

Appendix 33 - Family Survey frequencies for
CCS and Non-CCS CYSHCN

Demographic characteristics

Variable	Category	Respondents		CCS Client (N)		CCS Client (%)	
		Number	%	No	Yes	No	Yes
	Total	4,055	100.0	463	3,592	11.4	88.6
Child Age	Newborn-5	1,243	30.8	147	1,096	32.0	30.6
	6-10	992	24.6	96	896	20.9	25.0
	11-13	578	14.3	68	510	14.8	14.3
	14-16	576	14.3	80	496	17.4	13.9
	17-21	649	16.1	69	580	15.0	16.2
	Missing	17					
Race/ Ethnicity	White	921	23.4	104	817	23.2	23.5
	Black	201	5.1	23	178	5.1	5.1
	Hispanic	2,236	56.9	238	1,998	53.0	57.4
	Asian/PI	315	8.0	54	261	12.0	7.5
	AIAN/Other/Multi	256	6.5	30	226	6.7	6.5
	Missing	126		14	112		
Annual family income	Lt \$20,000	750	24.4	65	685	20.1	25.0
	\$20,000-\$34,999	1,013	33.0	81	932	25.1	34.0
	\$35,000-\$49,999	591	19.3	57	534	17.6	19.5
	\$50,000-\$74,999	329	10.7	39	290	12.1	10.6
	\$75,000-99,999	132	4.3	22	110	6.8	4.0
	\$100,000 or over	253	8.2	59	194	18.3	7.1
	Missing	987		140	847		
Highest education parent completed	Middle school	268	8.1	32	236	9.3	7.9
	Some high school	418	12.6	42	376	12.2	12.6
	High school or GED	935	28.1	73	862	21.2	28.9
	Some college	1,032	31.0	80	952	23.3	31.9
	College bachelor degree	429	12.9	66	363	19.2	12.2
	Graduate level or higher	245	7.4	51	194	14.8	6.5
Missing	728		119	609			
MCAH region	North Mountain	422	10.4	37	385	8.0	10.7
	Bay Area	1,085	26.8	155	930	33.7	25.9
	Sacramento	179	4.4	20	159	4.3	4.4
	Central Coast	175	4.3	34	141	7.4	3.9
	San Joaquin	274	6.8	52	222	11.3	6.2
	Los Angeles	118	2.9	38	80	8.3	2.2
	Orange	47	1.2	11	36	2.4	1.0
	San Diego	224	5.5	39	185	8.5	5.2
	Southeast	1,520	37.6	74	1,446	16.1	40.3

Variable	Category	Respondents		CCS Client (N)		CCS Client (%)	
		Number	%	No	Yes	No	Yes
	Total	4,055	100.0	463	3,592	11.4	88.6
Is English the primary language spoken in your home?	Yes	2,730	67.4	254	2,476	54.9	69.0
	No	1,321	32.6	209	1,112	45.1	31.0
	Missing						
If NO to Q04 and exclude not applicable on Q05:							
How often do you need an interpreter to help you speak with doctors and nurses?	Always	496	49.1	63	433	42.6	50.2
	Usually	155	15.3	25	130	16.9	15.1
	Sometimes	246	24.3	38	208	25.7	24.1
	Never	114	11.3	22	92	14.9	10.7
	Missing	310		61	249		
If Q05 = 1, 2, 3							
How often are interpretation services available?	Always	609	69.0	81	528	65.9	69.5
	Usually	159	18.0	20	139	16.3	18.3
	Sometimes	109	12.3	22	87	17.9	11.4
	Never						

Variable	Category	Respondents		CCS Client (N)		CCS Client (%)	
		Number	%	No	Yes	No	Yes
	Total	4,055	100.0	463	3,592	11.4	88.6
Q092 Insurance	Medi-Cal	3,550	87.5	292	3,258	63.1	90.7
Q093	Private	613	15.1	118	495	25.5	13.8
	Do not know	27	0.7	19	8	4.1	0.2
	Uninsured	9	0.2	6	3	1.3	0.1
Q111 Do you need more	CCS	1,061	26.2	80	981	17.3	27.3
Q112 information about:	Medi-Cal	991	24.4	120	871	25.9	24.2
Q113	Private Insurance	102	2.5	24	78	5.2	2.2
Q114	Do not know	106	2.6	23	83	5.0	2.3
Q115	My child is not insured	8	0.2	4	4	0.9	0.1
Q116	I do not need more	2,143	52.8	184	1,959	39.7	54.5
If Insured	CCS, MCal, or Private	3,979	98.1	387	3,592	83.6	100.0
Q16 Does your child's health insurance allow your child to see the health care providers that your child needs?	Always	2,666	74.5	223	2,443	63.0	75.8
	Usually	710	19.8	95	615	26.8	19.1
	Sometimes	175	4.9	31	144	8.8	4.5
	Never	28	0.8	5	23	1.4	0.7
	Not applicable	42		3	39		
	Missing	358		30	328		
Q17 Thinking specifically about this child's mental or behavioral health needs, how often does this child's health insurance offer benefits or cover services that meet those needs?	Always	1,117	62.2	123	994	53.7	63.4
	Usually	418	23.3	60	358	26.2	22.8
	Sometimes	152	8.5	27	125	11.8	8.0
	Never	110	6.1	19	91	8.3	5.8
	Don't Know/Not Sure	1,245		66	1,179		
	Not applicable	603		63	540		
	Missing	334		29	305		

Q15	In last year did your child need any services that their insurance did not cover	Respondents		CCS Client (N)		CCS Client (%)	
		N	%	No	Yes	No	Yes
		4,055	100.0	463	3,592	11.4	88.6
	Total insurance denied any services	794	19.6	123	671	26.6	18.7
Q15CAT	1 service	556	70.0	88	468	71.5	69.7
	2 services	127	16.0	15	112	12.2	16.7
	3+ services	111	14.0	20	91	16.3	13.6
Q1501	Communication aids or devices	61	1.42	13	48	10.6	7.2
Q1502	Dental checkup/teeth cleaning	108	2.51	17	91	13.8	13.6
Q1503	Durable medical equipment	158	3.68	26	132	21.1	19.7
Q1504	Eyeglasses or vision care	127	2.95	11	116	8.9	17.3
Q1506	Home health care	38	0.88	13	25	10.6	3.7
Q1508	Mental/behavioral health care	45	1.05	13	32	10.6	4.8
Q1509	Medications	203	4.72	27	176	22.0	26.2
Q1510	Other dental care	109	2.54	22	87	17.9	13.0
Q1512	Physical/occupational therapy	98	2.28	18	80	14.6	11.9
Q1513	Specialty care	66	1.54	13	53	10.6	7.9
Q1514	Speech therapy	92	2.14	15	77	12.2	11.5

Variable	Category	Respondents		CCS Client (N)		CCS Client (%)	
		Number	%	No	Yes	No	Yes
	Total	4,055	100.0	463	3,592	11.4	88.6
Q18 Is there a place that this child USUALLY goes when they are sick and you or another caregiver needs advice about his or her health?	Yes	2,679	72.2	254	2,425	66.1	72.9
	No	794	21.4	97	697	25.3	20.9
	Do not know	239	6.4	33	206	8.6	6.2
	Missing	343		79	264		
Q19 During the past 12 months, how many times did your child see a doctor, nurse, or other health care professional for sick-child care, well-child check-ups, physical exams, hospitalizations or other kind(s) of medical care?	0	115	3.1	11	104	2.9	3.2
	1	370	10.1	47	323	12.3	9.8
	2	641	17.4	66	575	17.3	17.4
	3	683	18.6	75	608	19.7	18.4
	4	329	8.9	38	291	10.0	8.8
	5	262	7.1	30	232	7.9	7.0
	6	1,279	34.8	114	1,165	29.9	35.3
7+	376		82	294			
Missing							
Q20 During the past 12 months, how many times did your child receive a well-child check-up, which is a general check-up, when they were NOT sick or injured?	0	364	10.0	47	317	12.5	9.7
	1	2,048	56.0	205	1,843	54.5	56.2
	2	641	17.5	70	571	18.6	17.4
	3+	605	16.5	54	551	14.4	16.8
	Missing	397		87	310		
Q21 During the past 12 months, how many times did your child visit a hospital emergency room?	0	2,009	54.7	228	1,781	60.2	54.1
	1	782	21.3	80	702	21.1	21.3
	2	390	10.6	29	361	7.7	11.0
	3	213	5.8	23	190	6.1	5.8
	4+	280	7.6	19	261	5.0	7.9
	Missing	381		84	297		
Q22 Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who focus on one area of health care. How many different specialist doctors has your child seen in the last 12 months?	0	346	9.4	59	287	15.4	8.7
	1	1,071	29.1	108	963	28.3	29.2
	2	790	21.5	79	711	20.7	21.6
	3	465	12.6	43	422	11.3	12.8
	4+	1,008	27.4	93	915	24.3	27.7
Missing	375		81	294			
Q23 How many times did your child see a specialist(s) in the last year?	0	282	7.7	42	240	11.0	7.3
	1	723	19.7	92	631	24.1	19.2
	2	721	19.6	66	655	17.3	19.9
	3	462	12.6	48	414	12.6	12.6
	4	380	10.4	37	343	9.7	10.4
	5+	1,102	30.0	96	1,006	25.2	30.6
	Missing	385		82	303		
Q24 In the last 12 months, how often was your child able to see a specialist when needed?	Always	2,562	73.5	240	2,322	68.4	74.1
	Usually	677	19.4	75	602	21.4	19.2
	Sometimes	204	5.9	28	176	8.0	5.6
	Never	43	1.2	8	35	2.3	1.1
	Not applicable	197		29	168		
	Missing	372		83	289		

Variable	Category	Respondents		CCS Client (N)		CCS Client (%)	
		Number	%	No	Yes	No	Yes
Q25 In the last 12 months, how often was your child able to see a specialist in a quick and timely manner?	Total	4,055	100.0	463	3,592	11.4	88.6
	Always	2,022	58.8	180	1,842	53.1	59.4
	Usually	924	26.9	100	824	29.5	26.6
	Sometimes	394	11.5	44	350	13.0	11.3
	Never	101	2.9	15	86	4.4	2.8
	Not applicable	239		40	199		
	Missing	375		84	291		
Q27 Do you know whom to call to get answers about your child's care or insurance (for example if services are denied and you want to ask why)?	Yes	2,780	76.4	257	2,523	68.2	77.4
	No	457	12.6	63	394	16.7	12.1
	Not sure	401	11.0	57	344	15.1	10.5
	Missing	372		83	289		
Q28 Do you know how to file a grievance or complaint about your child's health care?	Yes	1,666	47.1	161	1,505	43.5	47.5
	No	1,264	35.7	131	1,133	35.4	35.8
	Not sure	607	17.2	78	529	21.1	16.7
	Not applicable	135		13	122		
	Missing	383		80	303		
Q29 If yes to Q28, have you ever filed a complaint?	Yes	218	13.1	19	199	11.9	13.2
	No	1,444	86.9	141	1,303	88.1	86.8

Q26	What type(s) of specialist(s) were you NOT able to see in a quick and Total specialists not seen	Respondents		CCS Client (N)		CCS Client (%)	
		N	%	No	Yes	No	Yes
		4,055	100.0	463	3,592	11.4	88.6
		829	20.4	98	731	21.2	20.4
Q26CAT	1 specialist	537	64.8	58	479	59.2	65.5
	2 specialists	168	20.3	21	147	21.4	20.1
	3+ specialists	124	15.0	19	105	19.4	14.4
	<u>Specialist</u>	<u>N</u>	<u>%</u>				
Q2602	Cardiology	78	9.41	10	68	10.2	9.3
Q2604	Developmental Medicine	54	6.51	11	43	11.2	5.9
Q2606	Gastroenterology	123	14.84	11	112	11.2	15.3
Q2612	Neurology	186	22.44	21	165	21.4	22.6
Q2613	Neurosurgery	85	10.25	10	75	10.2	10.3
Q2615	Nutrition	47	5.67	12	35	12.2	4.8
Q2616	Ophthalmology	142	17.13	17	125	17.3	17.1
Q2619	Psychiatry	51	6.15	10	41	10.2	5.6
Q2620	Pulmonology	74	8.93	12	62	12.2	8.5
Q2622	Sports Med/Orthopedics	85	10.25	11	74	11.2	10.1

Variable	Category	Respondents		CCS Client (N)		CCS Client (%)		
		Number	%	No	Yes	No	Yes	
	Total	4,055	100.0	463	3,592	11.4	88.6	
Q30	Has your child/family been assigned a case manager?	Yes	1,826	49.7	138	1,688	36.4	51.2
		No	874	23.8	122	752	32.2	22.8
		Do not know	976	26.6	119	857	31.4	26.0
		Missing	379		84	295		
Q311	If case manager assigned, what agency? Check all that apply.	County CCS	1,315	72.0	65	1,250	47.1	74.1
Q312		Health Plan	647	35.4	25	622	18.1	36.8
Q313		Regional Center	367	20.1	38	329	27.5	19.5
Q314		CCS Special Care Center	338	18.5	24	314	17.4	18.6
Q315		Other	113	6.2	14	99	10.1	5.9
Q32	If case manager assigned, how satisfied have you been in the past 12 months with how your case manager helps your child connect with services?	Always	1,208	70.9	87	1,121	69.0	71.0
		Usually	372	21.8	27	345	21.4	21.8
		Sometimes	106	6.2	11	95	8.7	6.0
		Never	19	1.1				
Q331	In addition to yourself and your family, who helps to arrange or coordinate care for your child? Check all that apply:	CCS	474	11.7	30	444	6.5	12.4
Q332		Health Plan	320	7.9	17	303	3.7	8.4
Q333		Child's primary care doctor's office	630	15.5	60	570	13.0	15.9
Q334		Special Care Clinic/Center	553	13.6	40	513	8.6	14.3
Q335		County CCS Case	794	19.6	49	745	10.6	20.7
Q336		Child's school	187	4.6	18	169	3.9	4.7
Q337		Nobody helps	1,383	34.1	138	1,245	29.8	34.7
Q338		Dont Know/Not Sure	370	9.1	62	308	13.4	8.6
Q34	During the past 12 months, have you felt that you could have used extra help getting, setting up or coordinating your child's care among the different health care providers or services?	Always	505	15.7	69	436	22.2	15.1
		Usually	286	8.9	25	261	8.0	9.0
		Sometimes	749	23.4	85	664	27.3	22.9
		Never	1,667	52.0	132	1,535	42.4	53.0
		Not applicable	321		44	277		
		Missing	527		108	419		
	IF Q34=1,2,3							
Q35	If could have used help always, usually, sometimes, how often during the past 12 months did you get as much help as you wanted with arranging or coordinating your child's care?	Always	450	31.4	50	400	31.6	31.3
		Usually	371	25.9	32	339	20.3	26.5
		Sometimes	408	28.4	48	360	30.4	28.2
		Never	206	14.4	28	178	17.7	13.9
		Not applicable	77		10	67		
		Missing	28		11	17		
Q36	How often are your child's services coordinated in way that makes them easy to use?	Always	1,611	51.9	151	1,460	48.2	52.3
		Usually	889	28.6	89	800	28.4	28.7
		Sometimes	461	14.9	50	411	16.0	14.7
		Never	143	4.6	23	120	7.3	4.3
		Not applicable	238		33	205		
		Missing	713		117	596		
Q38	How often is it easy to coordinate therapy (physical therapy, occupational therapy) for your child in the school	Always	859	53.7	99	760	49.5	54.3
		Usually	395	24.7	59	336	29.5	24.0
		Sometimes	209	13.1	27	182	13.5	13.0

Variable	Category	Respondents		CCS Client (N)		CCS Client (%)	
		Number	%	No	Yes	No	Yes
setting?	Total	4,055	100.0	463	3,592	11.4	88.6
	Never	137	8.6	15	122	7.5	8.7
	Not applicable	252		42	210		
	Missing	2,203		221	1,982		
Q39 Have your child's doctors or other health care providers worked with you and this child to create a written plan to meet the child's health goals and needs?	Yes	2,313	65.6	222	2,091	62.2	66.0
	No	775	22.0	89	686	24.9	21.7
	Do not know	436	12.4	46	390	12.9	12.3
	Missing	531		106	425		
Q40 Do you and your doctor/provider work together as partners to make health care decisions?	Always	2,294	64.7	208	2,086	57.8	65.5
	Usually	772	21.8	88	684	24.4	21.5
	Sometimes	331	9.3	41	290	11.4	9.1
	Never	150	4.2	23	127	6.4	4.0
	Missing	508		103	405		
Q41 Do you and your doctor/provider talk about the range of treatment and care choices for your child/youth?	Always	2,326	65.7	206	2,120	57.2	66.6
	Usually	743	21.0	97	646	26.9	20.3
	Sometimes	354	10.0	46	308	12.8	9.7
	Never	120	3.4	11	109	3.1	3.4
	Missing	512		103	409		
Q42 How often did your child's doctor and/or other health care providers spend enough time with you and your child?	Always	2,236	63.1	200	2,036	55.6	64.0
	Usually	926	26.2	98	828	27.2	26.0
	Sometimes	323	9.1	54	269	15.0	8.5
	Missing	514		103	411		
Q43 Does your provider honor your requests for others (extended family, community elders, faith leaders or traditional healers that are designated by the family) to participate in the process that leads to decisions about	Always	1,993	59.6	201	1,792	59.6	59.6
	Usually	653	19.5	52	601	15.4	20.0
	Sometimes	273	8.2	32	241	9.5	8.0
	Never	424	12.7	52	372	15.4	12.4
	Missing	712		126	586		

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	Total	4,055	100.0	463	3,592	11.4	88.6	
Q46	Is your child 14 years or older?	Yes	1,094	30.3	115	979	31.8	30.1
		No	2,518	69.7	247	2,271	68.2	69.9
		Missing	443		101	342		
Q47	Have doctors or other health care providers talked with your child about how their health care needs will be met when your child turns 21?	Yes	400	37.8	37	363	34.3	38.2
		No	539	50.9	61	478	56.5	50.3
		Do not know	120	11.3	10	110	9.3	11.6
		Missing	35					
Q481	Have any of the following people or organizations helped your child find an adult medical provider?	CCS	240	21.9	19	221	16.5	22.6
Q482		Health Plan	147	13.4	12	135	10.4	13.8
Q483		Our Pediatrician	144	13.2	12	132	10.4	13.5
Q484		None of the above	528	48.3	64	464	55.7	47.4
Q49	If yes, were you able to find an adult doctor or provider?	Yes	230	62.7	23	207	76.7	61.4
		No	47	12.8	4	43	13.3	12.8
		Do not know	90	24.5	3	87	10.0	25.8
		Missing						
Q5001	If more information about moving from child to adult services would be helpful to you, in what ways would it be most helpful? (check all that apply below):	Face-to-face with provider	597	54.6	60	537	52.2	54.9
Q5002		Brochure or other reading	359	32.8	34	325	29.6	33.2
Q5003		Letter in the mail	352	32.2	38	314	33.0	32.1
Q5004		Social media group	60	5.5				
Q5005		Social media video	32	2.9				
Q5006		At school	76	6.9	10	66	8.7	6.7
Q5007		At Medical Therapy Unit (MTU)	118	10.8	12	106	10.4	10.8
Q5008		Patient support group/services	94	8.6	11	83	9.6	8.5
Q5009		Workshop or info session	135	12.3	18	117	15.7	12.0
Q5010		More information would not be helpful	82	7.5	11	71	9.6	7.3
Q50QUAL		Did not provide answer	169	15.4	19	150	16.5	15.3

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	Total	4,055	100.0	463	3,592	11.4	88.6
Does your provider ask about your family's well-being (adults and children) and their needs for support?	Always	1,518	46.3	139	1,379	40.2	47.0
	Most of the time	638	19.5	67	571	19.4	19.5
	Some of the time	580	17.7	62	518	17.9	17.7
	Never	542	16.5	78	464	22.5	15.8
	Missing	777		117	660		
How many hours per week do you or other family members spend arranging or coordinating care?	0 to 5	2,118	64.4	203	1,915	63.8	64.4
	6 to 10	462	14.0	47	415	14.8	14.0
	11 to 15	166	5.0	17	149	5.3	5.0
	16 to 20	79	2.4				
	20 +	466	14.2	45	421	14.2	14.2
Missing	764		145	619			
How many hours per week do you or other family members spend providing care for your child's medical condition at home for your child?	0 to 10	1,654	51.3	173	1,481	55.8	50.8
	10 to 20	340	10.5	44	296	14.2	10.2
	20 to 30	215	6.7	15	200	4.8	6.9
	30 to 40	138	4.3	16	122	5.2	4.2
	40 to 50	118	3.7	14	104	4.5	3.6
	50 to 60	68	2.1				
	60 to 70	61	1.9				
	70 +	630	19.5	42	588	13.5	20.2
Missing	831		153	678			
Have you or other family members ever cut down on hours or had to leave a job because of your child's health?	Yes	1,875	54.8	203	1,672	59.2	54.3
	No	1,456	42.5	129	1,327	37.6	43.1
	Do not know	91	2.7	11	80	3.2	2.6
	Missing	633		120	513		
Has a health care provider or case manager help linked you with support (e.g. family support groups, parent mentors, online support groups, etc.)?	Yes	1,110	32.5	111	999	32.2	32.5
	No	1,266	37.0	139	1,127	40.3	36.7
	Do not know	1,044	30.5	95	949	27.5	30.9
	Missing	635		118	517		
If you feel that more social and/or emotional support would help you or your family cope, what kind of social and/or emotional support would you like for you or your family? Please check all that apply:	Online or telephone support group	728	18.0	74	654	16.0	18.2
	In person support group	930	22.9	94	836	20.3	23.3
	Parent mentor or parent partner	455	11.2	49	406	10.6	11.3
	Not Applicable	1,612	39.8	161	1,451	34.8	40.4

Variable	Category	Respondents		CCS Client (N)		CCS Client (%)	
		Number	%	No	Yes	No	Yes
	Total	4,055	100.0	463	3,592	11.4	88.6
Q62 What is your overall satisfaction with CCS services? (Note: if you have never had CCS services for your child, please skip this question)	0				37		1.2
	1				8		0.3
	2				13		0.4
	3				14		0.4
	4				16		0.5
	5				93		3.0
	6				59		1.9
	7				137		4.4
	8				335		10.7
	9				366		11.6
	10				2,065		65.7
	sum				3,143		
Q62 What is your overall satisfaction with CCS services? (Note: if you have never had CCS services for your child, please skip this question)	0 to 5				181		5.8
	6 to 8				531		16.9
	9				366		11.6
	10				2,065		65.7
	Missing				449		
Q63 What is your overall satisfaction with the services that your Health Plan provides for your child? If your child does not have health insurance at all, please feel free to skip this question.	0			2	23		
	1			3	12		
	2			6	14		
	3			2	22		
	4			1	33		
	5			14	106		
	6			17	111		
	7			38	228		
	8			57	425		
	9			43	386		
	10			150	1,738		
	sum			333	3,098		
	Missing			130	494		
Q63 What is your overall satisfaction with the services that your Health Plan provides for your child? If your child does not have health insurance at all, please feel free to skip this question.	0 to 5	238	6.9	28	210	8.4	6.8
	6 to 8	876	25.5	112	764	33.6	24.7
	9	429	12.5	43	386	12.9	12.5
	10	1,888	55.0	150	1,738	45.0	56.1
	Missing	624		130	494		