



## Children with Special Health Care Needs Prevalence Information

### Prevalence of CSHCN Population

*From the National Survey of CSHCN 2005/2006<sup>i</sup>*

#### 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, 2005/2006<sup>i</sup>

	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 2005/2006<sup>i</sup>

	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”<sup>ii</sup>*

- 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 MediCal 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, 2005/2006<sup>i</sup>**

	0 - 99% FPL	100 - 199% FPL	200 - 399% FPL	400% FPL or greater
California %	7.1* <sup>^</sup>	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, 2005/2006<sup>i</sup>**

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, 2005/2006<sup>i</sup>**

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

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

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<sup>^</sup> 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 Survey<sup>iii</sup>

	Hispanic	White	Black
Los Angeles %	80.2	5.8	8.3

### Age of the CSHCN population

From the National Survey of CSHCN 2005/2006<sup>i</sup>

	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 Survey<sup>iii</sup>

	<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 2005/2006<sup>i</sup>

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 2005/2006<sup>i</sup>

	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<sup>iv</sup>:

- 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 2005/2006<sup>i</sup>

- 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

<b>CALIFORNIA</b>			
<b>Estimated cases for 529,245 total livebirths</b>			
	<b>Estimated Cases</b>	<b>Rate per 1000</b>	<b>Frequency</b>
<b>All Structural Birth Defects</b>	<b>16,038</b>	<b>30.3</b>	<b>1 in 33</b>
<b>Specific Conditions</b>			
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
<b>Infant deaths with birth defects</b>	<b>1588</b>	<b>~3.00</b>	<b>1 in 333</b>
<b>Mental retardation, school age</b>	<b>2646</b>	<b>5.00</b>	<b>1 in 200</b>
Source: Estimates use registry data and California birth totals			

[http://www.cbdmp.org/gd\\_california.htm](http://www.cbdmp.org/gd_california.htm)

<sup>i</sup> 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](http://www.cshcndata.org)

<sup>ii</sup> 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

<sup>iii</sup> 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.

<sup>iv</sup> 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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