Health Plans		Physicians	
	Occasionally a problem	Frequently a problem	Occasionally a problem	Frequently a problem
Too few DME providers being available due to low reimbursement rates.	36% (5)	50% (7)	23% (14)	71% (44)
DME providers refusing to provide certain kinds of equipment due to low reimbursement rates for that equipment.	36% (6)	36% (6)	24% (14)	69% (41)
Client discharges being delayed because of delays in getting DME (e.g. ventilators, apnea monitors, wheel chairs	29% (4)	43% (6)	27% (20)	58% (42)
Hospitals or families having to purchase DME so that clients can be discharged in a timely manner.	18% (2)	27% (3)	38% (21)	36% (20)
Clients missing school due to delays in getting or repairing needed DME.	20% (2)	20% (2)	37% (19)	45% (23)

Wait time between request for equipment (wheelchairs) and authorization

From CMS Net

- In 2005, the wait time between request for and authorization of equipment ranged from 0 to 1838 days, with average being 29 days, the mode (most frequent value) being 0 days and the median (middle value) being 12 days.
- In 2009, the wait time show improvement with a ranged between 0 and 321 days, an average of 22.2 days and a mode of 0 days.

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

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

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

Barriers to Providing Durable Medical Equipment

FHOP Survey of Durable Medical Equipment Providers 2010

Major barriers

Low reimbursement rates	53.8% (7)
Delays in payments for the services provided to CCS children	53.8% (7)
Time consuming and difficult paper work to complete to get reimbursed	92.3% (12)

- The majority of respondents indicated the following are not barriers at all: Having to get a Medi-Cal number, the process of applying for a Medi-Cal number, the length of time it takes to get a Medi-Cal number, and the length of time it takes to be approved as a CCS-paneled provider.

Respondents strongly agreed or agreed with all of the suggestions to reduce barriers to DME provider participation. The most popular suggestions were:

- Ensure that there are staff at the fiscal intermediary familiar with CCS to process claims for DME - 69.2% (9) of respondents strongly agreed
- Periodically adjust payments for equipment to correspond to the price of the equipment so as the cost goes up, the payment goes up too – 92.3% (12) strongly agreed
- Increase the ability of hospitals to be able to authorize DME when a CCS patient is discharged to speed up the authorization process and access to needed equipment - 69.2% (9) strongly agreed
- Extend the time line for authorizations for DME for some complex conditions that are expected to continue for some time. 76.9% (10) strongly agreed

Coordination of Services

Case management and Care Coordination

From the FHOP Survey of CCS Families 2010

Who provides case management for your child?

	Response %	Count
Private health insurance plan	12.9%	41
California Children Services (CCS)	43.5%	138
Specialty Care Center or Hospital	4.7%	15
Other state agency	14.8%	47
Other	14.5%	46
Don't know/Not sure	9.5%	30

- Of the 236 families reporting that their child received case management services, 64% (152) report having a CCS case manager while 14% (34) report having no CCS case manager and 21% (50) are not sure if they have a CCS case manager
- For “Other”, many respondents indicated “me” or “I do”.

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

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

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

How well is this doctor or other health care provider who is most important to your child's care doing on...

	Excellent		Good		Okay		Poor		Total
Communicating with my child's other health care providers?	47%	139	33%	98	14%	41	7%	20	298
Communicating with my child's school or early intervention program?	37%	76	31%	64	15%	31	17%	35	206
Communicating with other systems that provide services to my child (not including school)?	38%	93	33%	81	14%	35	14%	35	244
Communicating with my child's health insurance plan staff?	44%	102	32%	73	14%	33	10%	22	230

ⁱ Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved [04/08/10] from www.cshcndata.org

ⁱⁱ CMS Net

ⁱⁱⁱ Inkelas M, Samson K. *Specialty Health Care for Children in the Los Angeles California Children's Services Program (CCS) Report*. UCLA Center for Healthier Children, Families and Communities. 2005.

^{iv} Inkelas M, Ahn P, Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

* 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 Care Needs Health Insurance Coverage

MCHB Outcome #3: Families of CSHCN have adequate private and/or public insurance to pay for the services they need.

Research shows that for children generally, retention of coverage is important for health care continuity, quality of care, parent adherence to medical advice and parent self-management of children's conditions.

Current Insurance Inadequate

From the National Survey of CSHCN 2005/2006^d

	<u>Insurance inadequate</u>
California %	35.5
Nationwide %	33.1

- Differences are not significant between 2001 and 2005/2006.

Current Insurance inadequate by Race

From the National Survey of CSHCN 2005/2006^d

	Hispanic	White	Black	Multiracial	Other
California %:	36.1	36.5	36.4	21.0	38.5
Nationwide %:	37.3	32.2	33.4	29.4	34.9

- Nationally in 2001, Hispanics were more likely than all other groups to not have adequate insurance for their CSHCN (46.7%). In 2005/2006, Hispanic children are only more likely than White CSHCN to not have adequate insurance, and fewer Hispanic CSHCN report inadequate insurance (37.3%) than in 2001; these differences are significant.
- The CA data shows no significant differences.

Current Insurance Coverage for CSHCN

Type of Coverage

From the National Survey of CSHCN 2005/2006^d

	Private or employer-based insurance only		Public insurance only		Combination of public and private insurance		Uninsured at time of survey	
	<u>2001</u>	<u>05/06</u>	<u>2001</u>	<u>05/06</u>	<u>2001</u>	<u>05/06</u>	<u>2001</u>	<u>05/60</u>
California %	72.2*	63.6	16.6*	26.2 ^a	6.9	7.1	4.3	3.1
Nationwide %	64.9	60.3 ^a	21.7	28.6 ^a	8.1	7.5	5.2	3.6 ^a

- In California and nationally, more children have public insurance in 2005/2006 than in 2001 and this difference is significant.

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

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

^a Difference between 2001 and 2005/2006 significant at $p < .05$

Type of Coverage

From the “Your Voice Counts!!” Surveyⁱⁱ

	<u>Medi-Cal Managed Care</u>	<u>Private Managed Care</u>	<u>Medi-Cal Fee for Service</u>	<u>Private Fee for Service</u>
California %	53	26	20	1

No Insurance Coverage during Past Year

From the National Survey of CSHCN 2005/2006ⁱ

	2001	2005/2006
California %	9.9	8.0
Nationwide %	11.6	8.6**

No Insurance, by Race/Ethnicity

	White, Non- Hispanic	Black, Non- Hispanic	Hispanic
California %	5.4	-	11.9
Nationwide %	7.1**	11.0**	15.1**

Adequacy of Current Insurance

From the “Experiences with health care for California’s children with special health care needs” 2003ⁱⁱⁱ

Recent expansions of Medi-Cal and the Healthy Families program have improved children’s financial access to health care. However, having insurance coverage does not guarantee that CSHCN are covered for all the services that they need.¹

- Fewer parents of CSHCN in Medi-Cal (61%) compared to those with private insurance (86%) reported that their child’s needs are met by insurance benefits.
- Parents of 18% of CSHCN in Medi-Cal said that the benefits “never” meet their child’s health care needs.

From the National Survey of CSHCN 2005/2006ⁱ

Adequacy of Insurance by Type of Need, Nationwide

	Adequate Insurance
Managed by prescription drugs	72.5**
Functional limitations	59.0
Above routine needs/use of services	61.4
Both above routine needs/use of services and use of prescription drugs	67.0

- These rates are not significantly different from 2001. CA reflects a similar pattern but there are no significant differences.

¹ Most health services needed by CSHCN in Medi-Cal are covered benefits of the federal Medicaid program. Unlike adult services, children’s benefits in Medi-Cal come from the expansive federal Early and Periodic Screening Diagnosis and Treatment (EPSDT) requirements. The medical necessity definition in EPSDT requires the state Medicaid program to provide children with any federal Medicaid benefit that is needed to ameliorate a condition. Moreover, the CCS program covers specialty care for those children in Medi-Cal or Healthy Families with severe or disabling conditions. CCS also pays for some specialty services for commercially insured children whose health plans limit benefits.

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

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

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

^a Difference between 2001 and 2005/2006 significant at $p < .05$

Difficulties with Current Insurance Coverage

From the National Survey of CSHCN, 2005/2006ⁱ

Rating of costs not covered by Insurance by California parents of CSHCN

Never or sometimes reasonable	29.6%
Usually reasonable	27.4%
Always reasonable	36.9%

- These rates are not significantly different from 2001.

Impact of Coverage System on Families

From the FHOP Survey of CCS Families 2010

Experience of families who have a child covered by BOTH private insurance and CCS (n=167)

Having private insurance along with CCS makes it <u>easier</u> to get services	47% (78)
Having private insurance along with CCS makes it <u>harder</u> to get services	22% (36)
Not sure if also having private insurance make it easier or harder	32% (53)

Reasons families have trouble getting needed care

<u>Type</u> of insurance that covers their child insurance	37% (105)
<u>Lack</u> of insurance	22% (63)
<u>Changes</u> in insurance	21% (59)

From the "Your Voice Counts!!" Surveyⁱⁱ

- Over half of the parents reported spending some time each week providing health care at home. One-fifth spent 20 or more hours per week providing this care.
- One third of the parents reported that their child's health conditions caused financial problems; 28% said they stopped working; and 37% cut down the hours they worked.
- Almost half the parents reported spending between \$500 and \$3000 out of their own pocket for the special health care needs of their child in the past year. One-tenth said they spent \$3000 or more.

ⁱ Child and Adolescent Health Measurement Initiative. 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved [04/08/10] from www.cshcndata.org

ⁱⁱ Wells, N., Doksum, T., Martin, L., Cooper, J. (2000) What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.

ⁱⁱⁱ Inkelas M, Ahn P, Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

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

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^a Difference between 2001 and 2005/2006 significant at $p < .05$



Children with Special Health Care Needs Screening

MCHB Outcome #4: Children are screened early and continuously for special health care needs.

Screening for Special Health Care Needs

From the National Survey CSHCN 2005/2006¹

- 63.8% of CSHCN nationally are screened early and continuously for special health care needs² compared to 62.7% in California. Privately insured CA CSHCNs are significantly more likely to be screened than publically insured.

	% Screened
California overall	62.7
CA Private Ins	69.1
CA Public Ins	54.8
Nationwide	63.8

- In both California and Nationally Whites are more likely to be screened than Hispanics or Blacks. However, in California only the White/Hispanic difference is significant.

	Hispanic	White	Black	Multiracial	Other
California %:	53.9	68.8	56.9	77.9	53.6
Nationwide %:	55.5	67.2	56.5	63.2	61.7

Newborn Metabolic Screening

From Title V Reports, 2001-2003³

- CA had high rates of screening for the 4 conditions it mandated: 99.9% in 2001, 99.0% in 2002, and 98.5% in 2003

¹ Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved [04/08/10] from www.cshcndata.org

² Children achieve this measure if they receive both preventive medical and dental care during the past 12 months

³ Prior to 2005 all newborns were screened for Phenylketonurea, Congenital hypothyroidism, galactosemia and sickle Cell disease. In 2005, congenital adrenal hyperplasia, and non-PKU inborn errors of metabolism tested by tandem mass spectrometry were added. In July 2007, cystic fibrosis and biotinidase deficiency were added.

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

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

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

- In 2003, 100% of those needing treatment for PKU, congenital hypothyroidism, and galactosemia were treated. Rates for receiving needed treatment of sickle cell disease have been increasing for the last three years: 2001 = 94%, 2002 – 95.9%, 2003 – 97.6%

From the California Title V Application 2010

- 100% of newborns who screened positive received timely follow up for definitive diagnosis and clinical management for identified condition(s) in 2004, 2006 and 2007, and 99.2% in 2005.⁴

California Newborn Hearing Screening

From the State Newborn Hearing Screening Program (NHSP) Data 2003-4⁵

- In 2003, 90.7% of newborns at CCS-approved hospitals received hearing screening at birth, and 94.3% did so in 2004
- Screening rates in WBN in CCS approved hospitals that were certified to participate in the NHSP were 97.1% in 2004 and 97.2% in 2003
- Screening rates in CCS approved NICU that were certified to participate in the NHSP were 91% in 2004 and 86.3% in 2003
- There were some regional variations in NICU screening rates, with Regions A and B reporting the lowest levels of screening (Region A: 2003 = 85.9%, 2004 = 87.9%; Region B: 2003 = 73.4%, 2004 = 86%, and Region D reporting the highest: 2003 = 99.3%, 2004 = 98%)
- Regional screening rates for WBN ranged from 96.4% to 98.1%

From the California Title V Application 2010

Percentage of all newborns screened for hearing before hospital discharge

	2004	2005	2006	2007
Annual Indicator	70	70	75	75
Annual Performance Objective	68.6	75.0	75.7	73.3

⁴ Prior to 2005 all newborns were screened for Phenylketonurea, Congenital hypothyroidism, galactosemia and sickle Cell disease. In 2005, congenital adrenal hyperplasia, and non-PKU inborn errors of metabolism tested by tandem mass spectrometry were added. In July 2007, cystic fibrosis and biotinidase deficiency were added.

⁵ Data are from the California Newborn Hearing Screening Program, 2003 and 2004 In CA, all newborns born at CCS-approved hospitals are required to be offered hearing screening and all infants in CCS-approved NICUs must be screened.

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

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



Children with Special Health Care Needs Organization of Services

MCHB Outcome #5: Community-based services for children and youth with special health care needs are organized so families can use them easily.

From the FHOP Survey of CCS Families 2010

Thinking about services your child needs, are those services organized in a way that makes them easy to use?

Answer Options	Response %	Total
Always	24%	73
Usually	41%	124
Sometimes	26%	79
Never	6%	18
Don't know/Not sure	4%	11
<i>answered question</i>		305

- When families were asked in thinking about services their child needs, if it would be easier for them and their child if CCS covered ALL of the medical and therapy services their child needs, instead of just the medical and therapy services that are related to your child's CCS-eligible condition, 26% (75) didn't know or were not sure. Of the 226 families with an opinion, 83% (187) said it would be easier

From the National Survey of CSHCN, 2005/2006ⁱ

Community-Based Service Systems Organized for Easy Use

	Yes
California %:	85.3*
Nationwide %:	89.1

Community-Based Service Systems Organized for Easy Use by Race

	Hispanic	White	Black	Multiracial	Other
California %:	78.5	90.5	78.8	89.5	82.5
Nationwide %:	84.1**	89.9	89.7	89.5	88.1

- In 2001, nationally, this outcome was more likely to be achieved for Whites (77.4%) than for Hispanics (66.4% and Blacks (65.3%), or other (59.2%). Numbers are not comparable between survey years.

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

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

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

From “Experiences with health care for California’s children with special health care needs”ⁱⁱ

- In general, parents of CSHCN in Medi-Cal reported more difficulty in navigating the system of services and obtaining the health care benefits needed by the child than did parents of CSHCN in other state Medicaid programs.

From the “Your Voice Counts!!” Surveyⁱⁱⁱ

- Most parents were dissatisfied with the lack of “family-centeredness” of their primary health plan. Parents were most dissatisfied with the lack of information or newsletters about issues of interest or resources outside of their plan. Many were dissatisfied with or did not know whether their plan offered parent support groups or gave parents an opportunity to give advice to the plan.

Care Coordination

From the LA CCS Survey 2005^{iv}

- Most parents who report needing care coordination in the past year say that they received all of the coordination they needed. About 13 percent of all parents (one-quarter of those needing coordination) did not receive all of the coordination needed. The most common reasons are that help was not offered to them (10 percent of all children in Los Angeles CCS), not knowing that coordination was available, a language or translation barrier, and being unable to find help with coordination.
- About two-thirds of parents report knowing the name of the child’s nurse case manager at Los Angeles CCS.
- Parents enthusiastically support several hypothetical improvements to the system of care for children in CCS. The largest proportion of parents endorse the ideas of (1) having a single care coordinator, chosen by the family, who would help coordinate all of the child’s services across programs and providers, and (2) providing more information and help to parents.

Coordination and consistency of care for children in foster care

From the UCLA Health Services Assessment for Children in Foster Care:^v

- Fewer than one third of agencies report that judges review a child’s health plan when making decisions about a child’s placement.

Consistency across Counties

From the FHOP Survey of CCS Families 2010

- 15% of family respondents who had moved from one California county to another during the time when their child was covered by CCS
 - 35% (15) reported that their were some services their child was eligible for in one county by not in the other
 - 65% (28) report being eligible for the same services

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010) and the FHOP Survey of Physicians

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

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

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

There may be small variations between counties in medical eligibility determinations, but this does **not** create significant problems.

	Hospitals, Health Plans, and CCS Program Survey						MDs Survey Total
	Total	CCS Admin/ Mg./ Med. Const.	MTP Admin/ mg.	Hospital admin/ mg/ staff	Health Plan admin/ mg/ staff	Other	
Agree Strongly	19.3% (26)	27.1% (16)	20.8% (5)	0.0% (0)	23.1% (3)	7.4% (2)	4.3% (5)
Agree Somewhat	26.7% (36)	25.4% (15)	37.5% (9)	16.7% (2)	7.7% (1)	33.3% (9)	22.2% (26)
Disagree Somewhat	28.9% (39)	33.9% (20)	25.0% (6)	33.3% (4)	0.0% (0)	33.3% (9)	30.8% (36)
Disagree Strongly	14.8% (20)	8.5% (5)	4.2% (1)	16.7% (2)	69.2% (9)	11.1% (3)	17.1% (20)
Don't know/ Not sure	10.4% (14)	5.1% (3)	12.5% (3)	33.3% (4)	0.0% (0)	14.8% (4)	25.6% (30)
	135	59	24	12	13	27	117

Care Coordination and Case Management from the Program Perspective

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010

Case Management and Case Loads

- **76.3% (74)** of respondents from CCS County Programs report their county uses standardized case management protocols.
- Responded from Counties were asked for the average size of the case load for CCS. The responses ranged from 50 to 4100. The average from 86 responses was 503 and the median was 400.

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010) and the FHOP Survey of Physicians

Who should be able to provide case management for children in CCS

	Hospitals/Health Plans/CCS Program	Physicians
RNs, PHNs, Medical Consultants, or Social Workers	93.8%	83.3%
Certified case managers	42.8%	81.7%
Specially trained but unlicensed staff	24.1%	21.7%

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

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

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

Where should case management happen

	Agree Strongly	Agree Somewhat	Disagree Somewhat	Disagree Strongly	Don't Know/ Not Sure
County CCS staff can do the best job at case management since they are familiar with local providers and other resources.	69.4% (100)	15.3% (22)	11.8% (17)	2.8% (4)	0.7% (1)
For the children receiving the majority of their care at Special Care Centers, it would be more effective and efficient to have the Special Care Centers do the case management and care coordination.	16.0% (23)	22.2% (32)	33.3% (48)	25.0% (36)	3.5% (5)

- Out of several options for improving case management, **41.4% (55)** of respondents said it would **not** be helpful to have counties hire and pay case managers but have them work at Special Care Centers.

Organization of Services

One system of care

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010 and the FHOP Survey of Physicians 2010

- **84.1% (117)** of Hospital/Health Plan/CCS Programs respondents and **75.2% (88)** of Physicians agreed it would be more efficient and effective to have one system of care for children with CCS-eligible conditions.

More efficient and effective to have one system caring for ALL of the health needs of children with CCS-eligible conditions, by type of respondent

	Hospitals, Health Plans, and CCS Program Survey						MDs Survey Total
	Total	CCS Admin/ Mg./ Med. Const.	MTP Admin/ mg.	Hospital admin/ mg/ staff	Health Plan admin/ mg/ staff	Other	
Agree Strongly	56.8% (79)	67.2% (41)	50.0% (12)	41.7% (5)	69.2% (9)	41.4% (12)	53.8% (63)
Agree Somewhat	27.3% (38)	21.3% (13)	37.5% (9)	33.3% (4)	15.4% (2)	34.5% (10)	21.4% (25)
Disagree Somewhat	8.6% (12)	4.9% (3)	4.2% (1)	16.7% (2)	15.4% (2)	13.8% (4)	7.7% (9)
Disagree Strongly	4.3% (6)	4.9% (3)	4.2% (1)	0.0% (0)	0.0% (0)	6.9% (2)	8.5% (10)
Don't know/ Not sure	2.9% (4)	1.6% (1)	4.2% (1)	8.3% (1)	0.0% (0)	3.4% (1)	8.5% (10)
	139	61	24	12	13	29	117

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

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

Experiences in a carved out system

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010

Case management and care coordination are more difficult where services are carved out (that is, care for the CCS-eligible conditions is not the responsibility of the health plan).

	Percent	Count
Agree Strongly	29.4%	40
Agree Somewhat	29.4%	40
Disagree Somewhat	20.6%	28
Disagree Strongly	9.6%	13
Don't know/ Not sure	11.0%	15

Continuity of care is harder when the CCS-eligible condition is carved out (that is, care for the CCS-eligible conditions is not the responsibility of the health plan).

	Percent	Count
Agree Strongly	27.0%	37
Agree Somewhat	25.5%	35
Disagree Somewhat	24.1%	33
Disagree Strongly	14.6%	20
Don't know/ Not sure	8.8%	12

When care for the CCS child is divided, with care for the CCS-eligible condition being the responsibility of CCS and the rest of the child's health care needs being covered by the child's health plan, it creates confusion about who is accountable for paying for services, CCS or the child's health plan.

	Percent	Count
Agree Strongly	48.5%	65
Agree Somewhat	31.3%	42
Disagree Somewhat	11.2%	15
Disagree Strongly	6.7%	9
Don't know/ Not sure	2.2%	3

When care for CCS-eligible conditions is carved out of health plans (that is, care for the CCS-eligible conditions is not the responsibility of the health plan), it creates the incentive for health plans to try and identify conditions as CCS-eligible so CCS will have to cover the cost of treatment.

	Percent	Count
Agree Strongly	56.7%	76
Agree Somewhat	24.6%	33
Disagree Somewhat	6.0%	8
Disagree Strongly	0.7%	1
Don't know/ Not sure	11.9%	16

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

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

Experiences in a Carved In System

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010

When care for CCS-eligible conditions is carved in to a child's health plan (that is, care for the CCS-eligible conditions is the responsibility of their health plan), payment is inadequate to cover the services provided

	Percent	Count
Agree Strongly	30.1%	40
Agree Somewhat	15.8%	21
Disagree Somewhat	6.0%	8
Disagree Strongly	4.5%	6
Don't know/ Not sure	43.6%	58

When care for CCS-eligible conditions is carved in to a child's health plan (that is, care for the CCS-eligible conditions is the responsibility of their health plan), children have difficulty getting access to the CCS approved specialty services the child needs.

	Percent	Count
Agree Strongly	26.3%	35
Agree Somewhat	19.5%	26
Disagree Somewhat	9.0%	12
Disagree Strongly	10.5%	14
Don't know/ Not sure	34.6%	46

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010 and the FHOP Survey of Physicians 2010

If CCS services were integrated into Medi-Cal managed care plans, the CCS program, CCS standards, and CCS guidelines and special care centers would be compromised.

	Hospitals/Health Plans /CCS Program Survey		Physician Survey	
	Percent	Count	Percent	Count
Agree Strongly	49.3%	66	41.0%	48
Agree Somewhat	15.7%	21	17.1%	20
Disagree Somewhat	11.9%	16	14.5%	17
Disagree Strongly	8.2%	11	4.3%	5
Don't know/ Not sure	14.9%	20	23.1%	27

Medical Eligibility

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010

It is a problem for providers that children with Healthy Families do not have retroactive eligibility for CCS conditions the way that children covered Medi-Cal do.

	Percent	Count
Agree Strongly	53.3%	72
Agree Somewhat	23.0%	31
Disagree Somewhat	1.5%	2
Disagree Strongly	1.5%	2
Don't know/ Not sure	20.7%	28

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

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

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010 and the FHOP Survey of Physicians 2010

Medical eligibility determinations should be made at a regional or statewide level instead of by Counties' CCS Medical Eligibility consultants.

	Hospitals/Health Plans /CCS Program Survey		Physician Survey	
	Percent	Count	Percent	Count
Agree Strongly	10.4%	14	29.1%	34
Agree Somewhat	13.3%	18	37.6%	44
Disagree Somewhat	17.8%	24	7.7%	9
Disagree Strongly	51.5%	69	7.7%	9
Don't know/ Not sure	7.4%	10	17.9%	21

Medically-Eligible Conditions

From the FHOP Survey of Physicians 2010

CCS should re-examine CCS eligibility criteria for NICU care.

	Percent	Count
Agree Strongly	24.3%	17
Agree Somewhat	25.7%	18
Disagree Somewhat	2.9%	2
Disagree Strongly	10.0%	7
Don't know/ Not sure	37.1%	26

NICU care for infants should only be covered by CCS if the infant has been diagnosed with a CCS-eligible condition, otherwise the cost of the NICU care should be covered by the child's health plan.

	Percent	Count
Agree Strongly	32.1%	25
Agree Somewhat	26.9%	21
Disagree Somewhat	6.4%	5
Disagree Strongly	11.5%	9
Don't know/ Not sure	23.1%	18

The State should re-examine medical eligibility for CCS to focus on longer term conditions that need intensive case management and care coordination.

	Percent	Count
Agree Strongly	41.5%	49
Agree Somewhat	36.4%	43
Disagree Somewhat	7.6%	9
Disagree Strongly	5.9%	7
Don't know/ Not sure	8.5%	10

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

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

Working with Special Care Centers

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010

CCS should panel nurse practitioners working at the special care centers under the guidance of a CCS- paneled physician.

	Percent	Count
Agree Strongly	37.0%	50
Agree Somewhat	38.5%	52
Disagree Somewhat	8.9%	12
Disagree Strongly	4.4%	6
Don't know/ Not sure	11.1%	15

CCS should work with primary care physicians and care coordinators to develop approaches (such as implementing enhanced medical homes) that could decrease ER visits and hospitalizations for CCS children.

	Percent	Count
Agree Strongly	57.9%	77
Agree Somewhat	34.6%	46
Disagree Somewhat	1.5%	2
Disagree Strongly	1.5%	2
Don't know/ Not sure	4.5%	6

From the FHOP Survey of Hospitals, Health Plans, and CCS Program 2010 and the FHOP Survey of Physicians 2010

Special Care Centers should hire primary care providers (physicians and nurse practitioners) to provider primary care services to CCS clients.

	Hospitals/Health Plans /CCS Program Survey		Physician Survey	
	Percent	Count	Percent	Count
Agree Strongly	17.0%	23	22.2%	26
Agree Somewhat	27.4%	37	36.8%	43
Disagree Somewhat	17.9%	24	12.0%	14
Disagree Strongly	17.0%	23	14.5%	17
Don't know/ Not sure	20.7%	28	14.5%	17

ⁱ Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved [04/08/10] from www.cshcndata.org

ⁱⁱ Inkelas M, Ahn P, Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

ⁱⁱⁱ Wells, N., Doksum, T., Martin, L., Cooper, J. (2000) *What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants*. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.

^{iv} Inkelas M, Samson K. Specialty Health Care for Children in the Los Angeles California Children's Services Program (CCS) Report. UCLA Center for Healthier Children, Families and Communities. 2005.

^v Halfon N, Inkelas M, Flint R, Shoaf K, Zepeda A, Franke T. 2002. Assessment of factors influencing the adequacy of health care services to children in foster care. UCLA Center for Healthier Children, Families and Communities.

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



Children with Special Health Care Needs Transition to Adulthood

MCHB Core Outcome #6: Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

From National Survey of CSHCN 2005/2006¹

In the NS CSHCN, the transition core outcome measure is assessed by determining “CSHCN ages 12-17 whose doctors usually/always encourage increasing responsibility for self-care AND (when needed) have discussed transitioning to adult health care, changing health care needs, and how to maintain insurance coverage.”

- 37.1% of youth in California and 41.2% of youth nationwide achieved this outcome (not a significant difference).

Transition services by race/ethnicity¹

	Hispanic	White	Black	Multiracial	Other
California %	29.6	44.1	19.2	53.3	17.7
Nationwide %	26.3	46.5**	28.7	41.8**	33.9

- Patterns for race/ethnic groups appear similar between CA and the US but in CA differences are not significant

Transition Planning

From the FHOP Survey of CCS Families 2010

- 35% (99) of participating CCS families report having a child 14 or older that is/was covered by CCS
- Of these 99 families,
 - 41% (41) report that their child's doctors has talked with them or their child about how (his/her) health care needs might change when (he/she) becomes an adult
 - 21 (21%) report having a plan for addressing these changing needs has been developed with your child's doctors or other health care providers
 - 27% (27) report that their child's doctors or other health care providers discussed having their child eventually see a doctor who treats adults
 - 19% (19) report that their child received any vocational or career training to help (him/her) prepare for a job when (he/she) becomes an adult
 - 26% (26) report that their child's CCS case manager has talked to them and their child about their child's transition to adult providers

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

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

Transition to Adult Systems of Care

From the FHOP Survey of Physicians 2010

How easy it is for youth/young adults who have aged out of CCS to find a new primary care provider when one is needed?

	Percent	Count
Very Easy	0.0%	0
Somewhat Easy	3.4%	3
Somewhat Hard	22.5%	20
Very Hard	62.9%	56
Don't Know/Not Sure	11.2%	10
		89

How easy it is for youth/young adults who have aged out of CCS to find a new primary care provider when one is needed?

	Percent	Count
Very Easy	0.0%	0
Somewhat Easy	3.4%	3
Somewhat Hard	21.3%	19
Very Hard	68.5%	61
Don't Know/Not Sure	6.7%	6
		89

From the LA CCS Survey 2005²

Experiences of youth ages 13-21

Already seeing a physician who treats adults	12%
Transition has been discussed but no plan in place	7%
Not yet seeing a physician who treats adults and not discussed this change	50%

- 22.7% of parents had discussed changing to physicians who treat adults with their child's physician(s), including adolescents and young adults with and without transition plans.

Self-Management of the Condition

From the LA CCS Survey 2005²

How often providers encourage young adult to take responsibility for own health care, according to parents of CCS enrollees age 13-21

Usually or always	71.8%
Never	13.9%

Percent of young adults always encouraged to take responsibility for self-management, by age

18-21 years old	69.8%
13-17 years old	53.5%

- These percentages exclude the 12.1% of parents of teens/young adults who said that taking more responsibility for self-managing the condition was not relevant for the child. Possible reasons include the parent's perception of the child's age-related capacity, the type of health condition and care involved, and/or cognitive limitations.

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

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

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

Number of CCS Clients Age 20 with Insurance

From CMS Net 2005

- Out of the CCS cases active as of 3/15/05, there were a total of 2746 clients 20 years of age. Within 52 CA counties, the percentages of these clients with insurance range from 1 to 100% with an average of 22% having insurance.

Transition from the Program/Provider Perspective

From the FHOP Survey of Hospitals, Health Plans, and County CCS Programs 2010

- 86.4% (114) of respondents said they or their organization has a discussion about transition with CCS clients and their families.
- 38.6% (51) of respondents said it is very hard and 33.3% (44) said is somewhat hard for youth who age out of CCS to find a new specialty care provider if one is needed.

Barriers to successful transition

From the FHOP Survey of Hospitals, Health Plans, and County CCS Programs 2010

- Respondents identified the following as “**major barriers**” to successful transition

Lack of access to appropriate health care providers	54.2%
Lack of training for adult providers in care for particular special care needs transitioning youth have	50.8%
Lack of case management and coordination of services once the client transitions out of CCS	50.0%
Burdensome procedures for access to insurance	46.5%

Ways to encourage physicians to take CCS clients who age out

From the FHOP Survey of Hospitals, Health Plans, and County CCS Programs 2010 and the FHOP Survey of Physicians 2010

The majority of respondents to BOTH surveys rated all of the suggestions to encourage doctors who care for adults to take CCS clients that have aged out of the CCS program as “**very helpful**”. These suggestions include:

- If these clients have the skills or supports they need to effectively manage their care
- If the adult providers were given a prepared medical summary of the patient
- If the adult provider had easy access to Regional Center, Special Care Center, school, CCS and pediatric records
- If the adult provider were offered training, funding, and resources to help you care for these patients
- If these clients have insurance that covers the cost of their care and coordination
- If there is someone the adult provider can go to for consultation

For respondents completing the physician survey, clients having insurance that covers the cost of the care and coordination was the most highly rated suggestion.

1. Child and Adolescent Health Measurement Initiative. 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved [04/08/10] from www.cshcnadata.org
2. Inkelas M, Samson K. Specialty Health Care for Children in the Los Angeles California Children’s Services Program (CCS) Report. UCLA Center for Healthier Children, Families and Communities. 2005.

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

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