

CCS Family Survey for the Title V Needs Assessment

Preliminary Results

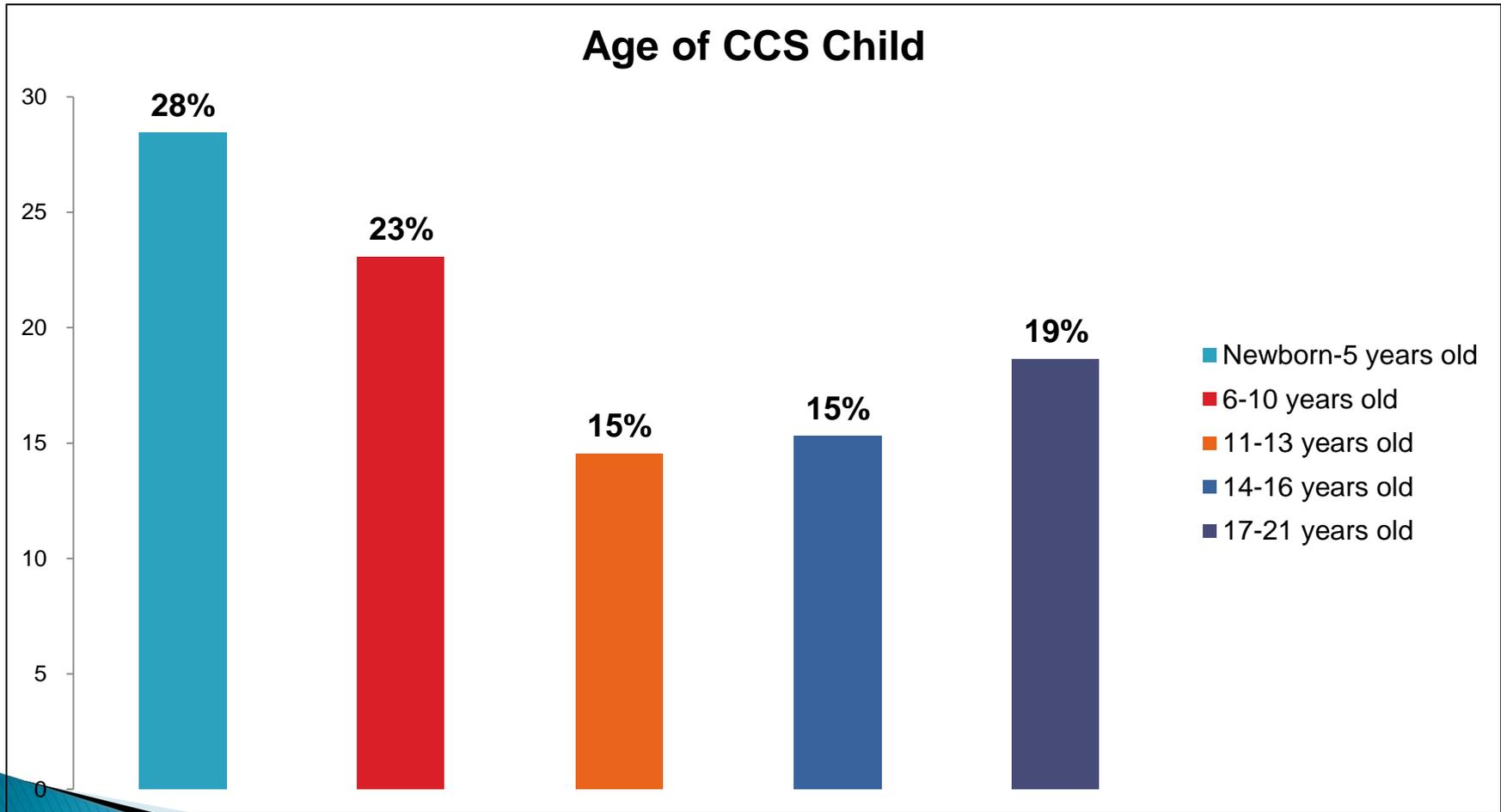
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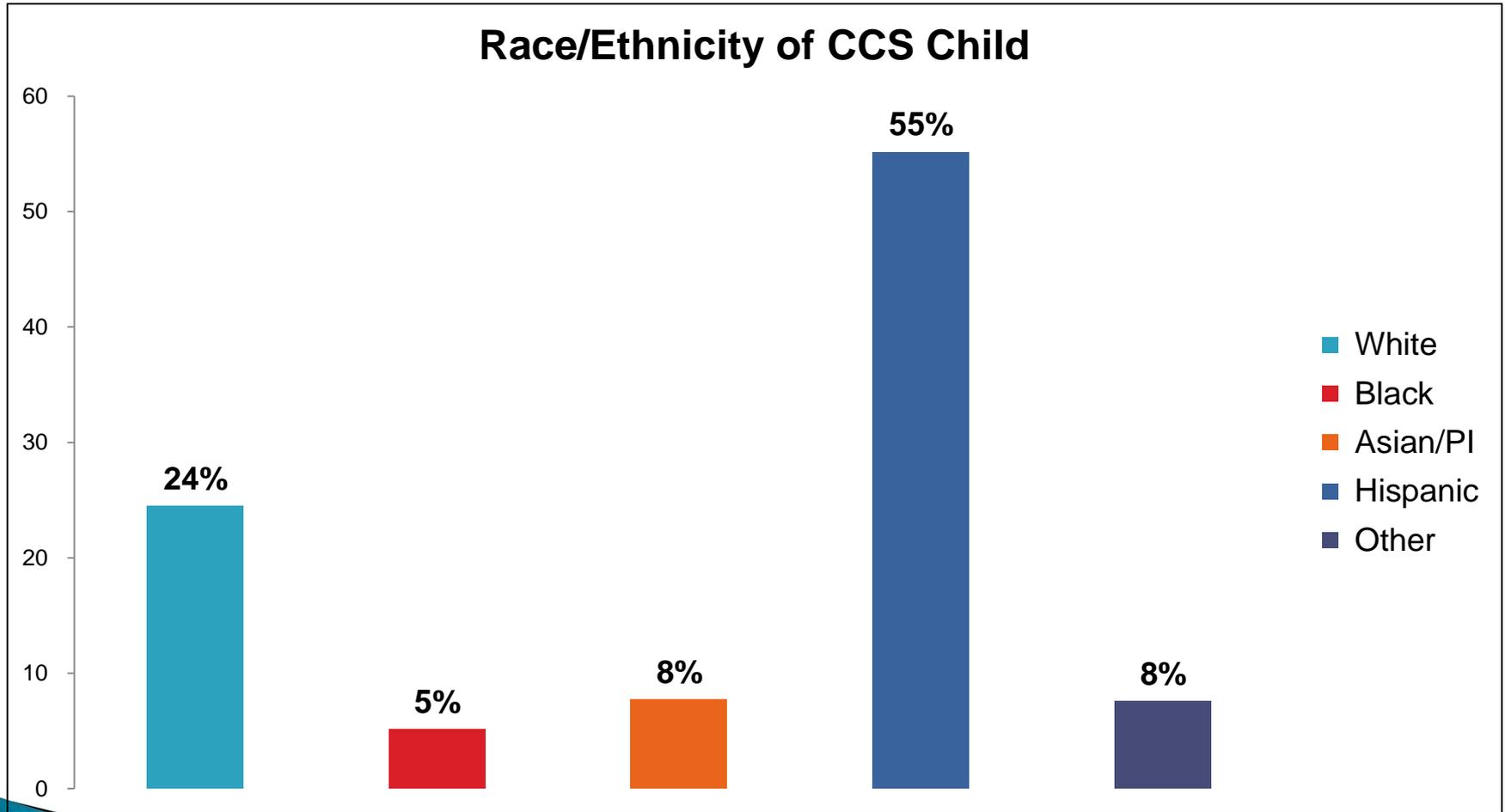
Survey Methods

- ▶ Administered by local CCS programs
 - ▶ Data collection from mid July – mid November
 - ▶ Multiple methods used:
 - CCS annual paperwork
 - Specialty Care Center
 - Phone - someone called
 - Computer - Survey Monkey
 - Smartphone - Survey Monkey
 - ▶ Sample size = 4,065 after excluding those with lots of missing data
 - ▶ Limitations: multiple methods of survey administration and many with missing data
- 

Results: Age



Results: Race Ethnicity



Results: Region and Survey Method

		N	%
Region	North Mountain	354	9
	Bay Area	554	14
	Sacramento	66	2
	Central Coast	404	10
	San Joaquin	1,025	25
	Los Angeles	195	5
	Orange	527	13
	San Diego	493	12
	Southeast	447	11

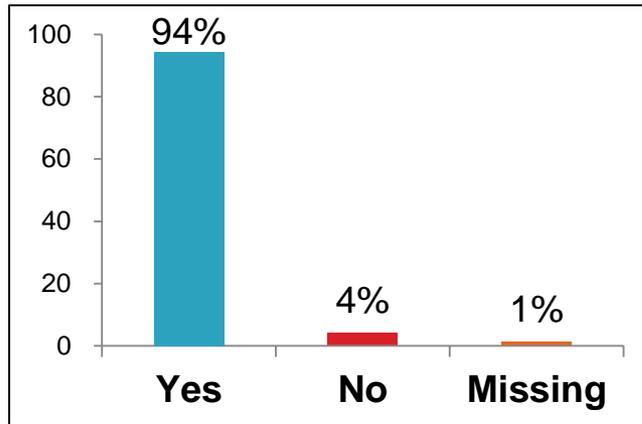
Method of Survey Completion	N	%
CCS annual paperwork	932	23
Specialty Care Center	161	4
Phone - someone called	1,492	37
Computer - Survey Monkey	561	14
Smartphone - Survey Monkey	91	2
Other	642	16
Missing	186	5

Results: Conditions

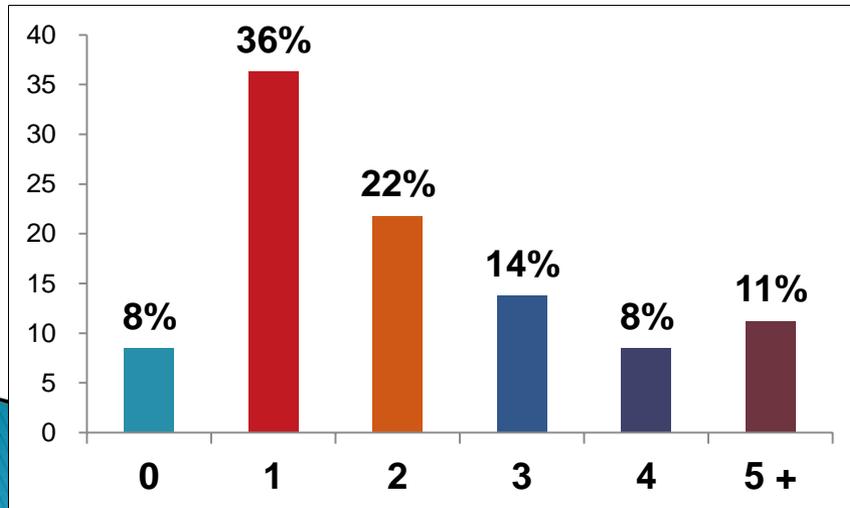
			Number					Percent				
	N	% Tot	White	Black	API	Hisp	Other	White	Black	API	Hisp	Other
Total surveys	4,065	100	2,045	210	313	1,188	309	100	100	100	100	100
Heart	523	13	127	29	39	297	31	6	14	12	25	10
Cancer/Tumors	181	4	39	7	17	101	17	2	3	5	9	6
Blood	149	4	25	16	25	73	10	1	8	8	6	3
Respiratory	284	7	59	21	26	150	28	3	10	8	13	9
Endocrine/Nutr/Metab	587	14	157	19	41	319	51	8	9	13	27	17
Genitourinary	198	5	48	6	16	110	18	2	3	5	9	6
Gastrointestinal	298	7	82	17	28	150	21	4	8	9	13	7
Birth defects	480	12	134	17	26	265	38	7	8	8	22	12
Sense organs	786	19	173	41	60	449	63	8	20	19	38	20
Nervous system	1,060	26	329	59	85	488	99	16	28	27	41	32
Musculoskeletal/connective	291	7	77	15	15	161	23	4	7	5	14	7
Immune	65	2	14	5	3	34	9	1	2	1	3	3
Injury/poisoning	183	5	53	13	18	79	20	3	6	6	7	6
Premature birth	237	6	61	15	15	114	32	3	7	5	10	10
Skin/subcutaneous	67	2	13	2	4	44	4	1	1	1	4	1
Malocclusion	132	3	27	3	7	85	10	1	1	2	7	3

Results: PCPs & Specialists

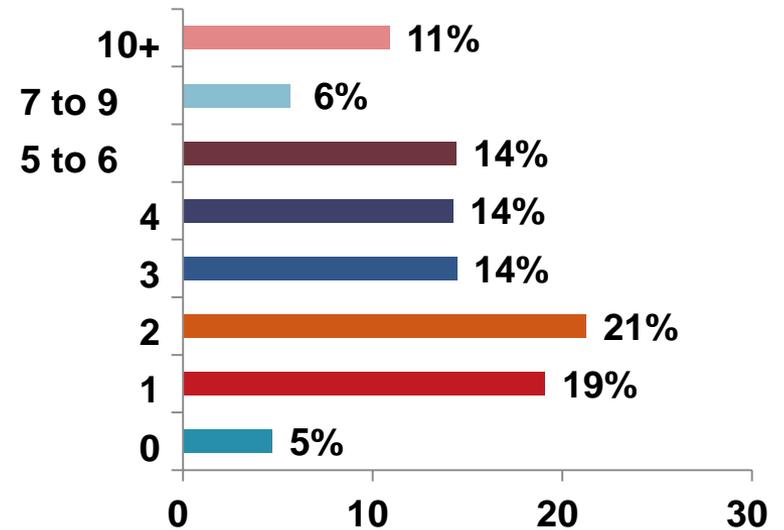
Have a primary care provider?



Number of specialist seen in last 12 mos.

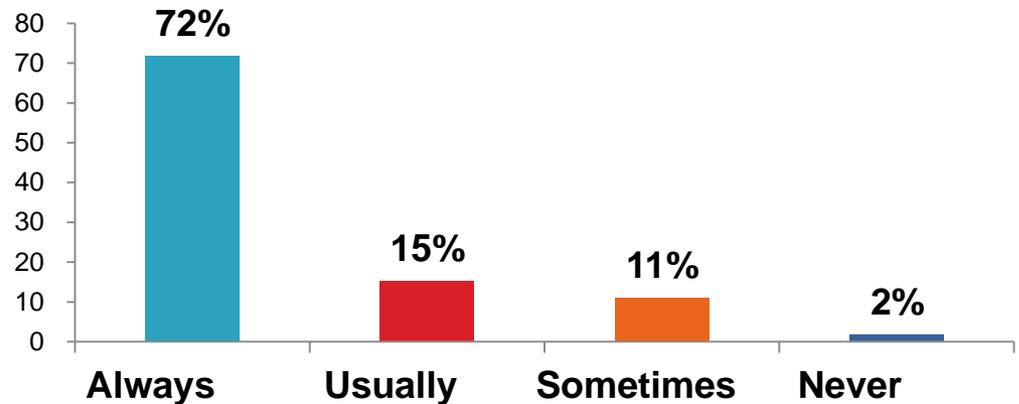


Number of specialist visits in last year?

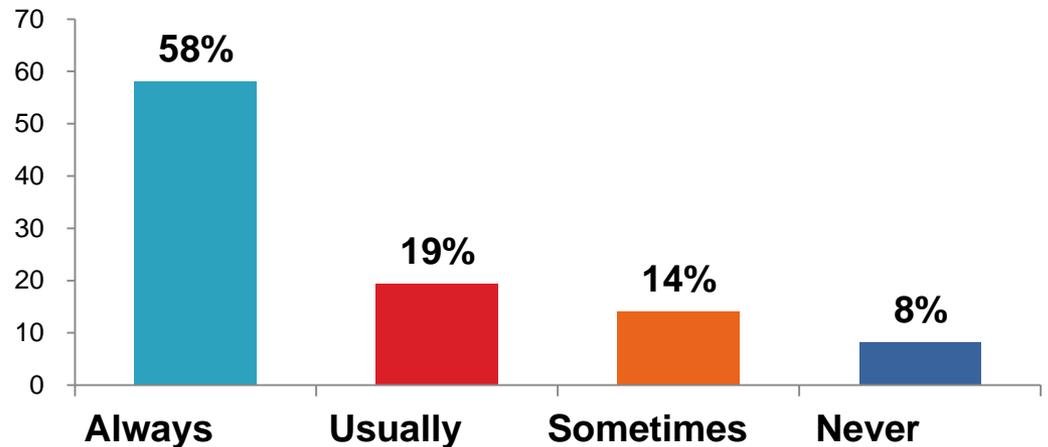


Results: Specialists

In last 12 mos., saw specialist when needed?



In last 12 mos., how often felt specialist and PCP were working together to provide care for child?

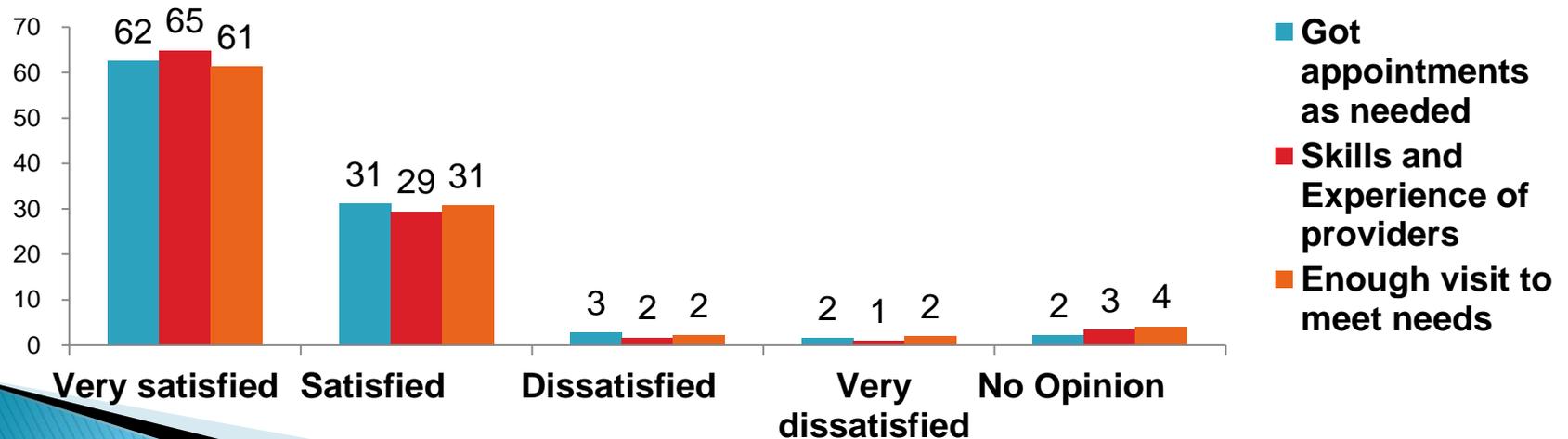


Results: Special Care Centers

Went to Special Care Center is last 12 mos.?

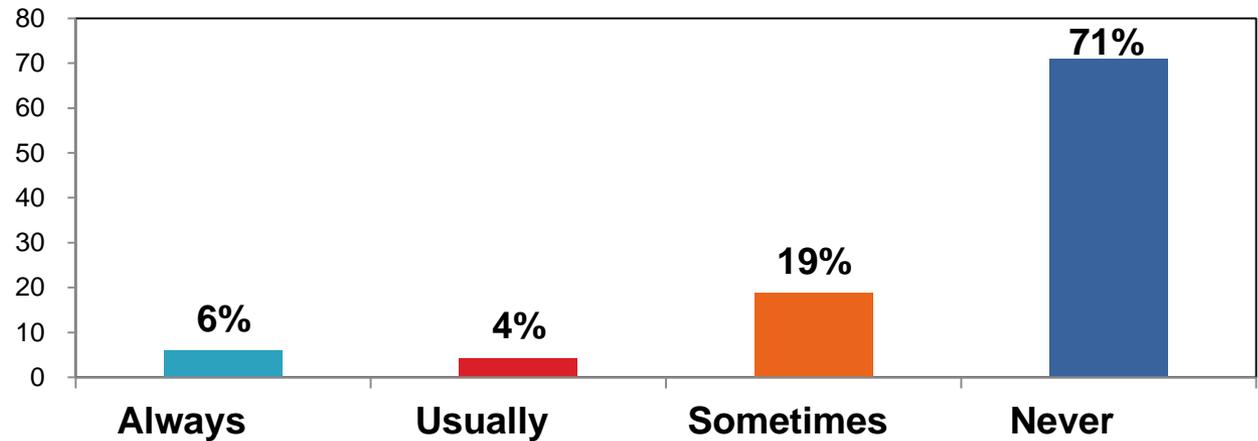
	N	%
Yes	1956	49
No	1762	44
Do not know	295	7
Missing	52	1

Satisfaction with Special Care Center...

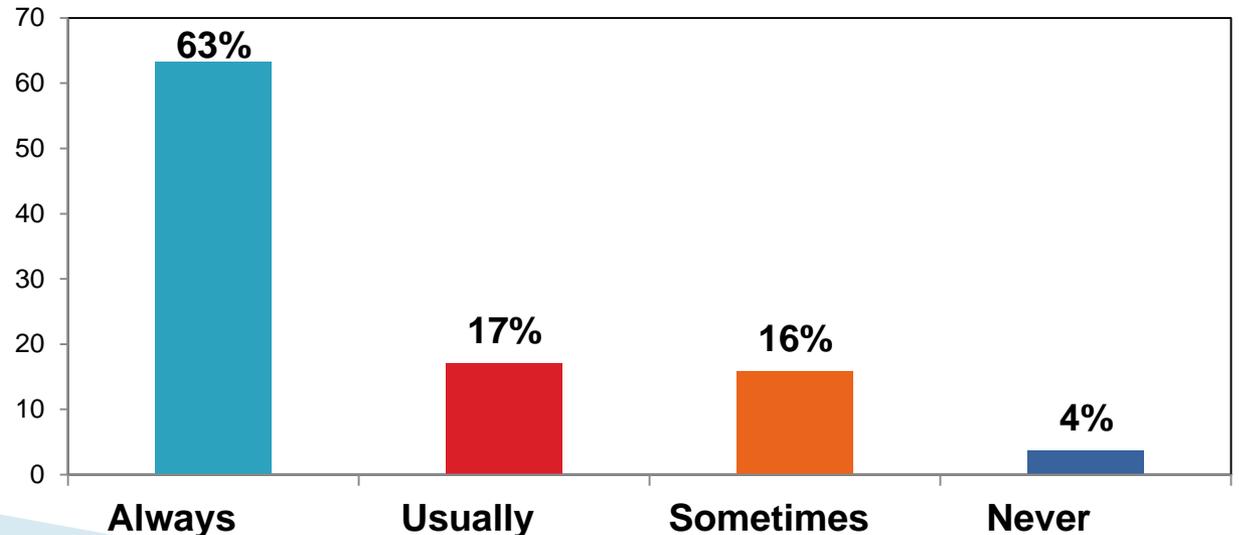


Results: Specialists Referrals and Care Coordination

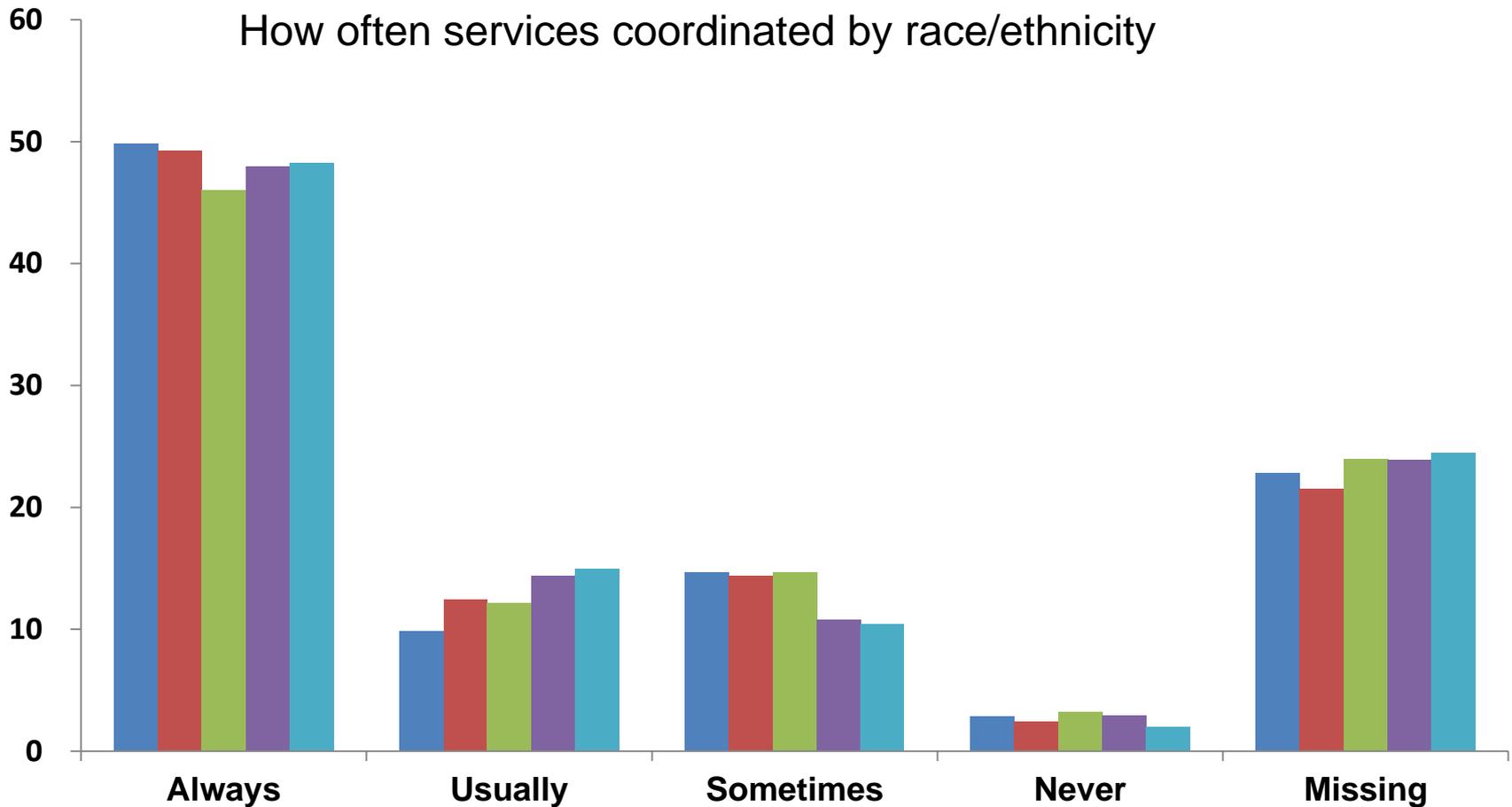
Delays or problems getting referrals to CCS Specialists?



Child's services coordinated in a way that makes them easy to use?



Results: Coordination of Services by Race/ethnicity

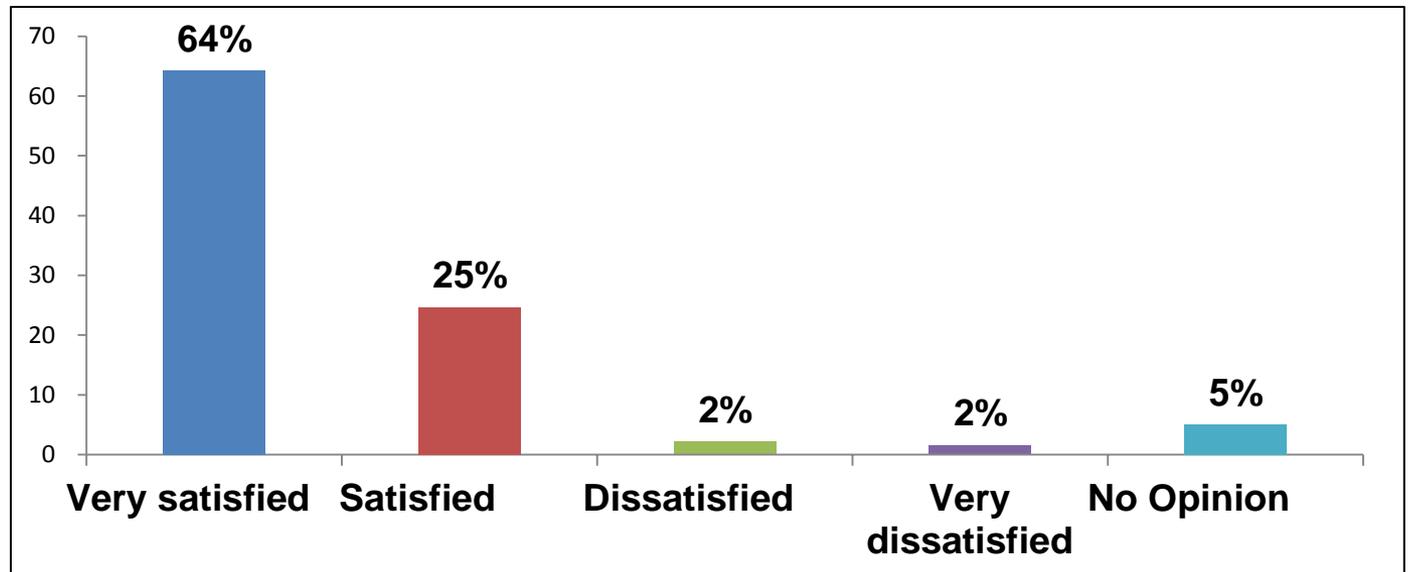


Results: Case Management

Does child have a CCS manager?

	N	%
Yes	2,658	65
No	526	13
Do not know	698	17
Missing	183	5

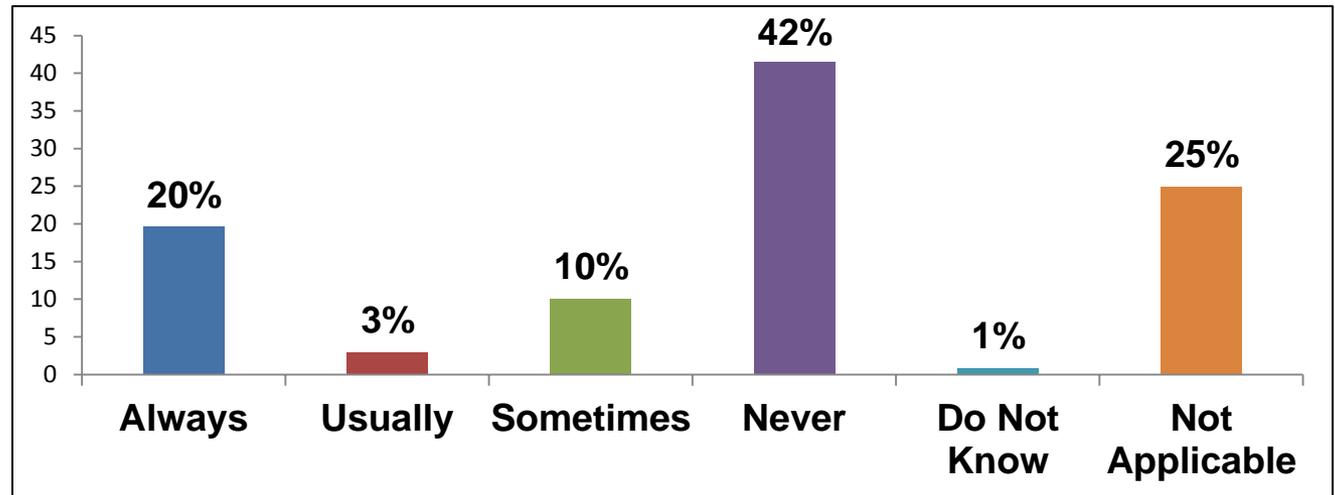
Satisfaction with CCS Case Manager?



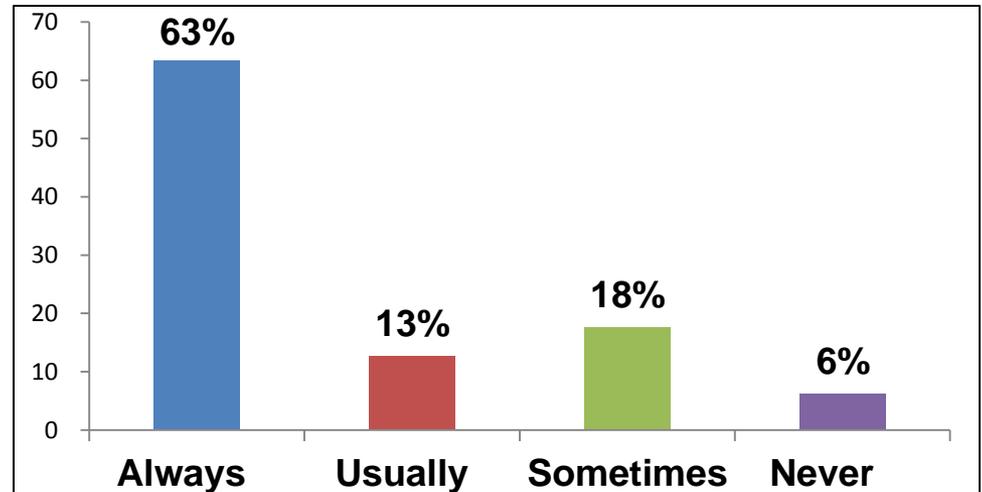
Results: Interpreters

How often do you need an interpreter?

- Of those with need, 95% need Spanish interpreter



When saw CCS specialists in last year, how often interpreter available?

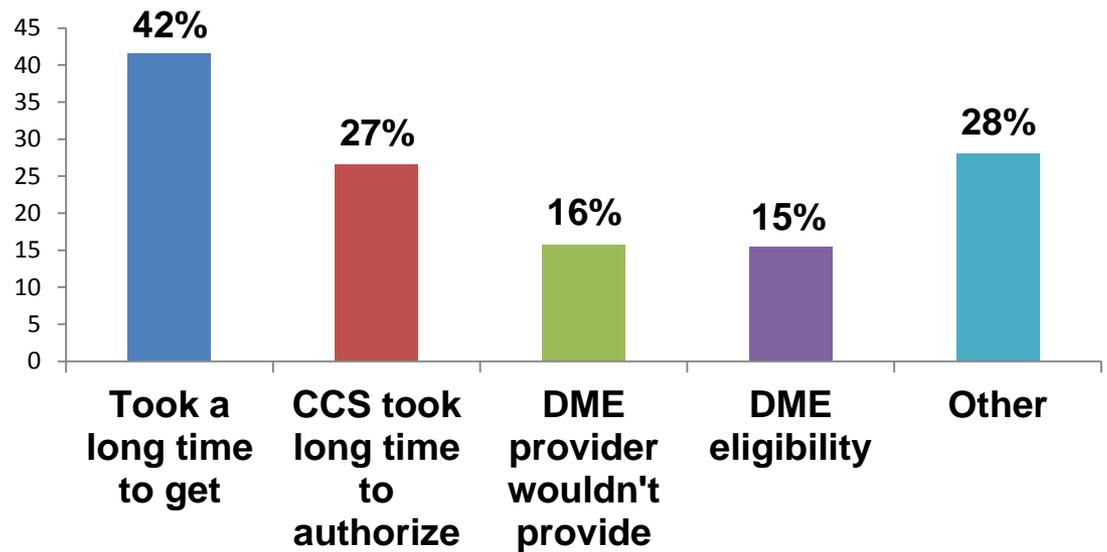


Results: DME

In last 24 mos., had problems getting medical equipment?

	N	%
Yes	407	16
No	2157	84
Not Applicable	1436	

Problems getting DME



Results: Transition

Child age 14 or older?

	N	%
Yes	1343	34
No	2629	66

- 28% of those with a child 14+ report providers talking to them about how their child's health care needs will be met when he/she turns 21
- 15% of those with a child 14+ report CCS helping to find an adult provider
 - Of those reporting CCS help finding an adult provider, 80% were successful
- 71% of those with a child 14+ would find more information on transition helpful

Results: Health Care Plans and Parent Support Groups

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

	N	%
Yes	1521	42
No	1462	41
Don't Know	611	17

- 61% of those without a health care plan would like to receive one

Interested in participating in a parent support group?

	N	%
Yes	1191	33
No	2236	62
I already belong to a parent support group	173	5

Results: Overall Satisfaction by Race/Ethnicity

			Number					Percent				
	N	% Tot	White	Black	API	Hisp	Other	White	Black	API	Hisp	Other
Total	4,065	100	994	209	313	2,242	307					
10 - Max	2,266	56	475	104	146	1,396	145	48	50	47	62	47
9	557	14	155	22	50	272	58	16	11	16	12	19
8	469	12	133	28	58	207	43	13	13	19	9	14
7	219	5	90	14	16	89	10	9	7	5	4	3
6	77	2	24	5	6	32	10	2	2	2	1	3
5	112	3	35	3	9	60	5	4	1	3	3	2
4 or less	184	5	45	16	16	86	21	5	8	5	4	7
Missing	181	4	37	17	12	100	15	4	8	4	4	5

Results: Comments about CCS

- ▶ 1289 Comments from parents
- ▶ Themes of comments:
 - Communication
 - Eligibility
 - Transportation
 - Transition
 - Other Concerns
 - Care coordination
 - Not enough providers, waiting lists for specialists
 - Copays
 - Conflict between private insurance, CCS, and MediCal

Results: Communication Comments

Issue/Concern

- ▶ Very little/poor communication
- ▶ Difficult getting appointments as needed due to a lack of communication (e.g., 1-lb premie had to wait 10 months for a pulmonology appointment)
- ▶ No knowledge of a CCS-sponsored case manager, who they are, how to connect, what they are for
- ▶ Little to no knowledge of services covered (or not) by CCS; lack of information in the community
- ▶ Unsure of service status
- ▶ Unsure of how CCS could help their child
- ▶ CCS staff at the same facility provide different answers to the same question from the same family about the same child
- ▶ Unsure of who to contact and how depending upon what the issue is (e.g., care provider, case manager, care coordinator, nurse, administrator); may not know who to contact for an issue and if they know who to contact, they don't know how to do so.
- ▶ Service lapse when families do not receive renewal notices

Results: Communication Comments

- ▶ *“Many parents don't know what this program is really about.”*
- ▶ *“Local case managers don't really engage with parents other than for compliances and travel/med/supplies, which they do very well.”*
- ▶ *“Not enough phone contact for follow up regarding administration.”*
- ▶ *“I am unsure what to expect from CCS what services CCS provides...not sure how this program actually works.”*
- ▶ *“I would like to know more about the program. My child came to me through foster [care] system and I did not receive info about CCS.”*
- ▶ *“Thank you for telling me I have a case manager.”*
- ▶ *“I appreciate the mail I get...I appreciate receiving paperwork from you.”*
- ▶ *“I would like to have a case coordinator. I would like to learn more about CCS. What programs do they offer that can help with my daughter's condition?”*
- ▶ *“Everyone is always helpful and understanding. I always feel as though my concerns are heard....”*

Results: Communication Comments

Suggestions

- ▶ Better/more/clearer communications regarding available reimbursements that are not lumped with other types of communications
- ▶ Faster response time
- ▶ More information about what the program provides
- ▶ More warning for renewals to reduce risk and length of gap in coverage including medications
- ▶ Notify families when caseworker, in charge of their children's case, is changed either via mail and/or telephone
- ▶ When patients are 18+ and parents are the primary care giver, providers should still ensure that interpreters are available for non-English speaking parents

Results: Eligibility/Coverage

Comments

Issue/Concern

- ▶ Difficulty getting prescriptions approved and covered by CCS including over-the-counter products
- ▶ What medications are covered by CCS? Questions as to what the pharmacy can charge
- ▶ Inconsistent coverage of diseases from county to county
- ▶ Delays in obtaining approval makes DME and prescriptions out of date, the wrong size, quantity, dosage, etc., particularly a problem for children with rapid progression; should not take 2-3 months for a prescription
- ▶ Unsure as to what lab tests are covered or not and why
- ▶ Discontinuation of therapies because child does not meet goals
- ▶ Lack of follow up with DME vendors

Results: Eligibility/Coverage

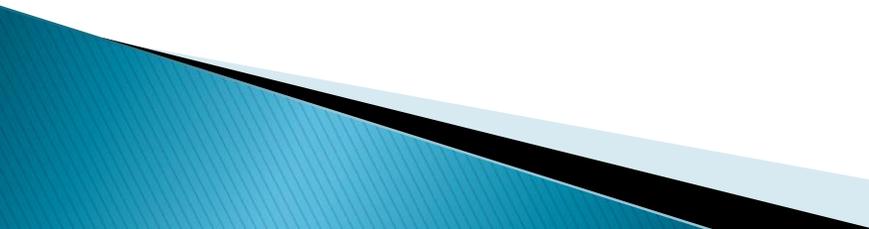
Comments

- ▶ *“I wish they hadn't discontinued my daughter's physical therapy because she wasn't meeting her goals.”*
- ▶ *“I feel that CCS should have a part in giving emergency coverage when there is a problem with insurance. A child could very well end up dead without the treatment they may need!!”*
- ▶ *“Takes too long to get authorizations. Authorizations are too vague and ambiguous, unclear what is covered.”*
- ▶ *“When a different claim was recently denied for my son, we didn't even bother fighting it, but rather paid out of pocket, to avoid the frustration of trying to get an approval with CCS.”*

Results: Eligibility/Coverage

Comments

Suggestions

- ▶ Update therapy guidelines to be more in line with evidence-based therapies used in other states (e.g., hydrotherapy, equestrian therapy, etc.)
 - ▶ Multiple months of prescriptions at a time (e.g., 90 days) vs. 1 month at a time - issues of copays and the amount of resources spent filling prescriptions monthly
 - ▶ Update eligible conditions to include diseases, disorders, conditions that are newly diagnosable
- 

Results: Transportation Comments

Issue/Concern

- ▶ Ability (or lack thereof) to follow through with referrals, particularly from rural counties, when there are limited to no transportation (e.g., no personal vehicle and/or no public transit), lodging, and food options
- ▶ Traveling out of county 2x/week for prescription refills
- ▶ Risk of injury and/or illness to child during transit (e.g., seizures) and stress of transit
- ▶ Adequate care not available in county but not able to obtain transportation support to reach care

Suggestions

- ▶ More and increased sharing/dissemination of information on transportation reimbursement eligibility
- ▶ Increased transportation reimbursements
- ▶ 2 nights of lodging per day of appointment(s)
- ▶ Allow case managers to add more hotel venues closer to specialty
services/clinics

Results: Transportation Comments

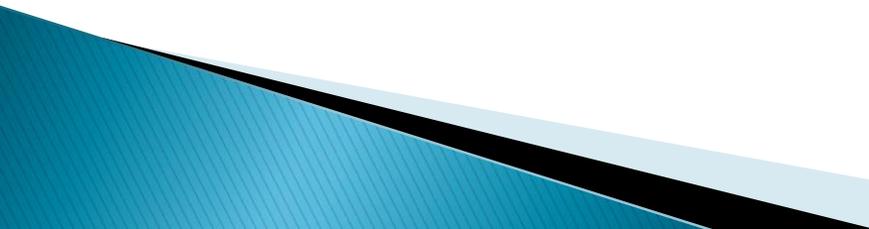
- ▶ *“Need to improve transportation reimbursement. Automatic reimbursement would be much easier on patient families.”*
- ▶ *“CCS needs to do better with transportation for the family. I don't have a car and they are trying to send me out of the city, it's incredibly complicated for me.”*
- ▶ *“Traveling out of the county is difficult I would have preferred to stay in town for these appointments.”*
- ▶ *“Travel is grueling, costly, and overnight accommodations are needed more than they are available.”*
- ▶ *“We are blessed to have CCS to help with motel and food vouchers and transportation expenses and medical care.”*
- ▶ *“Mileage reimbursements are extremely helpful, especially as a single mom.”*
- ▶ *“CCS always helps me with mileage and lodging when my child has to travel out of the county...I don't know what I would do without their help.”*

Results: Transition Comments

Issue/Concern

- ▶ Dissatisfaction with transition help or lack thereof
- ▶ Scared as to what will happen when child "ages-out"
- ▶ Lack of information
- ▶ Discrimination felt from CCS staff by Spanish-speaking family members

Suggestions

- ▶ Continue to educate families on transition services
 - ▶ Help needed in finding appropriate adult service providers
- 

Results: Transition Comments

- ▶ *“It will be sad when [my son] is 21 and [the services] will be gone...they make a big difference in my son's life.”*
- ▶ *“I pray when she gets to be an adult, she gets services equal to CCS.”*
- ▶ *“[The CCS worker] made me and my son feel as though she was being racist to us for the fact that my son has no legal documents here in the US. She answered us very short and stated there are no other services for you once your son is 21. I was very disappointed in her treatment towards us and felt very hopeless in an effort to keep treatment and services for my son after his 21st birthday.”*
[NOTE: translated from Spanish to English]

Questions?

