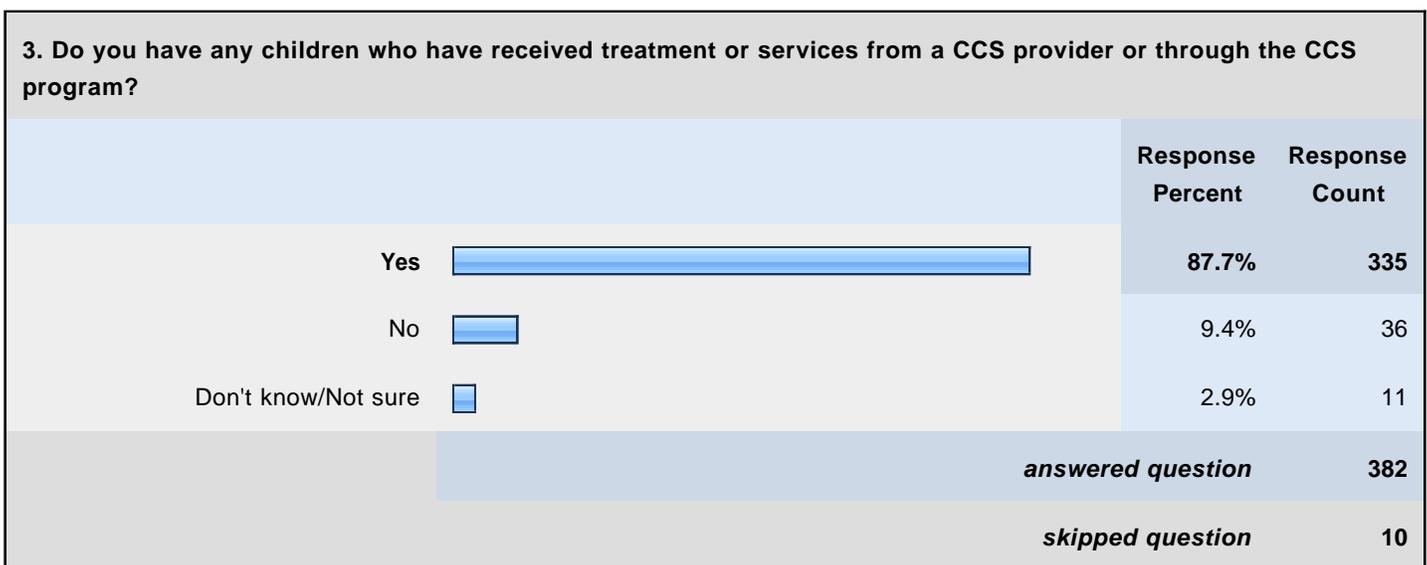
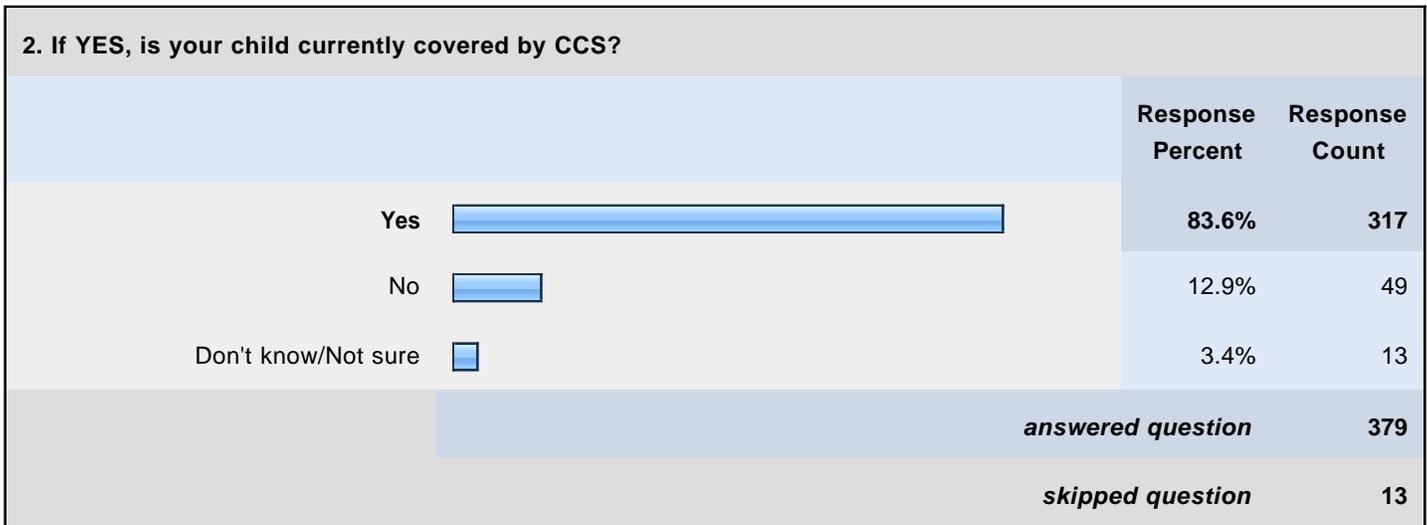
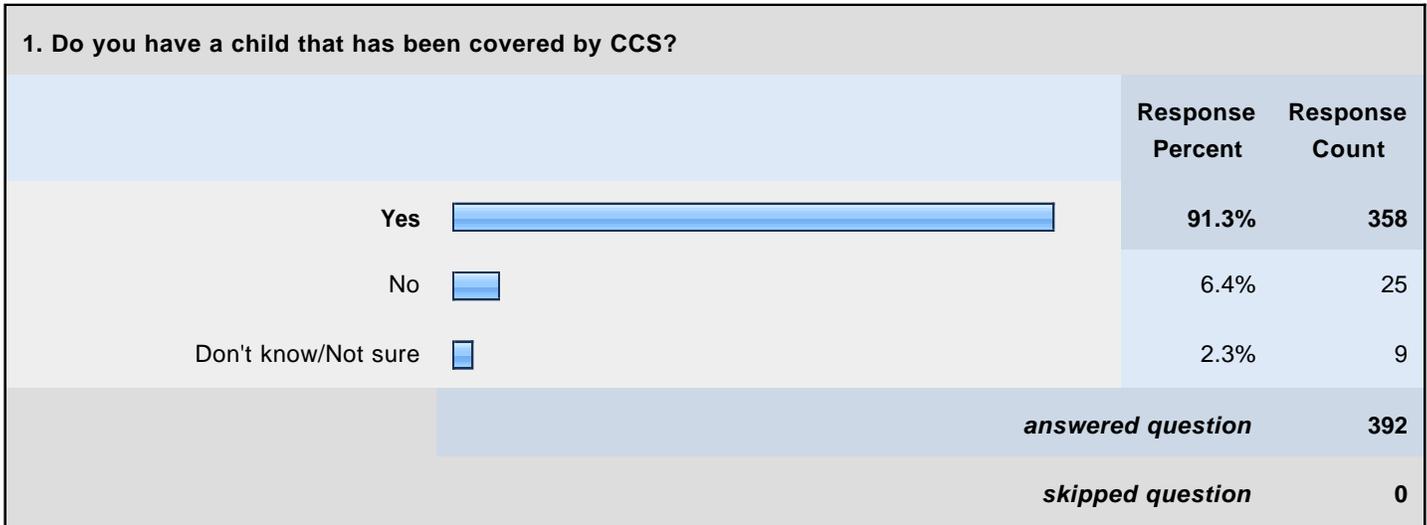
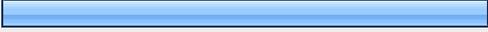
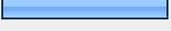
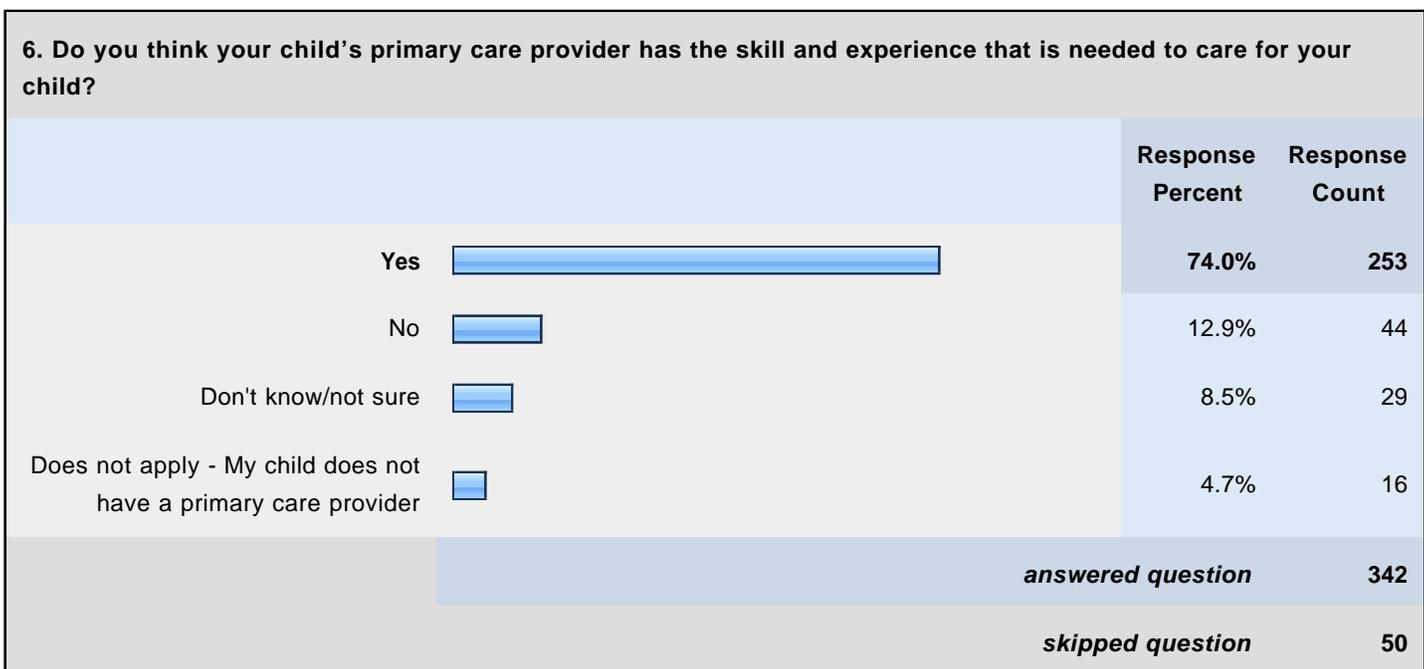
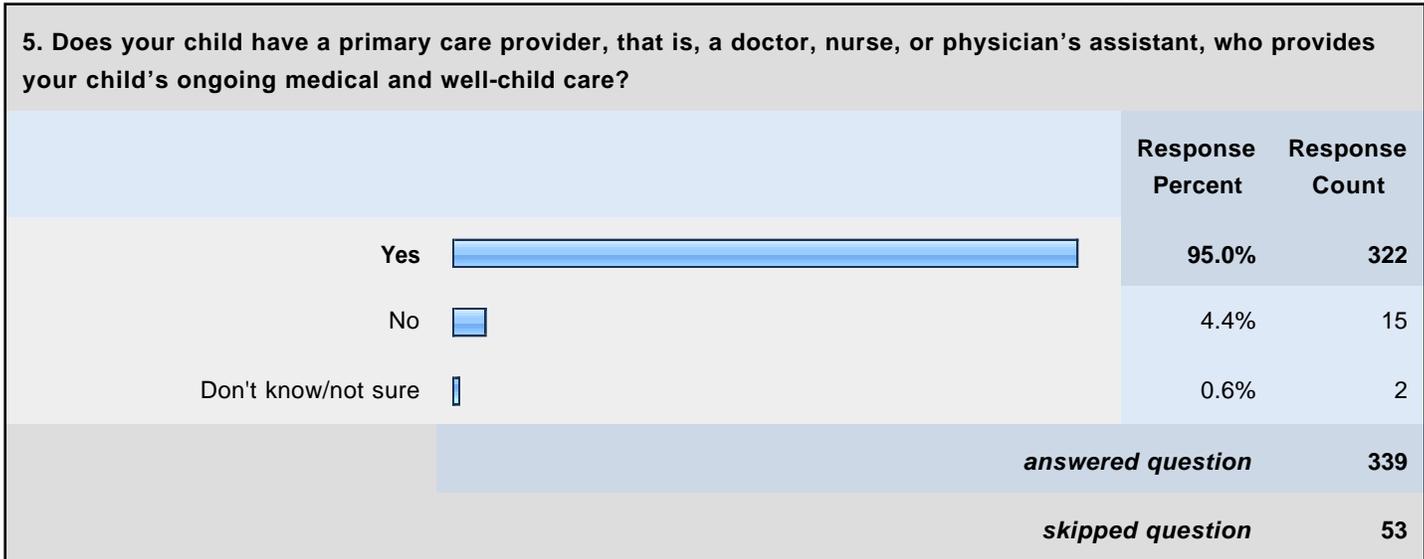


CCS Survey for Families

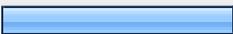


**4. What services for your child does the California Children Services (CCS) program pay for? Please check all that apply.**

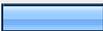
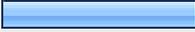
		Response Percent	Response Count
Therapy services, such as physical therapy (PT), occupational therapy (OT), or speech therapy		74.0%	270
Durable medical equipment, such as crutches, walkers, ventilators, communication devices, wheelchairs, braces, etc.		54.0%	197
Disposable medical supplies, such as gloves, swabs, diapers, etc.		21.6%	79
Inpatient hospital care		20.3%	74
Medical appointments		35.1%	128
Prescription medications		24.7%	90
Help in getting to medical appointments and therapy		8.8%	32
Home health care, such as nursing care, home health aid		5.2%	19
Hearing aids		6.8%	25
Don't know/Not sure		4.9%	18
Other		6.8%	25
	Other (please describe)		39
<b>answered question</b>			<b>365</b>
<b>skipped question</b>			<b>27</b>



7. What kind of doctor or other health care provider is most important to your child's care now? Check only one.

	Response Percent	Response Count
Primary care doctor (such as a pediatrician, or family medicine doctor) 	34.8%	118
<b>Specialist doctor</b> 	<b>59.6%</b>	<b>202</b>
Other health care provider 	4.4%	15
Don't know/Not sure 	1.2%	4
	<i>answered question</i>	<b>339</b>
	<i>skipped question</i>	<b>53</b>

**8. What kind of specialist or other health care provider is most important to your child now?**

	Response Percent	Response Count
Bone doctor (Orthopedist) 	14.9%	33
Allergy doctor (Allergist) 	1.4%	3
Heart doctor (Cardiologist) 	1.4%	3
Diabetes/hormone doctor (Endocrinologist) 	4.5%	10
Stomach/intestine doctor (Gastroenterologist) 	6.8%	15
Premature/sick baby doctor (Neonatologist)	0.0%	0
Kidney doctor (Nephrologist) 	2.7%	6
<b>Brain doctor (Neurologist)</b> 	<b>29.4%</b>	<b>65</b>
Nurse Practitioner 	0.5%	1
Cancer doctor (Oncologist) 	0.9%	2
Eye doctor (Ophthalmologist) 	0.9%	2
Teeth doctor (Orthodontist) 	0.5%	1
Physician Assistant	0.0%	0
Psychiatrist 	3.6%	8
Lung doctor (Pulmonologist) 	5.9%	13
Other 	26.7%	59
<b><i>answered question</i></b>		<b>221</b>
<b><i>skipped question</i></b>		<b>171</b>

<b>9. How well is this doctor or other health care provider who is most important to your child's care doing on...</b>							
	<b>Excellent</b>	<b>Good</b>	<b>Okay</b>	<b>Poor</b>	<b>Don't know/Not sure</b>	<b>Does not apply</b>	<b>Response Count</b>
a. Overall, providing quality care?	<b>56.8%</b> <b>(184)</b>	32.7% (106)	9.0% (29)	0.3% (1)	1.2% (4)	0.0% (0)	324
b. Explaining about my child's health needs in a way that I can understand?	<b>56.6%</b> <b>(184)</b>	33.2% (108)	8.0% (26)	1.2% (4)	0.6% (2)	0.3% (1)	325
c. Being easy to contact by phone?	<b>38.6%</b> <b>(125)</b>	30.9% (100)	18.5% (60)	8.0% (26)	3.1% (10)	0.9% (3)	324
d. Being available to give medical care or advice at night and on weekends?	<b>22.4%</b> <b>(72)</b>	18.9% (61)	18.0% (58)	14.0% (45)	14.9% (48)	11.8% (38)	322
e. Giving me reassurance and support?	<b>44.7%</b> <b>(144)</b>	26.1% (84)	18.6% (60)	6.5% (21)	1.9% (6)	2.2% (7)	322
f. Being easy to reach in an emergency ?	<b>30.7%</b> <b>(98)</b>	21.0% (67)	16.3% (52)	11.6% (37)	13.5% (43)	6.9% (22)	319
g. Including my family in decision making and Giving me updated information about medical research that might help my child?	<b>43.5%</b> <b>(141)</b>	25.0% (81)	14.8% (48)	9.6% (31)	3.4% (11)	3.7% (12)	324
h. Showing respect for my child?	<b>67.2%</b> <b>(217)</b>	23.8% (77)	6.8% (22)	1.2% (4)	0.3% (1)	0.6% (2)	323
i. Respecting our culture, ethnic identity, and religious beliefs?	<b>53.9%</b> <b>(174)</b>	26.0% (84)	5.0% (16)	1.2% (4)	3.1% (10)	10.8% (35)	323
j. Communicating with my child's other health care providers?	<b>43.3%</b> <b>(140)</b>	30.0% (97)	12.7% (41)	6.2% (20)	5.0% (16)	2.8% (9)	323
k. Communicating with my child's school or early intervention program?	24.1% (77)	19.7% (63)	9.7% (31)	10.9% (35)	10.6% (34)	<b>25.0%</b> <b>(80)</b>	320
l. Communicating with other systems that provide services to my child (not including school)?	<b>29.4%</b> <b>(94)</b>	25.0% (80)	10.9% (35)	10.9% (35)	10.3% (33)	13.4% (43)	320
m. Communicating with my child's health insurance plan staff?	<b>32.3%</b> <b>(103)</b>	22.6% (72)	10.3% (33)	6.9% (22)	13.8% (44)	14.1% (45)	319
<b>answered question</b>							<b>326</b>

10. A primary care provider is a doctor (for example a pediatrician or family practice doctor) nurse, or physician's assistant, who provides your child's ongoing medical and well-child care. In the last 12 months, did you have any problems getting medical care from *primary care providers* that your child needed?

	Response Percent	Response Count
My child did not need services from primary care providers 	9.0%	29
<b>My child needed services from primary care providers and we had no problems getting them</b> 	<b>74.4%</b>	<b>241</b>
My child needed services from primary care providers and we have had <b>some problems</b> getting them. 	13.6%	44
My child needed services from primary care providers and we have had <b>a lot of problems</b> getting them. 	3.1%	10
<i>answered question</i>		<b>324</b>
<i>skipped question</i>		<b>68</b>

11. If you had problems in the last 12 months getting services your child needed from primary care providers, please tell us about these problems. Check all that apply...

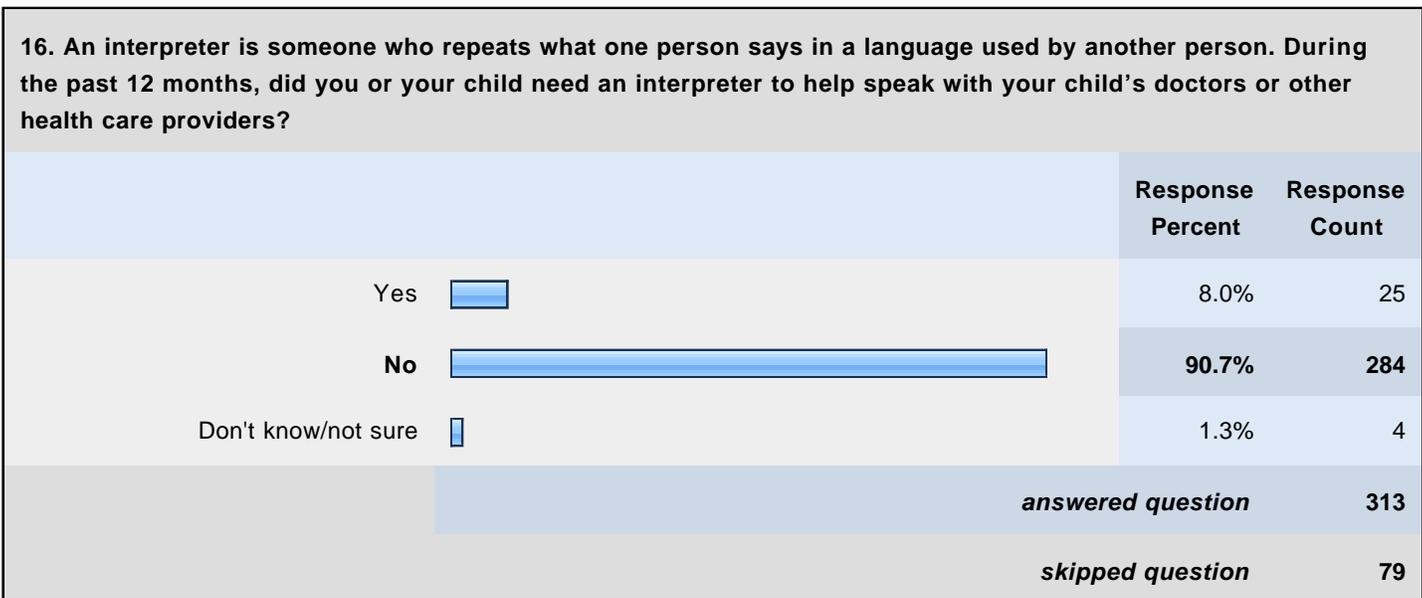
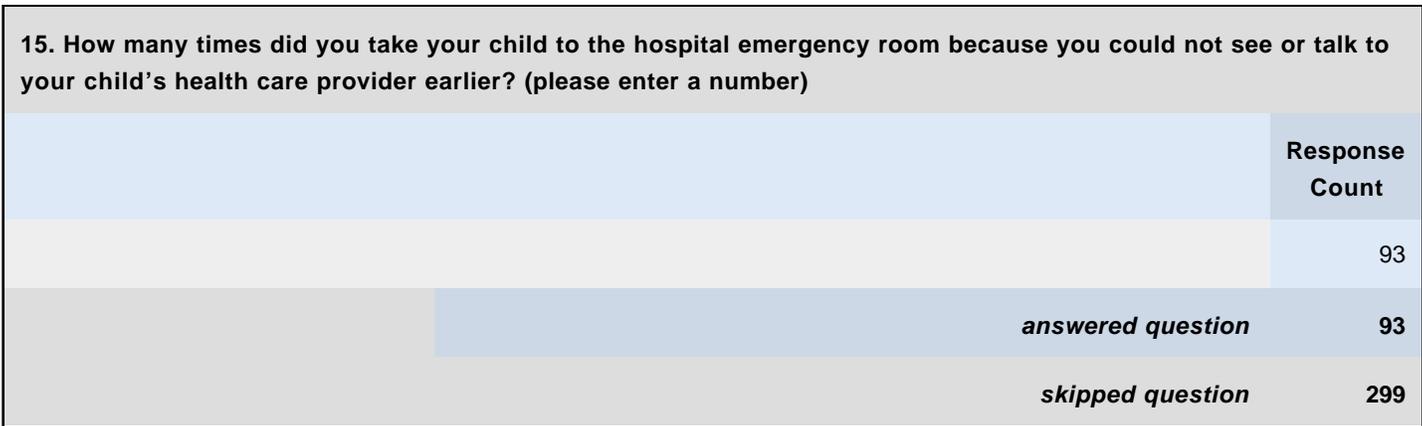
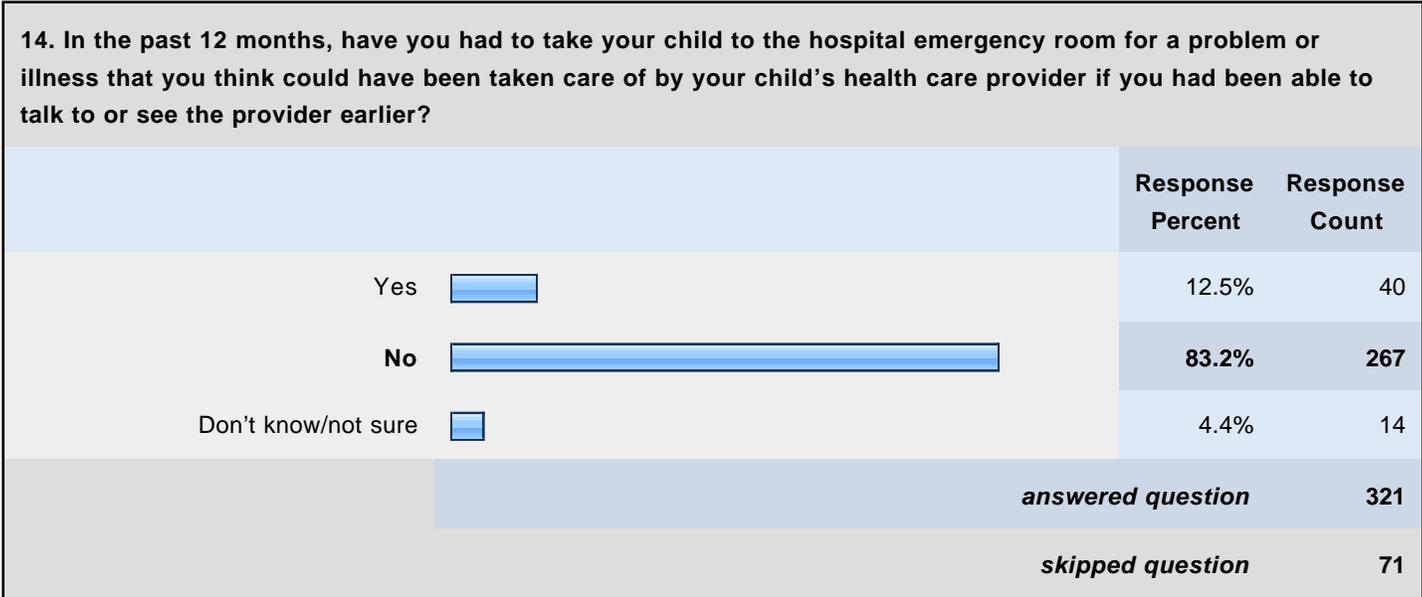
	Response Percent	Response Count
Getting appointments with primary care providers was a problem.	48.1%	26
Finding primary care providers with the <b>skill and experience</b> to care for my child was a problem.	33.3%	18
<b>Coordination</b> between my child's primary care providers and specialty doctors and other providers was a problem.	40.7%	22
The <b>amount we had to pay</b> for services from primary care providers was a problem.	7.4%	4
The <b>health insurance plan would not pay</b> for services from primary care medical providers	16.7%	9
My child needed but did not get services from primary care providers	13.0%	7
Other problems - describe below	33.3%	18
Does not apply - My child did not need services from primary care providers	0.0%	0
Does not apply - We had no problems accessing primary care providers.	7.4%	4
Other problems - please describe		22
<b>answered question</b>		<b>54</b>
<b>skipped question</b>		<b>338</b>

12. A specialty care provider is a doctor or nurse who gets extra training and becomes an expert in one part of the body or in one disease or condition (for example a cardiologist (heart doctor), an oncologist (cancer doctor), an orthopedist (a bone doctor), a neurologist (brain doctor). In the last 12 months, did you have any problems getting medical care from *specialty doctors* that your child needed?

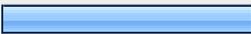
	Response Percent	Response Count
My child did not need services from specialty doctors 	8.8%	28
<b>My child needed services from specialty doctors and we had no problems getting them</b> 	<b>63.4%</b>	<b>201</b>
My child needed services from specialty doctors and we have had <b>some problems</b> getting them. 	19.6%	62
My child needed services from specialty doctors and we have had <b>a lot of problems</b> getting them. 	8.2%	26
	<i>answered question</i>	<b>317</b>
	<i>skipped question</i>	<b>75</b>

**13. If you had problems in the last 12 months getting services your child needed from specialty doctors, please tell us about these problems. Check all that apply...**

	Response Percent	Response Count
Getting <b>referrals</b> to get services from specialty doctors was a problem.	37.8%	34
<b>Getting appointments with specialty doctors was a problem.</b>	<b>64.4%</b>	<b>58</b>
Finding specialty doctors with the <b>skill and experience</b> to care for my child was a problem.	27.8%	25
Getting the <b>number of visits</b> from specialty doctors to meet my child's needs was a problem	17.8%	16
<b>Coordination</b> between my child's specialty doctors and other providers was a problem.	36.7%	33
The <b>amount we had to pay</b> for services from specialty doctors was a problem.	11.1%	10
The <b>health insurance plan would not pay</b> for services from specialty doctors	24.4%	22
My child needed but did not get services from specialty doctors	13.3%	12
Other problems - describe below	15.6%	14
Does not apply - My child did not need services from specialty doctors	0.0%	0
Does not apply - We had no problems getting services from specialty doctors.	1.1%	1
	Other problems - please describe	22
<b>answered question</b>		<b>90</b>
<b>skipped question</b>		<b>302</b>



**17. When you or your child needed an interpreter, how often were you able to get someone other than a family member to help you speak with your child's doctors or other health care providers?**

	Response Percent	Response Count
Never 	13.8%	4
Sometimes 	31.0%	9
Usually 	10.3%	3
<b>Always</b> 	<b>37.9%</b>	<b>11</b>
Don't know/Not Sure 	6.9%	2
<b>answered question</b>		<b>29</b>
<b>skipped question</b>		<b>363</b>

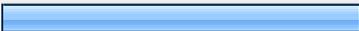
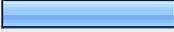
**18. During the past 12 months, how often did your child's doctors or other health care providers help you feel like a partner in your child's care? Would you say never, sometimes, usually, or always?**

	Response Percent	Response Count
Never	0.0%	0
Sometimes 	26.7%	8
Usually 	26.7%	8
<b>Always</b> 	<b>43.3%</b>	<b>13</b>
Don't know/Not Sure 	3.3%	1
<b>answered question</b>		<b>30</b>
<b>skipped question</b>		<b>362</b>

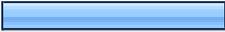
19. In the past 12 months, did you child need...?						
	<u>Yes</u> , we got the service and were satisfied	<u>Yes</u> , we got the service and were <b>NOT</b> satisfied	<u>Yes</u> , but we did <b>NOT</b> GET the service	<u>No</u> , my child did not need the service	Don't know/Not sure	Response Count
Dental care	<b>60.8% (183)</b>	5.3% (16)	12.6% (38)	18.3% (55)	3.0% (9)	301
Disposable medical supplies – Such as catheters, swabs, diapers, syringes, etc.	41.1% (122)	3.7% (11)	6.4% (19)	<b>45.5% (135)</b>	3.4% (10)	297
Durable medical equipment and medical technology – such as hearing aids, wheelchairs, ventilators, etc.	<b>54.9% (167)</b>	9.5% (29)	3.9% (12)	28.6% (87)	3.0% (9)	304
In home support services (IHSS)	34.7% (102)	2.7% (8)	10.5% (31)	<b>45.9% (135)</b>	6.1% (18)	294
Respite care	31.2% (92)	8.5% (25)	11.5% (34)	<b>40.3% (119)</b>	8.5% (25)	295
<i>answered question</i>						<b>306</b>
<i>skipped question</i>						<b>86</b>

20. During the past 24 months, were there any delays in your child getting all the medical supplies (for example catheters, swabs, diapers, syringes, etc.), that {he/she} needed?			Response Percent	Response Count
Yes			19.6%	60
<b>No</b>			<b>42.2%</b>	<b>129</b>
Don't know/Not sure			2.3%	7
Does not apply - My child did not need medical supplies			35.9%	110
<i>answered question</i>				<b>306</b>
<i>skipped question</i>				<b>86</b>

**21. Has your child ever had to wait to get out of the hospital because of problems getting medical equipment?**

	Response Percent	Response Count
Yes 	7.2%	22
<b>No</b> 	<b>54.4%</b>	<b>167</b>
Don't know/Not sure 	1.6%	5
Does not apply - My child did not need medical equipment when he/she got out of the hospital 	10.7%	33
Does not apply – My child has not been in the hospital. 	26.1%	80
<b>answered question</b>		<b>307</b>
<b>skipped question</b>		<b>85</b>

**22. During the past 24 months, were there any delays in your child getting mobility aids or devices, such as canes, crutches, wheelchairs, or scooters?**

	Response Percent	Response Count
Yes 	27.3%	84
<b>No</b> 	<b>37.7%</b>	<b>116</b>
Don't know/Not sure 	1.3%	4
Does not apply – my child did not receive mobility aids or devices 	33.8%	104
<b>answered question</b>		<b>308</b>
<b>skipped question</b>		<b>84</b>

**23. If your child had delays in getting mobility aids or devices, such as canes, crutches, wheelchairs, or scooters, were the items still the correct size when they arrived?**

	Response Percent	Response Count
Yes	32.0%	93
No	14.8%	43
Don't know/Not sure	2.7%	8
<b>Does not apply – my child did not receive mobility aids or devices</b>	<b>50.5%</b>	<b>147</b>
<i>answered question</i>		<b>291</b>
<i>skipped question</i>		<b>101</b>

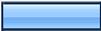
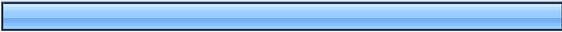
**24. Thinking about services your child needs, are those services organized in a way that makes them easy to use?**

	Response Percent	Response Count
Always	24.3%	74
<b>Usually</b>	<b>40.7%</b>	<b>124</b>
Sometimes	25.6%	78
Never	5.9%	18
Don't know/Not sure	3.6%	11
<i>answered question</i>		<b>305</b>
<i>skipped question</i>		<b>87</b>

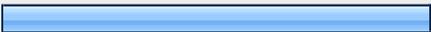
**25. Thinking about services your child needs, would it be easier for you and your child if CCS covered ALL of the medical and therapy services your child needs, instead of just the medical and therapy services that are related to your child's CCS-eligible condition?**

	Response Percent	Response Count
Yes 	60.8%	186
No 	13.1%	40
Don't know/Not sure 	26.1%	80
<b>answered question</b>		<b>306</b>
<b>skipped question</b>		<b>86</b>

**26. During the time your child was covered by CCS, did you ever move from one county to another county in California?**

	Response Percent	Response Count
Yes 	14.8%	45
No 	85.2%	260
<b>answered question</b>		<b>305</b>
<b>skipped question</b>		<b>87</b>

**27. Which best describes your experience with CCS services in different California counties?**

	Response Percent	Response Count
<b>My child was eligible to get the same services in both counties.</b> 	65.1%	28
There were some services my child was eligible for in one county but not the other county. 	34.9%	15
<b>answered question</b>		<b>43</b>
<b>skipped question</b>		<b>349</b>

**28. If your child was NOT eligible for certain services after moving to a new county, did your child ever receive those services?**

	Response Percent	Response Count
YES – CCS paid for them	16.7%	7
YES – But I had to pay for them myself	9.5%	4
YES – But someone else paid	9.5%	4
NO – my child never got the services	9.5%	4
<b>Does not apply - my child was eligible to get the same services in both counties</b>	<b>54.8%</b>	<b>23</b>
<i>answered question</i>		<b>42</b>
<i>skipped question</i>		<b>350</b>

**29. Who provides case management for your child?**

	Response Percent	Response Count
Private health insurance plan	13.6%	41
<b>California Children Services (CCS)</b>	<b>44.9%</b>	<b>135</b>
Specialty Care Center or Hospital	4.7%	14
Other state agency	15.3%	46
Other (specify on next page)	15.3%	46
Don't know/Not sure	10.0%	30
My child does not get case management	19.3%	58
<i>answered question</i>		<b>301</b>
<i>skipped question</i>		<b>91</b>

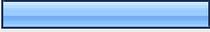
30. Who provides case management for your child - for other, please identify:		Response Count
		264
	<i>answered question</i>	264
	<i>skipped question</i>	128

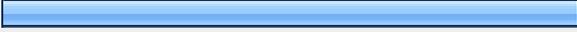
31. Does your child have a <u>CCS</u> case manager?		Response Percent	Response Count
Yes		64.7%	152
No		14.0%	33
Don't know/Not sure		21.3%	50
	<i>answered question</i>		235
	<i>skipped question</i>		157

32. If yes, please tell us how helpful is your child's CCS case manager is. Would you say the CCS case manger is...		Response Percent	Response Count
Very helpful		38.9%	79
Helpful		19.7%	40
Only a little helpful		12.3%	25
Not at all helpful		8.4%	17
My child does not have a CCS case manager		20.7%	42
	<i>answered question</i>		203
	<i>skipped question</i>		189

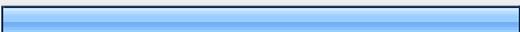
**33. We would like to know about what kinds case management services you get for your child and who provides them. Please put a check in the boxes to show what service you get from which program.**

	Private Health Insurance Plan	CCS	Special Care Center or Hospital	Medi-Cal Managed Care	Other	Response Count
Helps coordinate your child's care among the different providers and services that help your child	17.4% (34)	<b>50.8% (99)</b>	7.7% (15)	17.4% (34)	34.4% (67)	195
Helps you understand your child's health insurance plan benefits	30.1% (55)	<b>35.0% (64)</b>	6.0% (11)	18.6% (34)	24.0% (44)	183
Helps you to identify and use other community based programs or services for which your child may be eligible (for example, Early Start or Regional Center programs, special education, summer camps, after school programs, etc.)	6.1% (11)	42.5% (76)	10.6% (19)	7.8% (14)	<b>46.9% (84)</b>	179
Helps you to get other public programs such as SSI for your child?	4.4% (7)	24.5% (39)	8.2% (13)	10.1% (16)	<b>57.9% (92)</b>	159
Helps you to find other ways to pay for needed services and equipment	3.1% (5)	47.5% (76)	3.8% (6)	10.6% (17)	<b>48.1% (77)</b>	160
Provides a case manager that has a good understanding of my child's health care needs and services.	5.0% (8)	<b>50.9% (82)</b>	5.6% (9)	7.5% (12)	46.6% (75)	161
					Other (please specify)	90
<b>answered question</b>						<b>213</b>
<b>skipped question</b>						<b>179</b>

34. Overall, how satisfied are you with the help you have received in coordinating your child's care?			Response Percent	Response Count
Very satisfied			34.4%	100
Somewhat satisfied			31.3%	91
Somewhat dissatisfied			17.9%	52
Very dissatisfied			10.0%	29
Don't know/Not sure			6.5%	19
<i>answered question</i>				<b>291</b>
<i>skipped question</i>				<b>101</b>

35. How important is it to have ONE person who knows your child and can help you understand what your child needs and connect your child to the services he/she needs?			Response Percent	Response Count
Very important			87.7%	257
Somewhat important			8.5%	25
Only a little important			0.7%	2
Not important at all			0.7%	2
Don't know/Not sure			2.4%	7
<i>answered question</i>				<b>293</b>
<i>skipped question</i>				<b>99</b>

**36. In the last 12 months, has your child received any medical therapy - such as physical therapy (PT), occupational therapy (OT), or speech therapy?**

	Response Percent	Response Count
Yes 	78.8%	231
No 	20.8%	61
Don't know/Not sure 	0.3%	1
<b><i>answered question</i></b>		<b>293</b>
<b><i>skipped question</i></b>		<b>99</b>

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

	Yes	No	Don't know/not sure	Response Count
a. My child needed this therapy. [If NO, please go to question #38]	<b>91.0% (192)</b>	8.5% (18)	0.5% (1)	211
b. My child received this therapy.	<b>84.4% (162)</b>	15.6% (30)	0.0% (0)	192
c. My child needed but did not get this therapy.	26.5% (43)	<b>72.2% (117)</b>	1.2% (2)	162
d. I was satisfied with the therapy my child received.	<b>65.4% (123)</b>	28.2% (53)	6.4% (12)	188
e. Having therapy available at my child's school was helpful.	<b>57.6% (91)</b>	14.6% (23)	27.8% (44)	158
f. Having therapy appointment times from 7:00 AM to 6:30 PM was helpful.	<b>82.8% (144)</b>	5.2% (9)	12.1% (21)	174
g. Getting a referral for this therapy was a problem.	18.1% (31)	<b>77.2% (132)</b>	4.7% (8)	171
h. Getting an appointment was a problem.	16.4% (29)	<b>79.1% (140)</b>	4.5% (8)	177
i. Getting dropped from the therapy schedule because we missed too many appointments was a problem.	3.0% (5)	<b>86.1% (143)</b>	10.8% (18)	166
j. Finding a therapist with the skill and experience to care for my child was a problem.	23.4% (41)	<b>71.4% (125)</b>	5.1% (9)	175
k. It was a problem getting the number of visits my child needed.	42.4% (75)	<b>54.2% (96)</b>	3.4% (6)	177
l. It was problem getting transportation to the therapy appointment.	17.0% (29)	<b>78.9% (135)</b>	4.1% (7)	171
m. Coordination between my child's therapist and other providers was a problem.	18.6% (32)	<b>75.0% (129)</b>	6.4% (11)	172
n. The amount we had to pay was a problem.	7.1% (12)	<b>86.4% (146)</b>	6.5% (11)	169

## Responses to FHOP Survey of CCS Families

o. My child's health care coverage would not pay.	17.0% (28)	<b>66.1% (109)</b>	17.0% (28)	165
p. Other problems (Please explain below)	30.9% (30)	<b>59.8% (58)</b>	9.3% (9)	97
			Other problems - please explain	51
			<b>answered question</b>	<b>216</b>
			<b>skipped question</b>	<b>176</b>

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

	Yes	No	Don't know/not sure	Response Count
a. My child needed this therapy. [If NO, please go question #39]	<b>86.2% (175)</b>	11.8% (24)	2.0% (4)	203
b. My child received this therapy.	<b>87.4% (160)</b>	9.8% (18)	2.7% (5)	183
c. My child needed but did not get this therapy.	17.1% (27)	<b>79.7% (126)</b>	3.2% (5)	158
d. I was satisfied with the therapy my child received.	<b>70.6% (125)</b>	23.7% (42)	5.6% (10)	177
e. Having therapy available at my child's school was helpful.	<b>63.8% (95)</b>	10.7% (16)	25.5% (38)	149
f. Having therapy appointment times from 7:00 AM to 6:30 PM was helpful.	<b>76.5% (127)</b>	10.8% (18)	12.7% (21)	166
g. Getting a referral for this therapy was a problem.	11.2% (18)	<b>84.5% (136)</b>	4.3% (7)	161
h. Getting an appointment was a problem.	13.8% (23)	<b>82.0% (137)</b>	4.2% (7)	167
i. Getting dropped from the therapy schedule because we missed too many appointments was a problem.	2.5% (4)	<b>89.8% (141)</b>	7.6% (12)	157
j. Finding a therapist with the skill and experience to care for my child was a problem.	21.2% (35)	<b>73.9% (122)</b>	4.8% (8)	165
k. It was a problem getting the number of visits my child needed.	31.8% (54)	<b>64.7% (110)</b>	3.5% (6)	170

Appendix 25  
Responses to FHOP Survey of CCS Families

l. It was problem getting transportation to the therapy appointment.	13.0% (21)	<b>83.3% (135)</b>	3.7% (6)	162
m. Coordination between my child's therapist and other providers was a problem.	15.2% (25)	<b>77.6% (128)</b>	7.3% (12)	165
n. The amount we had to pay was a problem.	6.2% (10)	<b>87.6% (141)</b>	6.2% (10)	161
o. My child's health care coverage would not pay.	16.7% (26)	<b>69.2% (108)</b>	14.1% (22)	156
p. Other problems (Please explain below)	26.4% (24)	<b>62.6% (57)</b>	11.0% (10)	91
			Other problems - please explain	38
			<b><i>answered question</i></b>	<b>212</b>
			<b><i>skipped question</i></b>	<b>180</b>

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

	Yes	No	Don't know/not sure	Response Count
a. My child needed this therapy. [If NO, please go question #40 - on the next page]	<b>57.9% (110)</b>	38.4% (73)	3.7% (7)	190
b. My child received this therapy.	<b>68.6% (81)</b>	23.7% (28)	7.6% (9)	118
c. My child needed but did not get this therapy.	31.1% (32)	<b>60.2% (62)</b>	8.7% (9)	103
d. I was satisfied with the therapy my child received.	<b>50.0% (53)</b>	41.5% (44)	8.5% (9)	106
e. Having therapy available at my child's school was helpful.	<b>64.7% (66)</b>	16.7% (17)	18.6% (19)	102
f. Having therapy appointment times from 7:00 AM to 6:30 PM was helpful.	<b>52.7% (48)</b>	19.8% (18)	27.5% (25)	91
g. Getting a referral for this therapy was a problem.	26.5% (26)	<b>57.1% (56)</b>	16.3% (16)	98
h. Getting an appointment was a problem.	21.4% (21)	<b>61.2% (60)</b>	17.3% (17)	98
i. Getting dropped from the therapy schedule because we missed too many appointments was a problem.	4.3% (4)	<b>79.6% (74)</b>	16.1% (15)	93
j. Finding a therapist with the skill and experience to care for my child was a problem.	38.8% (38)	<b>48.0% (47)</b>	13.3% (13)	98
k. It was a problem getting the number of visits my child needed.	40.2% (39)	<b>46.4% (45)</b>	13.4% (13)	97
l. It was problem getting transportation to the therapy appointment.	10.8% (10)	<b>74.2% (69)</b>	15.1% (14)	93
m. Coordination between my child's therapist and other providers was a problem.	18.9% (18)	<b>64.2% (61)</b>	16.8% (16)	95
n. The amount we had to pay was a problem.	14.1% (13)	<b>71.7% (66)</b>	14.1% (13)	92

Responses to FHOP Survey of CCS Families

o. My child's health care coverage would not pay.	25.8% (24)	<b>55.9% (52)</b>	18.3% (17)	93
p. Other problems (Please explain below)	38.6% (22)	<b>43.9% (25)</b>	17.5% (10)	57
			Other problems - please explain	51
<b>answered question</b>				<b>195</b>
<b>skipped question</b>				<b>197</b>

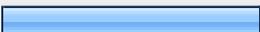
**40. Have you attended a family support group to help you and your family to cope with your child's health condition?**

	Response Percent	Response Count
Yes 	32.5%	95
No 	65.4%	191
Don't know/not sure 	2.1%	6
<b>answered question</b>		<b>292</b>
<b>skipped question</b>		<b>100</b>

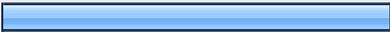
**41. If YES, how often do you attend family support group meetings?**

	Response Count	
	93	
<b>answered question</b>		<b>93</b>
<b>skipped question</b>		<b>299</b>

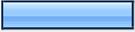
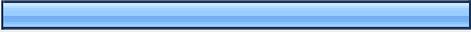
**42. If NO, would you be interested in attending a family support group to help you and your family to deal with issues related your child's health condition?**

	Response Percent	Response Count
Yes 	39.1%	93
No 	38.7%	92
Don't know/Not sure 	22.3%	53
<b>answered question</b>		<b>238</b>
<b>skipped question</b>		<b>154</b>

**43. Has anyone from the CCS program told you that they can help you find emotional support, community resources, and family/individual counseling for your child and your family?**

	Response Percent	Response Count
Yes 	29.3%	85
No 	59.0%	171
Don't know/Not sure 	11.7%	34
<b>answered question</b>		<b>290</b>
<b>skipped question</b>		<b>102</b>

**44. Has anyone from the CCS program referred you to any family to family support services?**

	Response Percent	Response Count
Yes 	19.5%	56
No 	71.1%	204
Don't know/Not sure 	9.4%	27
<b>answered question</b>		<b>287</b>
<b>skipped question</b>		<b>105</b>

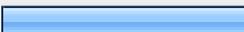
**45. What kind of health coverage does your child have? Please check all that apply**

	Response Percent	Response Count
<b>CCS</b>	<b>70.2%</b>	<b>203</b>
Medi-Cal Managed Care	41.9%	121
Medi-Cal Fee-For-Service	15.6%	45
Healthy Families	8.7%	25
Private health insurance offered through work or that I buy for my child/family	47.8%	138
Other (describe below)	9.3%	27
Don't know/Not sure	0.7%	2
Other type - please describe		43
<b>answered question</b>		<b>289</b>
<b>skipped question</b>		<b>103</b>

**46. If your child is covered by private insurance AND CCS, does also having private insurance make it easier or harder to get the care your child needs?**

	Response Percent	Response Count
Having private insurance in addition to CCS makes it EASIER to get the care my child needs	28.7%	77
Having private insurance in addition to CCS makes it HARDER to get the care my child needs	13.4%	36
Don't know/Not sure	19.8%	53
<b>My child does not have private insurance</b>	<b>38.1%</b>	<b>102</b>
<b>answered question</b>		<b>268</b>
<b>skipped question</b>		<b>124</b>

**47. Have you had problems getting the care your child needs because of the type of insurance that covers your child?**

	Response Percent	Response Count
Yes (specify below) 	37.1%	104
<b>No</b> 	<b>55.0%</b>	<b>154</b>
Don't know/Not sure 	7.9%	22
If Yes, Which type(s) of insurance causes the problems?		92
<i>answered question</i>		<b>280</b>
<i>skipped question</i>		<b>112</b>

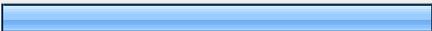
**48. Have you had problems getting the care your child needs because of a lack of insurance coverage?**

	Response Percent	Response Count
Yes 	21.6%	62
<b>No</b> 	<b>73.5%</b>	<b>211</b>
Don't know/Not sure 	4.9%	14
<i>answered question</i>		<b>287</b>
<i>skipped question</i>		<b>105</b>

**49. Have you had problems getting the care your child needs because of changes in insurance?**

	Response Percent	Response Count
Yes 	20.6%	59
<b>No</b> 	<b>74.9%</b>	<b>215</b>
Don't know/Not sure 	4.5%	13
<i>answered question</i>		<b>287</b>
<i>skipped question</i>		<b>105</b>

**50. My child is 14 years old or older.**

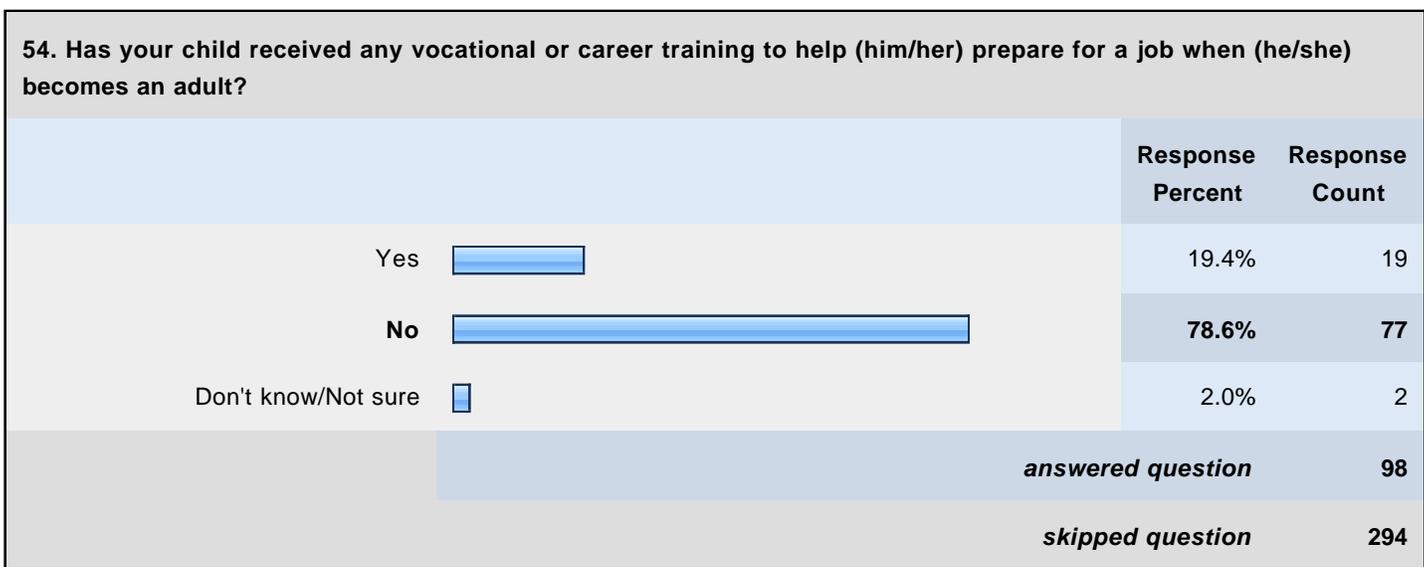
	Response Percent	Response Count
Yes 	34.6%	98
No 	65.4%	185
<i>answered question</i>		283
<i>skipped question</i>		109

**51. Have your child's doctors or other health care providers talked with you or your child about how (his/her) health care needs might change when (he/she) becomes an adult?**

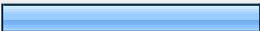
	Response Percent	Response Count
Yes 	41.8%	41
No 	58.2%	57
Don't know/Not sure	0.0%	0
<i>answered question</i>		98
<i>skipped question</i>		294

**52. Has a plan for addressing these changing needs been developed with your child's doctors or other health care providers?**

	Response Percent	Response Count
Yes 	21.6%	21
No 	75.3%	73
Don't know/Not sure 	3.1%	3
<i>answered question</i>		97
<i>skipped question</i>		295



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

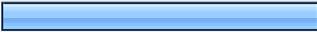
	Response Percent	Response Count
Very satisfied 	44.1%	127
Somewhat satisfied 	38.9%	112
Somewhat dissatisfied 	10.8%	31
Very dissatisfied 	4.9%	14
Don't know/Not sure 	1.4%	4
<i>answered question</i>		<b>288</b>
<i>skipped question</i>		<b>104</b>

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

	Response Percent	Response Count
Very satisfied 	42.5%	122
Somewhat satisfied 	23.7%	68
Somewhat dissatisfied 	9.4%	27
Very dissatisfied 	4.9%	14
Don't know/Not sure 	4.5%	13
Does Not Apply – my child does not use the MTU 	15.0%	43
<i>answered question</i>		<b>287</b>
<i>skipped question</i>		<b>105</b>

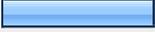
**58. If you have any other comments about your experience with the CCS program, please share them here:**

	Response Count
	131
<i>answered question</i>	<b>131</b>
<i>skipped question</i>	<b>261</b>

59. How would you describe the community where you live?			Response Percent	Response Count
City or urban			48.1%	137
Suburban			32.3%	92
Farming or rural			17.5%	50
Other			2.1%	6
		If Other - please describe		6
<b>answered question</b>				<b>285</b>
<b>skipped question</b>				<b>107</b>

60. What is the name of the county where you live? (please select from the list)

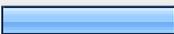
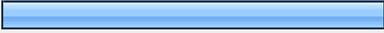
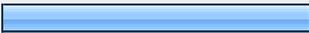
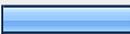
	Response Percent	Response Count
Alameda 	7.9%	22
Alpine	0.0%	0
Amador	0.0%	0
Butte 	1.8%	5
Calaveras	0.0%	0
Colusa 	1.4%	4
Contra Costa 	1.8%	5
Del Norte	0.0%	0
El Dorado 	0.4%	1
Fresno 	1.1%	3
Glenn	0.0%	0
Humboldt 	3.2%	9
Imperial 	0.4%	1
Inyo 	2.9%	8
Kern	0.0%	0
Kings	0.0%	0
Lake	0.0%	0
Lassen	0.0%	0
Los Angeles 	6.4%	18
Madera	0.0%	0
Marin 	1.8%	5
Mariposa	0.0%	0
Mendocino	0.0%	0
Merced 	0.4%	1
None	0.0%	0

Mono		0.0%	0
Monterey		0.0%	0
Napa		0.0%	0
Nevada		0.0%	0
Orange		3.9%	11
Placer		2.5%	7
Plumas		0.4%	1
<b>Riverside</b>		<b>22.9%</b>	<b>64</b>
Sacramento		4.6%	13
San Benito		0.4%	1
San Bernardino		1.8%	5
San Diego		1.8%	5
San Francisco		5.0%	14
San Joaquin		1.4%	4
San Luis Obispo		1.4%	4
San Mateo		8.2%	23
Santa Barbara		1.4%	4
Santa Clara		5.0%	14
Santa Cruz		0.0%	0
Shasta		2.9%	8
Sierra		0.0%	0
Siskiyou		0.4%	1
Solano		0.4%	1
Sonoma		0.4%	1
Stanislaus		1.4%	4
Sutter		0.4%	1
Tehama		0.0%	0
Title V CCS Needs Assessment 2010 Family Health Outcomes Project		0.0%	0

Appendix 25  
 Responses to FHOP Survey of CCS Families

Tulare	<input type="checkbox"/>	1.8%	5
Tuolumne	<input type="checkbox"/>	1.1%	3
Ventura		0.0%	0
Yolo	<input type="checkbox"/>	1.4%	4
Yuba		0.0%	0
<b><i>answered question</i></b>			<b>280</b>
<b><i>skipped question</i></b>			<b>112</b>

61. Does your child have any of the following conditions? Please read the list carefully and check all that apply, even if these conditions are not covered by CCS.

		Response Percent	Response Count
Allergies or sinus trouble		26.2%	72
Asthma		17.5%	48
Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)		11.3%	31
Autism		7.3%	20
Behavior problems		14.2%	39
Blood disorder (such as sickle cell anemia or hemophilia)		2.5%	7
Cancer or leukemia		2.5%	7
<b>Cerebral palsy or other neuromuscular condition</b>		<b>58.2%</b>	<b>160</b>
Chronic immune condition		3.3%	9
Chronic lung, or breathing trouble (such as BPD but not including asthma)		10.2%	28
Chronic rheumatic disease		0.4%	1
Cleft lip and/or palate		4.4%	12
Congenital disorder		9.8%	27
Congenital heart disease		5.8%	16
Cystic fibrosis		1.1%	3
Degenerative neurological disease		2.5%	7
Developmental delay		46.9%	129
Diabetes		2.2%	6
Digestive or gastrointestinal disorder		19.6%	54
Down syndrome		2.5%	7

Appendix 25  
Responses to FHOP Survey of CCS Families

Epilepsy/ Seizure Disorder		28.4%	78	
Head injury complications		6.2%	17	
Hearing impairment		13.8%	38	
Hydrocephalus		9.1%	25	
Kidney disease or renal failure		2.5%	7	
Mental health problems		6.5%	18	
Mental retardation		30.2%	83	
Muscular dystrophy		2.9%	8	
Orthopedic or bone problems		32.4%	89	
Paraplegia/quadriplegia		14.5%	40	
Respiratory distress syndrome		5.1%	14	
Scoliosis		16.0%	44	
Spina bifida /meningomyelocele		3.6%	10	
Technology dependent or assisted (Some examples are central venous line, colostomy, dialysis, feeding tube, shunts, tracheostomy, ventilator and others)		18.5%	51	
Vision impairment		29.5%	81	
Other (describe below)		10.9%	30	
Don't know/Not sure		1.1%	3	
			If Other - please describe	64
			<b>answered question</b>	<b>275</b>
			<b>skipped question</b>	<b>117</b>

62. Of the conditions you checked, which one would you consider to be your child's primary MEDICAL condition?	
	<b>Response Count</b>
	220
<i>answered question</i>	<b>220</b>
<i>skipped question</i>	<b>172</b>

63. How old is your child?		
	Response Percent	Response Count
Newborn - Less than 1 month old 	0.7%	2
1 month to 12 months old 	0.7%	2
1 year old 	1.8%	5
2 years old 	5.6%	16
3 years old 	5.3%	15
4 years old 	6.0%	17
<b>5 years old</b> 	<b>7.7%</b>	<b>22</b>
6 years old 	5.6%	16
7 years old 	7.4%	21
8 years old 	3.5%	10
9 years old 	4.2%	12
10 years old 	3.2%	9
11 years old 	6.7%	19
12 years old 	4.9%	14
13 years old 	3.5%	10
14 years old 	4.9%	14
15 years old 	5.6%	16
16 years old 	5.6%	16
17 years old 	3.9%	11

18 years old		3.2%	9
19 years old		2.1%	6
20 years old		3.5%	10
21 years old		1.4%	4
22 years old or older		2.8%	8
<b>answered question</b>			<b>284</b>
<b>skipped question</b>			<b>108</b>

**64. Which of the following categories best describes the race or ethnicity of your child?**

		Response Percent	Response Count
<b>White or Caucasian</b>		<b>53.6%</b>	<b>149</b>
Black or African American		4.3%	12
Asian, Pacific Islander, or Southeast Asian		5.4%	15
Hispanic, Latino/Latina, or Spanish		21.2%	59
Native American, American Indian, Aleut, or Eskimo		2.9%	8
Multiracial		8.3%	23
Other (specify below)		4.3%	12
	If Other - please specify		22
<b>answered question</b>			<b>278</b>
<b>skipped question</b>			<b>114</b>

65. In what language did you take this survey?		
	Response Percent	Response Count
English	0.0%	0
<b>Spanish</b>	<b>100.0%</b>	<b>34</b>
<i>answered question</i>		<b>34</b>
<i>skipped question</i>		<b>358</b>

Comments from the FHOP Survey of Families 2010

**11. Problems getting needed services from primary care providers (25 comments)**

My primary care provider did not accept CCS, so I paid for my child's visits, lab work and medication
I consistently asked her PCP to refer my child to an Orthopedics doctor who specializes in children with Special Needs. My daughter has been and still needs ankle braces and she still isn't getting approved by our insurance. Which is completely absurd considering I pay \$300.00 a month for insurance. Our healthcare system is ridiculous!
I need help getting my son a dentist, and a in endocrinology for his thyroid
que hablen espanol
The provider did not follow through with a much needed prescription.
The problems could come when he turns to 22, because he will not be treated by pediatricians anymore.
primary drs disregard or are suspicious of parents input because they seem too familiar with medical issues
DME requests have been lost and delayed due to lack of coordination and staff turnover
dental problem was not resolve because social worker remove insurance when all paper works was submitted
Disconnect between doctor and front office on time between checkups on chronically ill child w/ special needs.
PCP's office does not fill out necessary paperwork on time
Lack of knowledge regarding autism of assistive personnel (how to approach child with ASD)
child is deceased
medical
UNABLE TO GET APPTS WHEN CHILDREN ARE ILL WENT TO A NON CCS/MEDICAL MD TO RECEIVE URGENT CARE AND PAID FOR THE VISIT. THIS KEPT US FROM HAVING TO GO TO THE ER WHEN ER CARE WAS NOT INDICATED.
Sometimes the long wait in time to see a primary care provider comes into play. Always, whenever there have been issues which relate back to the CCS therapists, they have acted quickly and efficiently on behalf of our child.
getting medical supplies from a certain company,
trying to get certain equipment seems impossible
my child aged out of the pediatric clinic he grew up with. finding a replacement was difficult. we've only been to one appointment with the new NP.
THE APPROVE TAKE TO LONG BY TIME WE GET THE ITEMS THEY DONT FIT ANY MORE
Providing information on meds and coordinating specialist care information to CCS; providing info for IHSS; Providing info for conservatorship. Also, when our child turned 18, they were moved from pediatric care to adult care and the transition was/is horrendous. Poor understanding of CCS and other systems for individual to 21 years old and other systems of care.
The one phone number to our primary care provider's office is often busy. I need to try it repeatedly for an extended period of time to get through at times.
Getting the Pre Authorizations In A Timely Manner
Could not get immunizations through PCP

**13. Problems getting needed services from specialty care providers (24 comments)**

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Communication problems between CCS therapist recommending procedure for my child and my child's doctor

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My son needs orthotics and hasn't gotten them in years.

---

Not getting in to see the specialist in a timely fashion. I.E. orthopedic surgeon needed to cast my son's ankle and due to delay this did not occur (i.e. it was too late) all due to his availability!

---

Finding the doctors that would take Medi-cal...no where! ONLY clinics that do not have the doctors and we have to drive 2 hours to find if you can find that will take the insurance provided by the state.  
GARBAGE INSURANCE

---

The neurologist cancelled on us twice, causing a delay of over 2 months for a follow-up appointment. We then switched doctors.

---

dental problems - no insurance no dental

---

I would like my child to see a specialty doctor for assessment on her current condition & future expectation but the primary doctor says she's been seen initially (specialists from [Northern CA] Children's' Hosp) and will have to go back from where she started.

---

orthodontic, Down syndrome related specialties, OT/PT/Communication specialists on Down syndrome took 6 months to get approval for CT scan (epilepsy related) through medi-cal

---

difficult finding specialty providers closer to home that accept CCS or are approved by CCS

---

I'm having difficulty getting authorization for a repeat hearing screen for my son.

---

CCS did not want to authorize a pulmonary and ophthalmology.

---

Sometime takes long time to get the answer when we ask questions by phone

---

location of these doctors

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The neuro wasn't very smart and almost put my child on a high blood pressure medicine for sleeplessness that was potentially harmful

---

getting insurance to give names of specialists we could go to who were knowledgeable about problem

---

Post-operative problems caused by Shriners Hospital staff were not addressed properly, and we were forced to seek medical attention from 3 different specialists to find a solution to a problem caused by Shriners

---

My child is seen at [Southern CA Hospital] and was receiving bad service. I wrote a letter to the Dean of the medical school and services are starting to improve.

---

Because we see the GI specialist in a satellite clinic, he does not bring his whole team; therefore we do not have access to valuable resources such as a nutritionist. It seems without the team approach to addressing my child's GI needs she is not improving in this area.

---

At age 18, Kaiser discontinued pediatric specialist and primary care and moved our child to adult care. Adult providers did not understand CCS systems and requirements, and there has been and continues to be confusion and delay in getting necessary information. The Kaiser system does not align with CCS system at age 18. However, the CCS support has been good because we are well informed parents and we have been with the same CCS providers for a long time. It takes a long time for the CCS assessment and authorization system to work sometimes

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Could not get a letter from Neurologist for school needs

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The doctor said that my daughter would never walk therefore time and money was lost to get treatment that my daughter needed.

---

The Orthopedic Dr. at [-] MTU eyeball examined my daughter, after writing a letter to transfer from this office it has been difficult to but we finally were transferred to [-] MTU. This whole process took several months, time that passed without my daughter being seen by a Ortho Dr. It is well know of the [-] MTU Dr. manerisim however nothing is done about it. I submitted a written complaint with a response from the Dr. "If I don't like it , go somewhere else." The [-] MTU acts as gate keepers to the services my daughter requires.

---

Our specialist works out of Children's hospital and getting appointments to see them are horrible. I must constantly hound them to get an appointment for a child with uncontrolled seizures who's on a special diet. Forget about getting coorindating appointment with a neurologist and the nutritionist. It can't happen at this hospital.

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**47. Problems getting needed care because of type of insurance coverage (yes, 115, 35.9%; 103 comments)**

HMO INSURANCE (BLUE SHIELD)

medical

Kaiser

dental care

HMO - thought that sending me to any type of geneticist was adequate, but it turns out we needed a super-subspecialty which they refused to cover; same with neuro-ophthalmology.

Private insurance does not cover the procedure that the CCS doctor is recommending

At one point by the time my insurance send denial letter and I had to go through the process my son had outgrown initial measurements or item.

We have Blue Cross of California - Anthem. I pay \$300.00 a month and consistently get denied for services. I have to request a fair hearing to petition the insurance for NEEDED services.

private insurance wouldn't cover therapy services in the summer (before we had a diagnosis and were served through school district). Also lack of communication for needed DME between therapist and insurance

Private insurance limited # of appts/constant follow up and denials

HMO has problem approving therapies for "out of network" providers

Medi-Cal

Health Plan of San Joaquin cover San Joaquin County only. Can't get specialists out of SJ County

sometimes due to the fact I need to get a denial letter for services from the private health care first. sometimes this take a long time

Medi-Cal always has made it hard, even though the insurance is billed first, Medi-Cal has messed it up a number of times.

My daughter needs to see an Optometrist that specializes in special needs patients but it is a problem finding one that will take her Medi-cal since she is a CCS patient.

Medical-my son need AFO's, orthotics

Kaiser

Doctors and Dentist are limited in taking Medi Cal

When there is a break in contract between hospitals and insurance companies, we have had to change ALL her care providers to another specialty hospital.

Many of her necessary physicians (e.g. Pediatrician, Neurologist) do not take Medi-Cal/CCS because of the low rates so we pay out of pocket for the co-pays for their services, which limits the frequency of our visits. Our ability to find nurses has also been a problem because of Medi-Cal/CCS's low rate.

MEDICAL NON COVERED DOCTORS IN BUTTE COUNTY

Both HMO and Medi-Cal

HMO

Some therapies are not covered

Kaiser doesn't cover DME. Makes the process longer with denials, etc.

Dental work is in Atwater, CA, an overnight trip for us.

Had trouble getting a SPIO compression suit paid for by private insurance. Medi-Cal would have paid for it. Same with speech therapy.

Blue Cross Medi-cal

medi-cal

CCS and Medical

they severely limit the # of visits per yr

Blue Shield and Blue Cross HMO

Many doctors will not take Medi-Cal or they are not CCS paneled.

ccs and medical

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Anthem Blue Cross, we are getting less flexibility in scheduling appointments with our child's doctor.

---

Certain creams for her skin are not covered by medical for her scar treatment

---

We have an HMO. All requests have to be coordinated through our primary care provider. He and his staff are EXCELLENT and coordinating all of our requests. It's the HMO's local medical group that is a nightmare. They stall and drag out the denial/approval process.. I can't move on to the next step in the request process, which is CCS/Medi-Cal, until I get a denial or approval from the private insurance medical group.

---

KAISER PPO

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Private insurance has denied claims and will not pay for all the therapy sessions he needs.

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Our private insurance denies most medically necessary therapies and procedures because they know that Medi-Cal will cover. In fact the insurances make a note of inquiring as to whether we have Medi-Cal and encourage their customers to apply for Medi-Cal, although they continue to raise our premiums every year. Assessments, number of visits and equipment for therapies, specialists in Down syndrome, mostly the lack of coverage

---

Our private insurance isn't flexible when it comes to DME.

---

coordination of care is way too difficult

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Medi-Cal has had denied medications prescribed by MD several times - 6mo approval process for CT scan  
medi cal

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I have had trouble getting medi-cal to cover some of the necessary prescriptions

---

Kaiser

---

POS

---

SHE NEEDS ST

---

Forced to cancel/private provider

---

medical has been cancelled

---

dental cavities: my child needs anesthesia and I do not know where to go for that

---

Private frequently does not cover auxiliary but necessary therapies

---

Preferred providers for Blue Shield of CA HMO

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When we had CCS, we had to go through a minimum of nine months of applications, paper work, rejections, more applications, for any and all medical durable equipment. (Stander, wheel chair, etc.)  
diapers, braces

---

Medical/CCS is not taken from some providers/restriction by CCS that does not allow outside therapy but cannot cover all therapy that is needed do to lack of therapists is a problem.

---

would like to go [-] Rehabilitation, however my private insurance does not have a contract.

---

dental care for special needs child and the durable medical equipment my child needs

---

UHC dropped [-] Rehab as a provider it is difficult to find a vendor to repair wheelchairs etc

---

durable med equipment process slowed down by problems with communicating between CCS, Medical, regional center, and insurance

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Medi-cal

---

medi-cal

---

lost my pediatrician cause he would not except medi-cal

---

Medi-Cal

---

Difficulties in deciding who will cover what

---

Speech Services and OT

---

Many medical providers choose not to take Medi-Cal.

---

When we had private insurance it was difficult to get help and medical professionals often said it would be easier if we just had Medi-Cal and not the combination of the private insurance.

---

Mental Health.

number of visits are limited, have to fight with insurance to cover additional
CCS
difficulty getting private insurance to cover services CCS doesn't
Finding a Primary Care physician, right now my child goes to the Teaching Office
Medi-Cal managed care
updated equipment, chiropractor, massage therapy, any alternative medicine needs
Medi Cal, not very many doctors in our are except Medi Cal. We have to travel over 50 miles for specialty care
A couple times, child's medical paperwork got lost in Kaiser Medical system; I had to find out who to call to get it going again, like Durable Medical Equipment
Medi-Cal
No therapy anymore as per Blue cross
insurance just not covering what she needed
Determining payer responsible and getting letters of denial is a challenging job that parents must do and it delays everything.
Medi-Cal
private ins and Medi-Cal have different Rx formularies; don't always cover the Rx my daughter needs
HMO. if my HMO doesn't pay a portion of the medication then medi-cal won't pay at all.
Health insurance
CCS promised to care for my daughter's cranio facial issues, but specialist we see is not covered by CCS, so we had to pay out of pocket for everything at Oakland children's Hospital.
private
doctors who does not accept Medi-Cal
Emergency Medi-Cal
Having private insurance and CCS or Medi-Cal at the same time is problematic for receiving attention (Tener Seguro privado y ccs o medical amismo tiempo es mucho problema a recibir atencion)
Medi-cal fee-for-service
while out of state (Utah)
Limited # of DME providers, cannot always get equipment/supplies in timely manner
hmo
dental
HMO...just takes longer to wait for denial or approval
CCS screwed up getting my son's most important life-saving medication-he nearly required hospitalization
Does not coordinate well with private insurance doctors
not covered for his illness
Medical often doesn't pay their vendors on time -we have been turned down because of this.
United HealthCare arbitrarily dropping Children's Hospital Oakland

**Other comments about CCS (151 comments)**

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I love the CCS program and how they have helped me with my son's medical care. One phone call does it all!

---

Location of CCS therapy unit is a problem, as it's in a rough are of town, so I would never allow my child to take the bus by herself to her therapy appointment (even though she would be able to do so if it was in a better location).

---

The only problem I've had is not being able to coordinate the time of appointments and my work schedule, its been hard.

---

thank you! thank you! There is no way we would could have survived without CCS. We have private insurance and have sometimes been over income and private insurance does not cover half the costs of raising our son with cerebral palsy. Again, thank you very much.

---

I was extremely satisfied with the [-] MTU facilities. However, since my daughter transition to [-], they have not called AT ALL to set up appointments. I am EXTREMELY upset with this Therapy Unit! I am looking into legal assistance so my voice is heard! I understand they have a heavy case load but they do need to follow up with open cases. I've left messages for [-] and still no response. I did have an appointment initially to sign the paper work, and they did not even have my appointment on their books. I'm egregiously concerned with the way [-] is running their agency.

---

Over concentrated on young children and not maintenance of function in young adults.

---

inability to qualify for MTU services when we knew our child had a neuromuscular disease, but no definite diagnosis. This delayed our ability to access school district services as well, as they were sure we belonged to CCS so delayed doing their own assessments (this led to a 5 month delay, and then summer started, and had to wait 3 more months to start PT and OT.)

---

In the last 12 years and two children in CCS I have watched the program be more worried about their quotas and percentages, and less about the children it serves. It abandons it's most vulnerable clients because they are not equipped to give the amount of services needed to make it a successful program. It provides just enough service to negate receiving therapy from other sources. It has become another misguided government program.

---

I think this program needs to be seriously re-evaluated to return to it key focus: providing children with the therapy they need to overcome the challenges they have been dealt.

---

Unfortunately, we've seen the therapists taking on a bigger workload of non-therapy related items that assistant used to do. Our therapists at are wonderful and friendly and helpful and caring. But they seem pulled in too many directions and it seems they are starting to look to reduce hours to meet budgets.

---

My child only receives OT and not PT, so we have to pay for PT out of pocket.

---

CCS Has "been there" but because of our private pay insurance and Medi-Cal they have not had to pay for much. I once needed them for denistry, but was turned down and had to jump through so many hoops it was ridiculous. My son has congenital deformities of his mouth and they told me he was not eligible. Also the rate of pay for providers is so low that no one want to take the reimbursement they offer, thus it is like being uninsured

---

My daughter adores everyone at the [-] MTU. They are very helpful and I enjoy taking my daughter for her visits.

---

I appreciate the help we got when my son came home from the hospital. Excellent service. I'm a little confused on how to get his AFO's (orthotics) so he can walk/run better.

---

My daughter had CCS as needed in conjunction with Medi-Cal.

---

One thing that always occurs to me is that the therapists are happy to see my son. They genuinely care and want to help.

---

Only contact we have with CCS is annually to ensure our child is still eligible, Case workers change almost every year and we have to explain why our child is eligible to receive CCS every year.

---

The majority of the staff has been great, the system is what impinges success.

---

Something is inherently wrong with the system when the individuals who most need the therapy to prevent worsening of their medical condition cannot obtain the necessary services for prevention/maintenance. Requiring an arbitrary amount of progress sets these children up to fail the system and to not be adequately served by the system. If we didn't have private insurance and therapists (at the school) to cover the majority of our costs and work with my daughter her medical

condition would likely be even more severe than it already is.

[.] has served as my daughter's Case Manager for the duration of her CCS coverage. She is efficient and supportive. I am very thankful for that.

It would be beneficial if CCS provided in-home therapy services post surgery.

I have found that the therapists make note in reports about the medical status of my child but don't really know. And if he is having difficulties, they do not try to work with him. Recently a doctor diagnosed multiply muscle spasms in his back which was causing pain. The therapists missed it and didn't want to work with him because he was crying. where the therapy could have relieved his pain.

CCS provides a valuable link to therapy for my child. The stress of special needs on a family is tremendous, and at least with the CCS PT and OT we receive, I feel like we have a little bit of a safety net to catch us when we feel like we are drowning in the stress of it all.

Love our PT, don't love our OT, but my son loves both. :-)

CCS has been our foundation for dealing with our daughter's CP. I am not sure what we would have done without their direction. The Therapist explain everything to us and assist us in all we need for her. The other programs help to but not to the degree that CCS does. Thank you!

Wonderful, wonderful therapists at our MTU - but overscheduled/overworked. Our family really appreciates that MTU services are provided for families without regard to income - otherwise we would have a difficult time arranging services through private insurance or EI.

We have worked with wonderful, caring people, and are very grateful for their concern and help.

Very satisfied with our physical therapist, somewhat satisfied with the occupational therapist, not at all satisfied with the equipment available at the MTU for my child - not enough sizes and varieties of standers, walkers and gait trainers (opportunities for movement) for a moderately disabled kid who wants to move but can't support himself.

I actually just stopped our CCS program yesterday.

We can not have CCS and HIPP at the same time. We chose to discontinue CCS since they only thing we get through CCS is DME.

We still will be able to see the same Dr my son sees through the MTU clinic. I am actually excited because I will not just have 2 dates per year that he can be seen. I will be empowered to make the appts and the Dr will still be able to write a script for the DME and since we have private insurance, medi-cal and the regional center the equipment will still be covered.

Due to budget constraints, you can see how they have been forced to reduce caseload and try to transition kids to the school system once they reach school age which is unfortunate. Therapists are very skilled and provide very valuable services but are definitely forced to try to limit the amount of time they can see your child, and frequency, due to larger caseloads.

Not close to home. Services not available at school.

I believe that all kids deserve therapy, at least once a month but with the shortage of therapists this is not the case. Although when I go in there they are usually not busy at all.

ccs should make parents aware of all options available to them thru CCS - I feel like I know very little and it's like pulling teeth to find out

the fact that you can't also get private OT or PT in addition to CCS is ridiculous

All the therapists are nice people but operate like government employees....they do their job well enough but don't benefit from the kinds of stimuli that private sector folks face everyday like competition and job performance reviews that actually have ramifications. They operate on a medical model, not an educational one and are what I would call "stuck in their ways" or perhaps too worn down by the system to care too much anymore...In most ways I don't blame them...there are many crazy parents out there that act as though their child is entitled to the very best of everything...I just wish that our therapists had more incentives to do well, to do better.....to keep trying as hard as our kids do.

Yes, for the last 10 years they have been very aware on all my son's necessities at home, school and in the MTU. In general I'm happy with them.

The individuals at the MTU do try hard, but the bureaucracy of the overall system & main office and the paperwork is frustrating.

I know my child has used CCS as [Northern CA Hospital] has said so, but I have no idea what they have paid for, how one qualifies for the program, what they will pay for in the future, or if there are any

alternatives

The CCS therapists in [-] are incredible. I wish there was more available in terms of access to other therapies, therapy at school, and more information about managing my child's orthopedic needs.

The help from CCS has made it very significant in improving my granddaughter's medical condition.

WE are appreciative for CCS and all that it has done for my son and our family through his 14 years, but believe there are changes that could be made that would be beneficial to families, especially in case management.

It's very hard to get in touch with a CCS provider in our area, at times. I'd like to know what other services our benefit from

CCS is good about covering my daughter's endocrine issues, but was not able to help with her skin issues i.e.; her severe keloid scars.

The CCS staff we have encountered are all skilled and caring people. They do the best they can with very limited resources. The PT equipment available from MTU site to site varies substantially. They should all be equipped with everything they need to employ the latest and best PT practices. Private PT clinics are typically much better equipped. I think that after it's been determined CCS will not longer be providing a child regular PT, the family should be given a subsidy to continue some PT on their own, at a discount, if they choose whether it's weekend swim therapy or some sort of group classes etc.

I don't fully understand the role of CCS vs. other groups like GGRC, Medi-Cal.

[-] MTU staff are very helpful in meeting all the needs of my daughter

because we are rural we are extremely limited in providers. The dr. that comes up for clinic is offensive and there is not a lot of proactive looking to change or improve services.

Excellent at providing direct services (MTU), support and referral services through their staff and through [-] Family Resource Center.

Must wait too long to see Dr. Paperwork for referrals sit on desks at CCS too long.(emergency cardio or seizures cannot wait) Not informed how to expand coverage so she gets the orthodontic (endless pain) care she needs and the therapies for speech, OT, PT. No case management as far as I can see.

The questions at the beginning of this survey were confusing because it didn't specify the difference between a CCS client that receives only PT/OT and one with financial support as well. The questions could be interpreted differently.

previously used MTU services - not happy, now received services that I pay for and provided by the school district

The cutbacks have been tough. I think my daughter could use more appointments per week than she receives. It has been more than cut in half in the past year and not being allowed to go out and supplement does not make sense to me.

I ABSOLUTLY LOVE OUR PHYSICAL AND OCCUPATIONAL THERAPIST. THEY HAVE MADE A HUGE DIFFERANCE IN MY CHILDS LIFE.

We have two children in the ccs program, and we are thankful to have these services, but several times we have had to deal with very rude employees. That is my only complaint and or concern, I could not believe that someone could be that rude to a family. Thanks !

I have had a very positive experience with the CCS program. The few bumps that we have had in my child's care have not been due to CCS. I consider the program a huge blessing. A lot of my child's progress in his development would not have been possible without this program.

This case worked is sometimes difficult to reach. I had to be proactive and contact her for issues. Are they supposed to contact us to offer us services? The best support we have had is from the Alcott Program.

The ccs program is a God send for our family. My son sees some of the best juvenal diabetes doctors and all his prescriptions our covered which is huge to our family. We have been truly blessed by this program. This situation was very difficult and heart wrenching for our family. The ccs program has truly lighten the load of my sons' diabetes in our life. I truly thank the program for that.

It would be wonderful if speech therapy services could be rolled into the MTP

I don't have any problems to your services, I'm very thankful because it helps me a lot to my daughter's needs. Thank you very much for your full support.

thank you for all of your help I just wish that there could be more therapy for people who make slow progress. I think that the budget cuts make it difficult for the therapists to keep clients who are not making great strides and they should have the opportunity to keep progressing instead of being dropped by CCS.

we are happy with most things but the lack of therapy that he gets because they say he will not advance that is silly he will only get better if he has therapy he needs each day repetitive actions is how we all LEARN he has come a long way in eating because no one has given up on him which is really problem with docs not pushing them but ccs themselves are usually helpful and take good care of us and our son thank you

---

Because of the constant threat of cuts in gov't funding, CCS tends to focus on the less severe children, ones that should marked improvement with therapy. Those who need intensive long term therapy are left behind.

---

Build a better facility in [-] with equipment that is as good as the equipment in San Mateo

---

The CCS staff is great. My son sees [-] and [-]. There are both encouraging and supportive. My son is thriving because of CCS.

---

Would like to see CCS continue helping parents manage care for their children. It is very important to also continue therapy at school sites, so that parents do not have to leave their work to take children to therapy. CCS needs to have more office support, so that therapist can do their important job with children. Thank you.

---

Not every child does well with the programs offered at CCS (mine certainly didn't), but it appears to be a good program for most.

---

At first our experience was very good. My son could only handle about 45 minutes of therapy (OT or PT) every week. We had a change of therapists, and they cut back on our services because they claimed that there was a lack of progress. It happened to be that his favorite therapist went on a maternity leave, and he never liked the new therapist and refused to perform for her. It also became a very big issue that she would miss an average of every other therapy and not have the time to make it up. At one point, after seeing how much he did in a classroom setting with other people she even stated to me, "His new goal is for him to begin to like me." Maybe if she were to have begun with that attitude, we would have had a much better outcome. When CCS finally dropped us, I warned his new therapists of his refusal to work for people he did not like. It only took them a few appointments for him to warm up to them, and now he performs better for them than he does for me. We as a family truly felt pushed out of the CCS program. And even in the end when we asked to be considered for Durable Medical Coverage, as far as making sure that the equipment that was already ordered for us through CCS was checked on, we were told they do not do that. I have it on good authority from many sources, that since they were the ones to request it, they are supposed to be the ones to be sure that it still functions properly, fits properly and that any repairs are followed through them. We were told by CCS, that they do not do this and that if anything goes wrong with the equipment, it is up to our family to go out and find a solution on our own.

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IT HELPS

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Nel is great!

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I have been extremely happy with the care my son has received from [-] at [-] MTU.

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The care is standard at best and the center isn't very inviting. These children feel like lab rats as it is and the therapists are sweet but the work for the Count of LA and there isn't much variation and assurance of the use of progressive treatments.

---

Cuts on staff and funding make it nearly impossible to get appointments during reasonable times, or to reschedule missed appointments due to illness!

---

I am very pleased with [-] ot and [-] pt

---

Up until the last year we were able to get approval for needed supplies or therapy in a timely manner. The last year has brought slow response in approvals. Such as AFO approvals. If a child needs AFO's, it is for a reason. You should not need to wait 4 months. We have a private insurance. We make sure we always have a PPO. We are grateful we have CCS for our child. There are both therapists and nurses that have in the past been a wonderful support. But, this past year has brought changes to the MTU that are not beneficial to clients. There are problems that doctors and other providers are having that may cause them to no longer provide services for CCS.

---

It would have been a more positive experience for my child and me if my child's CCS case manager (CCS Public Health Nurse) were more supportive with regard to understanding how difficult it is to schedule appointments with, and promote communications between my child's numerous specialists and his primary care physician.

---

My CCS Manager has not been helpful in assisting with anything.

---

We as a family are so thankful for CCs and their support, I have no complaints. I am active in my child's health care and appreciate so much the aid with medical issues

The therapists at ccs seem to be caring and have knowledge for working with my child. The bureaucracy and the funding problems that CA state has makes the service mediocre at best and insufficient at worst. My child will not be able to have the skills to care for himself because of these lack of services. I am very disappointed in the system.

---

Thank you CCS!

---

There is not any communication from ccs. mtu clinic therapists are great, but the people who schedule appts. need some training.

---

It took fourteen years to get qualified for the MTU. Seizures alone do not qualify. Very frustrating

---

I WOULD LIKE TO PUT MY KIDS ON MY PRIVATE INSURANCE BUT IN TALKING WITH OTHER FAMILIES, HEALTH CARE PROVIDERS AND TEAM CENTERS IT CAUSES NOTHING BUT PROBLEMS. THE ONLY ADVANTAGE WOULD BE I COULD GET PEDIATRIC CARE WHEN MY KIDS ARE SICK THUS ALLEVIATING THE NEED FOR A HOSPITALIZATION OR ER VISIT. I HAVE HAD NO ISSUES AT ALL GETTING DME, BRACES, SPECIALTY CARE ETC. JUST FREQUENT PEDIATRIC CARE.

---

THEY ARE THE BEST! WITHOUT THEM WE WOULD'NT BE WHERE WERE AT TODAY.  
EXCELLENT

---

Our child needs more than 30 minutes of weekly therapy. And it needs to be at home or school, where our child functions, not in a therapy center. Our child does not live his life everyday in a therapy center.

---

My child would not be doing as good as he is now is not for CCS!

---

I have a major problem getting CCS to let my daughter see a local nutritionist. The nutritionist I see locally is CCS approved but they insist I drive every 4 months from Chico to Sacramento GI clinic. This means my daughter is in her car seat for 4 hours. Then in her wheelchair for 3 hours at the GI clinic to see a nutritionist. She comes home every-time with pressure sores on her body then I then can't send her to school because she needs to stay off of the pressure sores. I have an approved nutritionist that is CCS covered that comes to my house for a short 45 minute visit. So why must my daughter have pain and suffering? On the road I must pull over the van every 25 minutes to suction her mouth and take her out of the sitting position which is causing a pressure sore. She screams and screams because she should not be sitting for more than 45 minutes. Seven hours sitting is not good therapy for my daughter. I have been told for almost a year that I have no choice CCS children that live in Butte County who are tube feed must she a nutritionist in Sacramento. WHY WHY does my daughter have to suffer??

---

I think CCS is a great resource and out therapist, Ms. [-] has been fabulous for us from the start!!!! very pleased !!

---

Love the therapists

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I feel there needs to be more done therapy wise for kids that are slowly declining. They say if they do not have any signs of improvement w/ot or pt they have no reason to continue. As a parent I feel we should get more guidance when it comes to how to deal w/ this decline. Our MTU is horrible in getting a hold of anyone and making appt. for adjustments to equipment. It has taken over 9 maybe 10 months for a car seat to be ordered and we still haven't received it. By the time the equipment comes he has grown so much I don't know if it will fit. Same w/ bathchairs and wheelchairs. His wheelchair is 4 almost 5 years old and I feel we need to order on now so when it takes a year to year and half to get we will at least have one on order. Very frustrating as a parent and all we deal with to have to continually call and check up on so many things; there has to be a better way.

---

very satisfied with the mtu except dropping therapies down to quarterly visits only

---

Big difference from Hawaii. There we received physical therapy once a week, occupational therapy once a week and aqua therapy twice a week. Here we will get physical, maybe occupational therapy for 3 months and take a break?

---

In the past I have had problems, but currently the staff at the but is very helpful and competent

---

VERY HAPPY WITH ALL THE SERVICES AN HELP WITH CCS.

---

I would say that all of my child's medical needs were addressed and taken care of through CCS or Medical. CCS dealt with the majority of services and we didn't have any problems with the authorization of any services that were needed. The wait for authorization may be the only complaint that I have and all in all it isn't a major problem because none of the services were emergencies. When I needed to get authorization for a specific procedure to be done on a specific date I called and it was pushed through, so we could be accommodated. You have provided everything that was ever asked for and my husband and I will forever be in your debt.

The most important thing my child needs ot, pt, and speech therapist, please if u can add more hours for him, coz these services helps him a lot. no cuts for the hours pleaseeeeeeee.

FANTASTIC THERAPISTS AND GREAT SUPPORT!

It takes to long to get a service approved

I wish that the braces and shoes were paid for in full by ccs

I feel like the MTU thinks that they have done their job when the child can walk and they don't work on improving endurance or quality of life.

Don't have much to say. Overall I am pleased with the services

The MTU is great, but understaffed. Sometimes it takes a while to get an appt and we went over a year before receiving OT services that were prescribed.

I have more then one child with a disability (3) and could use help and support for them all but I am only able to get help for one. So that leaves me with more appointments in different locations to deal with. My child with low tone CP need services just as bad if not more so then my child with high tone CP, ect..... I also have to say that I am not sure what CCS has to offer my family. It is really hard to find time to do my own research when I have 3 children under the age of 9 with multiple disabilities.

We could not ask for a better experience with the therapists that work with our child.

My child has just begun services with CCS. My answers are based on the speed of the process of getting her into the program and follow up in getting her initial appts established. Her first PT eval isn't until 5/6/10 perhaps I should repeat the survey after being in the program for awhile.

MY CHILD NEEDS ONGOING pt, OT, SPEECH AND IS NOT OFFERED IT. ONLY GIVEN A PAPER AND SHOWN HOW TO DO BASIC ROM AND STRETCHES 1X YEAR.

I believe the SF MTU has my child's best interests at heart, but are sometimes hampered by the system in being able to provide proper equipment.

Words cannot express our thankfulness for the expertise the CCS Team has provided for not only our daughter but our family unit. The MTU Staff in [-] has been a life source for us.

My son's Physical Therapist is not very nice to my son. It feels as if she doesn't like children. I don't know why she is working w/ children? She seems very agitated with my son and with other kids that I have seen there. She stopped seeing my son about 4 months ago and doesn't even call us in for monthly visits and she didn't show up for his IEP either.

quality of therapists is excellent. program administration is fair. Case conference meetings every six months seems like a waste of time; would prefer once a year. Also, the 'rent-a-doc' brought in for these meetings is not well-informed about my child and appears not to be particularly well informed about childhood disability in general.

Has helped me obtain emergency medicine when pharmacy was having problem with Medi-Cal.

I wish CCS would cover alternative medicine care, like holistic care, and physical therapy like massage, or reike

We attend the MTU in [-]. Our PT is friendly and tries hard to work with our child and the office manager is nice, but the rest of office staff is NOT friendly or welcoming at all. They never greet you nor acknowledge your presence. A friendly "Hello, someone will be right with you" is all it would take. Also, when you call them on the phone, the office staff is very rude!

The [-] CCS staff is amazing. Our case worker has always responded quickly to our questions and provided the guidance we need. The MTU staff is well trained and has provided my child and family with exemplary support. The MTU therapists seem to always hold the child's best interest at heart and appropriate advocate for the child. We're extremely appreciative for the support CCS has been able to provide our family.

Very efficient program. Good communication by phone and mail

The only complaint I have about CCS is the delay in approval of necessary supplies. Occasionally, there is a lag in approval of my son's feeding and/or respiratory supplies.

I do not like negotiating through additional layer whenever my child needs DME. Denial letter from CCS can take time. also, my child needs speech services and I was not aware it was provided through CCS

We are very happy with the Indio MTU and our therapist has helped us so very much. We are Blessed to have known [-] and he has helped my son cope with his spinal cord injury for the last 5 years. I don't know what we would have done without him. He taught my son to live again and be independent. He is the best, [-] at the [-] MTU. Thank you so much for your services. May the Lord Bless [-] back for actually bringing my son back to believe in himself after this car accident with a drunk driver. He has also taught

me his mother how to deal with this too. I am a stronger person and can take better care of my son and not be afraid like I was in the beginning. Thank you again CCS.

---

great, concerned therapists

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My son was diagnosed with CP as a toddler, but I knew nothing about CCS until he was 4 and we were referred by [-] Hospital.

---

My child doesn't receive a lot of services because the people that work there have said that it would be a waste of time to help her. She's paralyzed from a gun shot wound at T4 level that she received when she was just 10 months old. I requested to have therapy or exercises, and while she was a child she received some, but as she grew older many services were taken away. The therapists/evaluators said that it was unnecessary and a waste of time because she was never going to walk. The only good services that she's received is anything regarding receiving equipment that she needs.

---

Too much paper work for therapists. Reports not sufficiently shared with families so that goals are known. Children dropped too early and forgotten, often during their biggest time of need. CCS therapists have a very unique understanding of the needs of children with physical disabilities. The MTU's combined expertise is hard to match when dealing with special conditions, braces for legs/feet, wheelchairs, and other mobility needs. Without the services provided by CCS, many children's potential would not be realized and families would be on their "own" or helpless.

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CCS people are very negative. They emphasize what my daughter can't do rather than what she can do (Other providers are more positive, even when discussing her disabilities). CCS therapists are compromised in their medical roles by their bean-counter/money gatekeeper roles: They are advocates for the system, not advocates for my daughter. Their first answer is always "no" and I have to fight each step of the way. Their systems are antiquated: paperwork is not electronic, I can't reach them by email, and they only got individual voice mail a few months ago! They work absurdly short hours, making it difficult to reach them. Getting DME always takes months and months. They won't talk to my insurance company, I always have to do it. They never take the initiative to figure out what equipment or approach would be best; they offer the same thing to everyone. If I want something else I have to research and advocate for it. If it weren't for the wonderful people at my daughter's school (an NPS) she wouldn't have much of any good equipment or services. My daughter has a permanent, chronic condition yet I have to go every six months for an "eligibility" clinic appointment. What a waste and my daughter has to miss school. The physiatrist at that appt is great but I still dread the appt b/c the other CCS people are so gloomy and negative. I know they have a hard job and are always underfunded but they behave as if they are defeated. I know I have a reputation among them as a "difficult" parent but that's because I advocate for my child and don't hesitate to do what's best for her even if they don't agree. I am a white woman from a privileged background; English is my first language; and I have a BA and a graduate degree; yet it took me years to understand how the insurance/CCS connection functioned and how to use it; and I still get confused by the funding process for DME. I don't know how non-native speakers, people without education, people without an empowering sense of entitlement, or people working shifts/two jobs could get any services at all out of CCS. For me taking care of my daughter is a second job. It shouldn't be that hard.

---

I am very satisfied with the therapists at the MTU, but dissatisfied with how difficult it is to access for p.t. and o.t. use. The MTU is too far for us to travel.

---

I think it would hugely benefit families if there were options available to them - even if not offered by CCS per se - above and beyond what CCS offers. Parents are generally told that there is nothing that can be done (I specifically speak of the condition of CP) for their child when they are in NICU or when their condition is diagnosed. It is no wonder then that you see so few families take advantage of what CCS offers, and that you see even more drop out over time. Traditional PT/OT simply has very limited results for kids with CP. Imposing a therapy onto a child's body is effective to a very small degree, whereas the type of learning that a child can accomplish using either Feldenkrais or ABM (Anat Baniel Method, based on Feldenkrais) has over and over shown not only better results but concrete change in a body that has spasticity and limited movement range/ability. In closing, I implore you to look at better models of learning and therapy for infants and children with CP, spina bifida, and other motor challenges.

---

sometimes family doesn't agree with the treatment doctor recommend, and not open for discussion.

---

I would like to understand more about what CCS has to offer my children. They need services, and I am not in a position to pay for what they need, however, because some of their issues are not directly related to their PHYSICAL cleft, the emotional problems we are having most likely are due to the cleft, and are very expensive.... bipolar, adhd, ODD, hospitalization for bi polar episodes, etc.

---

CCS needs to reach out to the community further to identify children with special needs. The diagnosis that is eligible for CCS services are too narrow and causes a lot of confusion. CCS staff follows the medical diagnosis eligibility very narrowly and often times, deny services. Medical care providers do not understand CCS eligibility clearly and so, do not provide enough information in their referral to actually get services. CCS needs to make the conditions eligible for services easier especially for certain complex conditions that has motoric impairments but do not have a specific diagnosis (idiopathic cases). Ultimately, CCS needs to be fair in providing services to all children with special needs and must not discriminate the children based on their diagnosis.

we are very happy and satisfied with CCS therapy also "hay unas lindas personas"

QUE NO LES QUITEN LA TERAPIA A LOS NINOS PORQUE LOS NINOS LA NECESITAN PARA SALIR ADELANTE Y NO SE ATRASEN EN SUS MIVIMIENTOS A MI HIJA LE QUITARON LA TERAPIA Y YO NO ESTOY DEACUERDO PORQUE ELLA ANTES DE UNA CIRUGIA CAMINABA MAS Y CON LA OPERACION DE CADERA SE ATRASO MUCHO Y NO CUMPLIO LAS METAS Y LE QUITARON LA TERAPIA Y ES INGUSTO QUE SE LA AHIGAN QUITADO.

"It is the best program we have...please keep keeping it because it is very necessary for many people and thank you very much" Es el mejor programa que tenemos y que hay en el estado por,favor sigan manteniendolo porque es muy necesario para muchas personas Ymuchas gracias por ayudarnos.

Without CCS, my mouth would not work

Because they do not want to approve a chair appropriate for his/her size (Porque no me quieren aprobar una silla apropiada para su Tamaño.)

i can only say thank you for their support in general and I think that is an exemplary program, without you my children would not have their therapies and the chair and braces, and the attention of specialists, Thanks

I did not always feel that my concerns during occupational therapy were addressed. My concerns instead were addressed by her orthopedic doctor. The occupational therapist was not pleased that I went elsewhere to solve issues.

It has taken me over 6 months to have my son evaluated by the MTU. There is never any follow up other than the calls I make. I coordinate my child's care. It's a pain to find out what is/is not covered by CCS. The therapists and officer worker at our local MTU are fabulous!

[-] is the most wonderful PT I could imagine. My son has received exactly what has been needed, at his pace -pushing him only when she needs to (which he does quite often). The staff has been incredibly understanding and patient. P.S. my son just turned 14 (with regards to those questions)

These cuts that the CCS program is making to SERVICES, STAFF, and PROGRAMS is ridiculous. The only ones that get affected by these cuts are the disabled children that have to deal with this torment, as if they need more on their plate. I'm extremely upset that the CCS program has FAILED it's mission to it's patients. Furthurmore, I'm disgusted with the fact that no one seems to care.

[-], RN and Dr. have been helpful with information to help me get medical care for my child. I don't know who my CCS SW is, she doesn't call.

I am very dis satisfied with this program on all levels. I written letters and will continue to write until there is a change

CCS therapy services are vital to our son and we greatly appreciate the care he has gotten from infancy till now.

I have 4 children on CCS. The treatment was great . My son was diagnosed with Retinoblastoma at the age of 2 and I did not know what I was going to do about insurance. I was just trying to Keep my child alive. Everyone was so great!!!!

We love our CCS therapists. They are very helpful, and know our daughter so well. They are flexible and caring, and very knowledgeable.

If this program was not part of my daughters life she would not be where she is today. I was told she would just lay there. She feeds herself, is talking and is very aware of her surroundings. Thank you [-] medical therapy unit!!!!

My only problem has been with obtaing this special medication for my son. It has been a problem every month since the first of this year. Never a problem prior 7 years he has been on it.

my son was born with a cleft lip it wasn't a severe one he only had one major surgery and 1 touch up he now has to have teeth fixed but other than that we have been so lucky and ccs has been great without their help i don't know what would have happened.

Only limit with satisfaction is the range of services and lack of coordinator. The services we do receive

---

are excellent.

---

Thank God for this program. gracias a DIOS que hay este programa porque si no estuviera este programa mi hijo no estuviera aqui con nosotros es lo mas grande que tenemos nosotros los pobres gracias a DIOS y al programa de ccs

---

I was not happy with the way that I was talked to during MTU. It has been many years since we participated though.

---

I am very satisfied with CCS. Today my daughter esta kasi completa mente aliviada. Thank you CCS.

---

I am concerned about our sons future. Both Ccs and Regional center seem to fight against each other to provide care. They are both very good at pointing the finger at the other provider. Both seem to forget they are dealing with children's needs and providing those services.

---

Very difficult to receive speech therapy for my daughter, it was not until we moved to another county that her services began. She could have progressed so much if she would have had these services sooner.

---

some people are very overbearing

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### **37. Experiences with Physical Therapy (60 comments)**

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continued reduced service from CCS is impacting the health of my child.

---

My daughter was previously seen [-] Therapy Units - very satisfied with the services. We recently relocated to [-], thus part of the [-] Therapy Unit. They have not contacted me about my daughter's case. It has been well over 3 months. I've contacted [-], case manager, numerous times and still have not received a call. I also left several messages for the Main office in [-] and still no response. I am extremely disappointed with [-] MTU and would prefer to go back to [-].

---

child was "not progressing and not compliant with home program so services were discontinued. Therapists didn't know how to work with him

---

The medical model neglects the very children who need it the most. The more they need, the less they get. It is a formula, suit and tie driven system that abandons children.

---

We did not have times avail to 6:30 or at school but I checked yes because it would be important

---

The problem was my son was cut off because he didn't make enough gains! If he made gains he wouldn't need PT!

---

Our MTU is in other town and does not do ongoing therapy to maintain strength etc. better if at school.

---

My child's "physical therapy" wasn't really therapy but monitoring and equipment management once every three months. She has severe cerebral palsy and is at great risk for contractions and other physical limitations without therapy yet she is not receiving the necessary therapy because she does not progress fast enough to make it worth her therapists' time and "therapeutic handling." This is ludicrous in my opinion that a child who needs services the most given her severe condition is unable to receive them and her doctors' agree with me.

---

CCS provides excellent physical therapy. However, when child needed in-home therapy after surgery, none was available.

---

Child does not get enough and varied therapies and the CCS therapists have not been able to work from a preventative perspective.

---

she gets it at school

---

CCS therapy only available Tues, Wed & Thursday

---

PT was recieved by NPA;

---

Our PT has had frequent illnesses and we've missed many sessions because of this. There should be a fill-in PT available.

---

My child needs PT but does not qualify for Medical Therapy Unit.

---

#6 There is NO PT in his School District and My son had PT in his IEP

---

CCS stops providing regular physical therapy if they determine the child has reached a "plateau." for my child that plateau was determined to have been reached about 12 months after the brain injury she sustained that made her CCS eligible.

---

there are no pediatric physical therapists up here. we cannot get referrals to places where there are

---

Therapists will NOT do a written assessment so child can have it at school. Need them for IPP and IEPs. Will not do an assessment because medical will not cover it. Need assessments for doctors and school application.

Took a long time between home care pt and outpatient pt. My son had to be re-evaluated, which held up the process.

therapist BASICALLY DO NOT want to work with him they want to consult once or twice a year maybe every few months but do no real daily work with him

Having a child with severe impairments with little improvement means little service offered

Would prefer that PT continues after the age of 12 years old.

received therapies thru school, not CCS

CCS Dropped my son from their therapy for lack of progress, yet in the six months leading up to this decision, they drastically cut back on his scheduled therapy (2 times a week) and then missed numerous appointments (over 6 appointments missed in 6 months) because of the therapist being unable to attend. It then took us another six months for them to completely drop him from services, and he now sees all of his therapists weekly through the school and has been progressing very well.

my child's walking degraded and had a hard time trying to justify the need for more therapy and something more aggressive or progressive than the standard of care that was being offered

Shortage of Physical Therapists does not allow all of my child's needs to be met

Regional assigned PT.

the budget cuts are preventing the kind of therapy I think my child needs and deserves. therapy appts were not available after 4pm and were not available at all some days

THERAPY CUT DOWN TO MONTHLY CHECKS DUE TO BUDGET CONSTRAINTS.

State of CA reducing PT and OT to 30 minutes per week. What good does that amount do????

She only receives once a year consultation. The state they are only able to help with school equipment I'm not allowed extra hours for therapy and assists needed at home.

My son need continuing therapy and was dropped down to being seen only once every 3 months.

getting cut because my child is not progressing makes no sense, should cut if child is progressing and it is working at home

My son was dropped to once a month PT instead of 2 times a week like he needs.

the number of visits my child needed, my child need more but they cut the ot and pt hours

My child's behavioral problems inhibit the receiving of PT/OT

I have a child with multiple disabilities. One disability prevent the other from getting the right service. For example: My child has CP, Autism, Seizure Disorder, Dev Delays and vision impairment. For CP he needs OT and PT, but because he has autism he needs sensory integration but that is not provided because CCS does not treat autism. Since we are not treating the whole child with all his disabilities he is not getting the help he needs. Example #2: My child has a therapy session and has a seizure and needs some time to recover there is not time for him on another day or when he snaps out of it.

inconsistent billing amounts

Getting dropped from 2x per week to 2x per month, when my child clearly needed more visits!!

no PT past year

My child is being monitored 1 time per year now; Main problem, child diagnosed in report, but that doctor never talked to parent or had seen child, based information on other reports, then I not told, found out on own when saw report in open file

ALL I HAVE TO SAY IS MY DAUGHTER GETS HER THERAPY IN THE INDIO CA OFFICE AND SCOTT SMITH IS HER THERAPY AND HE DID A GREAT JOB CAUSE SHE NOT EASY TO DO THINGS AND HE CAN GET HER TO DO IT HE A FINE WORKER ALWAYS HAPPY AND SMILES ALOT

lack of transportation and lack of therapists; filed compliance complaint; matter resolved informally.

No problems with our office at [-] MTU and our therapist was great [-].

Physical therapist only monitors my child once a month

No PT from CCS-we were told no because we see a private PT.

Medical Therapy Unit is too far from our home (45 minutes away from us in [-]) therefore, we are forced pay out of pocket

---

My problem with CCS is that they only offer very traditional and not very effective therapy. We had more gains in an extremely short period of time using the Conductive Education model of learning. Hippotherapy has been helpful as well. Currently we are in therapy with [-] in [-]. At the VERY least it would have been helpful YEARS ago had we even know these therapies existed. We were told that the only effective therapy is traditional PT and OT. This is simply put, a lie. A lie that takes years for parents to discover, often too late for any real gains with any other type of therapy. By this time spasticity has almost inevitably become severe, pronation irreversible. I feel that it is imperative to let parents know that there are many different approaches to healing their child and offering some real solutions to their individual conditions. Feldenkrais is another very effective therapy for children.

---

NO ESTOY DEACUERDO QUE LES QUITEN LA TERAPIA A LOS NINOS QUE LA NECESITAN  
ESTO ME PASO A MI CON MI HIJA Y ES ALGO INGUSTO QUE LE AHIGAN QUITADO LA TERAPIA

---

my daughter does not receive this therapy "mi hija todabia no recibe esa terapia y si la ocupa"

---

the regional center will not provide PT & OT at my sons school any longer I will have to take him twice a week and take off work and I can't do that so he won't have therapy anymore

---

Trouble coordinatin who would pay: school district, [-], CCS, Medi-cal so my child never received the service

---

My child needs a therapist that will work with us everyday , not order equipment and send it home, and make myself the fulltime therapist, with the MTU just doing weekly checks to see if we're doing things the right way.

---

The protocols that we as parents are required to follow from CCS are strict, harsh and unfair!!!

---

six month delay from time service was asked for through foster care SW until services were received

---

My day off is on Monday and NO services are provided on Monday. My daughters therapist are off on Monday. The Vendor only comes on Friday.

---

Getting dropped for not making progress is a problem.

---

there's no therapist in school and there's no suficient therapists in the city

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staying employed while attending at least 4 therapy appointments a week was a challenge

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### **38. Experiences with Occupational Therapy (45 comments)**

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occupational therapy was provided by the school district. Therapist did not return emails due to heavy work load.

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My daughter was previously seen at [-] Therapy Units - very satisfied with the services. We recently relocated to [-], thus part of the[-]Therapy Unit. They have not contacted me about my daughter's case. It has been well over 3 months. I've contacted [-], case manager, numerous times and still have not received a call. I also left several messages for the Main office in [-] and still no response. I am extremely disappointed with Montebello MTU and would prefer to go back to [-].

---

The more involved a child is , the more therapy they need. These children are abandoned by CCS because they are formula driven.

---

We did not have times avail to 6:30 or at school but I checked yes because it would be important

---

My son didn't make good enough gains to make it worth it for CCS to do th ething!

---

email with therapist when at a satellite site

---

Difficult co=ordinating school responsibility and CCS responsibility

---

My child's "occupational therapy" wasn't really therapy but monitoring and equipment management once every three months. She has severe cerebral palsy and is at great risk for contractions and other physical limitations without therapy yet she is not receiving the necessary therapy because she does not progress fast enough to make it worth her therapists' time and "therapeutic handling." This is ludicrous in my opinion that a child who needs services the most given her severe condition is unable to receive them and her doctors' agree with me

---

Therapists are not proactive. If child is uncomfortable they don't treat instead of pursuing why he is uncomfortable.

---

school OT was GREAT. CCS OT wasn't so great.

---

timid therapists

---

My child needs OT but does not qualify for Medical Therapy Unit.

---

school ot only. it helps but she needs to be in touch with teacher, parent, and aide more. not helping

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much
I would like to see better integration between the OT and school on sensory and motor issues in a full inclusion setting.
insurance coverage and not eligible for this with CCS unless she is and we don't know.
not provided by CCS
took a long time between home care and outpatient pt scheduling and approval. My son had to be re-evaluated, which held up the process.
same as above they dr [-] does not push for therapy
distance between house and therapy united posed some problems
Would like OT to continue more intense even after the age of 12
received therapies thru school, not CCS
My son's therapy was dropped from every 2 weeks to 1 time every 6 months, due to lack of progress. He now receives therapy from the school once a week and is progressing nicely.
the low standard of therapy is obvious
shortage of OT caused a problem, had to go outside CCS. The turnover of therapist and their opinions as to what is important causes ineffective follow thru to areas needing therapy.
It is difficult to get my child's IEP team administrators (School District, County SELPA, the OT provider) to provide the actual amount of OT services which my child needs.
Regional assigned OT.
the budget cuts are preventing the kind of therapy I think my child needs and deserves. therapy appts were not available after 4pm and were not available at all some days
MY CHILD WAS CUT DOWN TO MONTHLY CHECKS DUE TO BUDGET CUTS.
State of CA reducing PT and OT to 30 minutes per week. What good does that amount do???!!!
Therapist was good, but my child needed someone with experience with extreme cases.
same as last question at the top
My son was dropped to once a month PT instead of 2 times a week like he needs.
the number of visits my child needed , my child need more but they cut the ot and pt hours
Same as above.
Getting dropped from 2x per week to 2x per month, when my child clearly needed more visits!!
MY child only has OT once a month!!
See above.
Please explain: I believe that much focus on the behavior of the child and say why and unable to work or see results with the child.
only received through school district
Same as above, I'm not trained as a therapist .
Same as above!!!!!!!!!!!!!!
CCS reduced # of therapy visits due to lack of functional gains
ssa
Getting dropped due to not making progress.
staying employed while attending at least 4 therapy appointments a week was a challenge

**39. Experiences with Speech Therapy (56 responses)**

Speech is provided by the school in our county. Speech therapists are hard to find to cover CCS eligible conditions
N/A
we've always gotten speech therapy through the school district, not CCS
AAC should be considered into the CCS programs because it is a major part of therapy for some children, but CCS refused to acknowledge or help these children receive their alternative speech needs and won't allow therapist to help under their current guidelines
no in home speech therapy, nearest speech therapist insurance would pay was 30 miles away.

Difficulty with school system. Previously provided at school and great therapy.

My child has severe cerebral palsy, is non-verbal and has Cortical visual impairment so her "speech therapy" has to do with her ability to access switches which is supposedly nested within her "occupational therapy" which she receives for monitoring/equipment management only once every 3 months

speech therapy was through the school, not CCS

My child receives this only because he gets it from school not CCS

08-09 therapist was terrible. 09-10 therapist is great.

Speech was at the local elementary school and was a mess so we are doing it ourselves thru a pvt organization.

Speech Therapy was "dropped" from Early Intervention and now our Private Medical Insurer (Blue Shield HMO) requires a \$15 co-pay for every visit. We can't afford that X 3 times per week, so we dropped the service until our child turns 3 and can receive it through the school district.

This is the school's responsibility. I feel they are not adequately addressing the issue of communication.

No speech through CCS, School speech therapy lacking. Paying for private to get help. didn't know speech was available!!

CCS does not cover his speech therapy...the school district does as far as I know.

Speech was never recommended by CCS; parents obtained speech via School and NPA

My child qualifies for Speech Therapy but does not qualify for Medical Therapy Unit. He does, however, receive PT, OT ST through his school.

Speech therapy is extremely important to us and in my opinion, it's a critical service. CCS does not cover speech therapy. The school district is supposed to provide it and my daughter only gets about 30 minutes a week. I am trying to find an independent provider and will have to pay out of pocket.

he needs more than the school provides, but this is never offered

He only get it at school need more speech Therapy.

She needs CTEC assessment for communication for IEP and IPP plans and no coverage for this. provided by the school district

early start provided services but was discontinued too early.

Just denied, despite physician referral. Speech therapist at OT feeding group surprised as with SLP at school.

this therapy was excellent

ps. this was not thru CCS

School therapists have little skill with severely challenged children. Most are newly graduated

Continued Speech would be good to continue after the age of 12

received therapies thru school, not CCS

CCS did not cover this service. We receive speech therapy through Regional Center of the East Bay haven't had a good one in four years

Again, I found it difficult trying to get the funding administrators to agree to provide the necessary amount of Speech Therapy services which my child actually needed.

Regional will assign once age appropriate

difficult to find a s/l specialized in swallowing/chewing and able to work with my child

NONE OF MY CHILDREN HAVE RECEIVED SPEECH THERAPY AND ALL THREE WOULD BENEFIT.

No ST offered to us by state of CA. ST from school district is terrible, and they give our child few hours.

We had to hire attorney to get speech therapy. My child is now speaking Spanish and English.

does not offer my son speech at my mtu

my child needs a lot more hours than he gets for the speech therapist

Speech was provided by my daughter's school.

Could not get a speech generating device

Speech is not offered at my child's MTU.

paying out of pocket - CCS & insurance wouldn't approve and school-based therapy inadequate

Due to the Regional Center budget cuts, I have to do more paperwork and continue advocating for my child to receive speech services. I have to continually document my child's progress in speech and write letters of appeal for services.

My child is 20 years old and now receives only DME and OT/PT consults with CCS

No speech thru CCS-private only

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private ins. won't pay for enough speech. School did not give speech during summer.

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we did not require speech therapy.

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a limited amt of speech therapy was administered at school, but not qualified to help my daughter as I would like. Was told she could speak clearly enough.

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I think my daughter [could use it] and they do not give it to her "creo que mi hija la ocupa y todabia no se la dan"

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my child receives language therapy but the county has limited staff

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only received through school district

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I wasn't aware that speech therapy is avail via CCS

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School provided the therapy, not CCS

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school refusal to provide requested evaluation

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