

TITLE V CCS NEEDS ASSESSMENT: FAMILY FOCUS GROUPS & SURVEY SUMMARY REPORT

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PRESENTATION OBJECTIVES

- Describe the work being done for the Title V CCS NA
- Summarize focus groups of Families of CYSHCN through several topic areas
- Summarize preliminary data analyses of the survey of Families of CYSHCN through several topic areas

TITLE V CCS NEEDS ASSESSMENT

- DHCS/ISCD contracted FHOP to conduct a 5-years Needs Assessment
 - Title V Block Grant
 - Components of the Needs Assessment:
 - Key Informant Interviews;
 - Focus Groups with Families, Providers, CCS Administrators, and Health Plans;
 - Survey of Providers, Administrators, and Families;
 - Analyses of administrative data; review of other relevant data and research

TITLE V NEEDS ASSESSMENT

Today's presentation will cover two components of the Needs Assessment Process:

- **Family Focus Groups:**

- CCS families (26 participants total)
- 2 groups in Southern CA , 1 group in Northern CA
- Mix of Whole Child Model (WCM) and non-WCM counties

- **Family Survey:**

- CSHCN Family Survey – 3,419 responses from CCS families used in preliminary analyses, number of responses from non-CCS CYSHCN to be determined
 - Administered in English and Spanish

CCS FAMILY FOCUS GROUPS SUMMARY

FAMILIARITY WITH CCS

How familiar are you with CCS?

For non-Whole Child Model counties (WCM), families were mostly familiar if they'd had a child in CCS for a while:

“Pretty familiar, have had to deal with it since our son began.”

In WCM counties, families are feeling less familiar:

“I feel like until they made the changes, I had a little more knowledge what was covered. Now there are things that still exist, but I'm not aware of them. Though things have changed. I feel like 'this time' I don't know everything.”

TRANSPORTATION SERVICES

For children in Whole Child Model counties that are now under Medi-Cal Managed Care Plans, transportation services previously authorized by county CCS are now being authorized by the Medi-Cal Managed Plans

- Some families have had no issues using this service
- Other families have experienced concerning difficulties b/c transportation services are not always able to accommodate medically fragile children:

“[Health plan] will not reimburse parents for mileage; they have to take [the health plan’s] uber or angel van that isn’t set up for our specific child. Sometimes we have a van or a car and [health plan] won’t pay for that—you have to submit a grievance....”

“I’d rather be in debt than entrust my daughter’s life to some random uber driver through [health plan].”

HOW WELL ARE YOUR CHILD'S NEEDS BEING MET?

“It was wonderful, before the change. I liked CCS. They did the AFOs, they did the tubes, the diapers, they did PT, they were awesome. They were always there.”

Most families have had positive experiences with CCS, but they feel that Whole Child Model is really changing the way that their children are being cared for...

“In the beginning, when you have a child with a life-changing, lifelong diagnosis, there are so many agencies coming at you. In CCS, my daughter had the same case manager the entire time, maybe two in all of her years, she had CCS until she turned 21. If I had a question, I could call Patty [case manager], if I had a “share of income letter,” that scared me, I could call Patty. Supplies were covered very constantly. They even helped with transition.”

HOW WELL ARE YOUR CHILD'S NEEDS BEING MET? BY HEALTH PLANS...

...And they had a lot to say about how the implementation to Whole Child Model is addressing the needs of their CYSHCN:

“I complained to [health plan] and I asked them why they were doing this, they aren't becoming more familiar with my daughter—CCS used to be like my family away from family because I didn't have to justify with them. They knew my child's history; if they had questions, they'd call me or get back to me.”

“The difference between CCS and [health plan] is, that CCS errs on the side of the child and [health plan] is cost-saving.”

“One of the problems that [health plan] is having is that they hired people that don't know what CCS does and they don't provide direct care. If this is the same care, why do we have to work so much harder for it?”

ENROLLMENT ISSUES & DELAYS IN CARE

Lack of communication & clarity around enrollment/eligibility contributes to delays in care & reimbursement for some families:

“I had difficulty applying for CCS, and getting reimbursed from the time of diagnosis. The steps to apply were not clear and resulted in a delay in getting services for my CCS child.”

Some Families had experienced being dropped from CCS with little or no explanation:

“A lot of cases have been closed by CCS without a lot of explanation and it looks and feels like they are closing cases so that other insurers can pay for the services. Medi-Cal is supposed to pick it up, but in all of these cases mentioned, Medi-Cal does not pick it up, they then leave our kids with nothing.”

ENROLLMENT & MEDICATION ISSUES

Some families expressed being dropped from CCS due to a lack of citizenship status (some quotes are from translators):

“She [the parent] does not speak English, and then she found out that they removed CCS because she was undocumented and her family and children with conditions were undocumented—she would like to get it back because she is seeking immigration status.”

Some families shared that their difficulties with administration have led them to seek alternate methods of care for their child:

“Medi-Cal has removed my child from CCS for their asthma, they had covered them when they were little, but then dropped them. The coordinator at the regional center hasn't been helpful in finding out how to get back on CCS. I have had to go to Tijuana to purchase asthma medication because it has been too expensive here.”

A BRIEF NOTE FROM FHOP...

We know that regulations do not permit removal from CCS if the parent or child is undocumented. However, as researchers hosting a focus group where parents of CYSHCN took time out of their already busy days to share their experiences, it would be inappropriate for us to fact check or question the experiences of these families.

MEDICAL SUPPLIES

Most families had experienced minor issues with medical supplies, but we heard the biggest complaints regarding medical supplies from families in Whole Child Model counties that have Health Plans:

“I never had a problem with the diapers before, they would come all of the time and on time and then we started to notice that they weren’t showing up. When [month of WCM implementation] came, I called to find out and they said that she needed to get a prescription from the vendor. When I called the vendor they said that due to the changes they were not contracted with [health plan], and then I called CCS and they said that the vendor should be contracted and expected me to call and figure out who they are contracted with. Then finally, I got a list for three places in [my county], and all they said was ‘we don’t know why they keep referring you here, we don’t offer those services.’ Then I finally called [health plan] and they were explaining she didn’t qualify for drugs. I had to go back to the original vendor to get the list of what they sent her in the past, and I had to go to the MD to get an authorization. **Why do I have to keep asking for something that they know my daughter has a lifetime need for?** They didn’t even have my daughter’s chart in front of them. That is what the state is paying for. Do they want to pay for people that aren’t sufficient at their job?”

DURABLE MEDICAL EQUIPMENT (DME)

Experiences with DME vary...

- ...Some families expressed really easy and positive experiences (especially when working with their county CCS case managers)
- ...Other families expressed that a lack of access to DME outside of physical therapy and the MTU setting can contribute to **delays in development:**

“...The biggest issue that I had is that a lot of the treatments are not consistent—there was a period of time when my daughter did not get any [physical] therapy, and I was given all of the excuses in the book. One thing is that they only allow you to get one necessary medical equipment and then are only granted one when the child is actively able to use it, for example a gait trainer. I had to get the regional center involved asking for medical equipment that CCS would not grant us (a light gate trainer). In therapy—they give her all kinds of equipment to use and then they tell the parents to duplicate it at home, but CCS won’t give them more than one piece of equipment—how are parents supposed to duplicate therapy at home so that she doesn’t lose what she has gained...Other children with private insurance are surpassing my daughter and we lost a year because of CCS. A lot of the “prescriptions” they grant have to be signed off by an MD and there are always delays due to this. There is a long wait between prescription and administration, MDs sometimes don’t return authorizations and they don’t carry over, you have to go back to the new MD for a new authorization.”

DURABLE MEDICAL EQUIPMENT

Equipment is sometimes broken or incorrect & the vendor won't cover costs to fix it

“When my child was younger, they would fix her wheelchair all the time. But now we can't fix anything until the vendor can accommodate and sometimes she goes months without the wheelchair because CCS rules don't allow us to find a new vendor.

Parents have to take alternate measures to get their child the equipment needed due to regulations and restrictions

“We had to get a used bathroom chair and also gait trainer from a “covert” program through private therapy. CCS does not have an official lending or re-use program for equipment, but private insurance will take and give. This is important because gait trainers can cost \$3K. **CCS could benefit from something like this**”

SPECIALISTS & SPECIALTY CARE CENTERS

Families expressed:

Many positive experiences with specialists

Difficulty getting appts, resulting delays in care

Difficulty getting appts w/ dentists & optometrists for CYSHCN

Specialists (and all MDs really) need to listen to parents about their child's care...

“Lots of trouble with getting an appointment with a specialist, seven months it took to make the appointment—if they switch doctors they have to start that wait time over. Even if this is for a life-saving procedure, DME or medication.”

“My son has always seen a specialist. Takes a long time to get the pharmacies to get approval for special formulas—pharmacies sometimes have made me pay out of pocket before authorization. My specialist always sends things before approval because she knows my son needs it.”

“I had to wait five months for glasses that a 5 year old needed to see, Medi-Cal didn't explain that if someone could call the specialist on their own and pay cash, they will be seen.”

SPECIALISTS & SPECIALTY CARE CENTERS CONTINUED

One example of the need to listen to families and include them as part of the care team:

“The neurologist gave my granddaughter medication even when both me and my daughter disagreed that the medication was right for her, and told her just to give her the medication, even though it messes up her stomach. She [my daughter, the child’s mother] explained this to another doctor that would answer her questions and this new doctor [a new doctor that was not the neurologist that gave her granddaughter the medication that upset her stomach] said that the medication would have killed her because it kills people with [specific diagnosis].”

ACCESS TO MENTAL & BEHAVIORAL HEALTH CARE

Families told us that it is incredibly difficult to access MH & BH care, specifically because:

- Lack of quality providers in general and in-network that can adequately address the needs of children with special needs
- CCS does not cover behavioral health conditions or the mental health issue is not considered related to the CCS condition

Families also shared that:

- They often utilize county mental and behavioral health services
- Parents and family members are almost never offered mental or behavioral health care, even though there is a great need for it

ACCESS TO MENTAL & BEHAVIORAL HEALTH CARE: FAMILY QUOTES

“The entire mental health system in [our county] is very poor. So many parents have called and they get no help. Even with suicidal, self-harm children.”

“In the assessment they asked me about if she is depressed, but I don’t know if I could figure that out because she is non-verbal.”

“Children with schizophrenia and bipolar disorder are not being served by CCS and they are having a hard time.”

“I have a therapist that is literally just helping me with paperwork to coordinate my child’s care, but we don’t talk about my issues or how to cope with everything and keeping everything afloat.”

“Our grief continues, am I sad about my child every day? No, they bring great things. Then there are those sneak attacks of grief that come and take you to the floor. So I think that mental health services would be great, especially for our young parents. Their wounds haven’t scabbed over even though it will never really heal.”

CASE MANAGEMENT

- Many families have very special and valued relationships with their Case Managers
- Case Managers limitations in capacity and ability to authorize services sometimes frustrates families
- Families feel that the shift to Whole Child Model has caused mostly negative changes, but also positive changes to the role of Case Management:

“Most case managers were relocated or ‘retired’ when [health plan] came in. They tried to explain how to care for kids, but the [health plan] didn’t listen. I’m not saying that they aren’t trying, but they didn’t educate themselves in advance.”

“...This is one thing that might be positive; the DME is more smoothly covered. Better than getting the state to pay the vendors.”

CARE COORDINATION

Who coordinates care for your CYSHCN?

“We do! **Parents coordinate care for their children.** But beyond that, MTUs seem to have yearly care plans. Physicians have care plans for specific diagnoses, but not specific to the child. CCS never provides us with a care plan.”

Primarily parents and families of CYSHCN...

...Parents also provided us with examples of MDs that they felt were their partners in care coordination

...Sometimes also regional centers

“Our pediatrician is in communication with us all the time. If my younger child gets sick, then he works with us on a plan for preventing my CCS child from getting sick.”

...Some parents have had particularly bad experiences with WCM Health Plans

“I take it personally that Whole Child Model and [health plan] wanted her [my daughter] to sit in her diapers for longer, and it makes me sad that instead of focusing on things that really need improvement they [instead decide that they will] will reduce diapers for CYSHCN.”

TRANSITION TO ADULT CARE

For the most part, families in focus groups did not have children that were at the age of transition yet, however:

- If their child was 14 or older, they still hadn't been spoken to about transition
- Many parents expressed concern given the lack of adult providers for special health care needs
- Parents that had children older than 21 had largely handled it themselves:

“For us, it went smooth. We were not able to find an adult provider though; I pick up where medical leaves off. I found the PCP for her, the pediatrician gave three recommendations and none of them would take her because of her need. The equipment that they gave us after transition was good quality enough and we haven't had a need for DME. This was before Whole Child Model, our case manager made sure that we had every bit of equipment we needed when she aged out.”

FAMILY SUPPORT

Families shared their experiences of family support from CCS or Health Plans, most did not receive much and many felt that CCS created unnecessary barriers to family support:

“Not nearly enough to cover all of the gaps.”

“We are to a certain degree, but just lately it has been a lot of difficult. It scares me because my job is to take the best care of my daughter and I have to go on FMLA and I also need to work and having to do CCS’s job for them. And now I have to go home and worry about a million different things. How can I give her the best care if they are putting up all of these road blocks. I don’t have the energy, I’m tapped out and tired.”

Things families suggested CCS could do to provide them with additional support:

- Better access to respite care
- Childcare for siblings that are not SHCN
- Nurses that can work off hours (not only 9-5)
- More skilled respite aides (ex: ones that know how to change diapers)
- Therapy for parents’ mental health needs

SUGGESTIONS FOR IMPROVEMENT OF CCS OVER THE NEXT 5 YEARS

“Consistency among providers about recommendations for medications and treatment.”

“Proper case or care coordination.”

On WCM: “I just feel, why did they try to fix something that wasn’t broken? They wasted thousands of dollars trying to train people that don’t know anything. Just to let them know that we are humans and we try to do our best and if you don’t provide the services that we need, our children’s health is going to suffer. We are families and children that need help.”

“Parent advisory committees to talk about transition overall.”

“There used to be a parent-friendly guide booklet to CCS and we would like this again! They never recreated it.”

“My daughter’s condition is a lifelong condition, it would be great if they didn’t make us get proof every year that she isn’t “meeting the progress” and making sure that she still has this obviously lifelong disease. There is a PT and OT appointment every year where they do this. This doesn’t benefit my child at all, especially when they make us come up with new goals each year when she hasn’t met the goals. Does it always have to be measurable; can’t her yearly goal just be to “walk better” over time? She is only ever going to make small improvements. **This doesn’t allow children to guide what they do, which is an important part of their treatment.**”

“If CCS has a re-use program for equipment.”

CSHCN FAMILY SURVEY

CSHCN FAMILY SURVEY

- ▶ Launched in mid-April, 2019. Some counties requested an extension and are still collecting responses for county-level analyses
- ▶ 3,419 responses from CCS families used in PRELIMINARY analyses (data collected through Sept. 4)
- ▶ Number of responses from non-CCS CSHCN to be determined
 - ▶ Challenges with missing data, primarily for non-CCS CSHCN
- ▶ Administered in English and Spanish

REGION, DEMOGRAPHICS AND SURVEY METHOD

Region	%	#
North Mountain	11.4	391
Bay Area	25.1	857
Sacramento	4.7	162
Central Coast	3.9	133
San Joaquin	4.4	152
Los Angeles	2.2	75
Orange	1.1	37
San Diego	4.5	154
Southeast	42.5	1,452
Missing	0.2	6

Who asked you to complete this survey?	%
County CCS	74.2
Health Plan	24.5
Local Family Resource Center	0.7
Family Voices	0.1
Children Now	0.0
My child's doctor	0.5
Missing	15.4

Race/Ethnicity	%
White	22.6
Black	5.0
Hispanic	55.4
Asian/PI	7.0
Amer. Indian, Alaskan Native/Other/Multi	6.3
Missing	3.7

How did you complete this survey?	%
At CCS as part of annual paperwork	5.3
At my child's specialist	1.4
By phone (someone called me)	54.8
By computer (Survey Monkey)	11.0
By smartphone (Survey Monkey)	12.7
Interviewed over phone in English	8.0
Interviewed over phone in Spanish	6.3
Interviewed over phone other language	0.6
Missing	12.5

DIAGNOSES

Has a doctor or other health care provider ever told you that your child had or has any of the conditions in the list below? If yes, does the child currently have the condition, and is/was that condition mild, moderate, or severe? (check all that apply)

Number of Conditions	% Any
1	31.7
2	17.3
3	11.9
4	9.5
5	7.6
6-7	10.5
8+	11.7

Diagnoses	Total	Mild	Mod	Sev
Attention deficit disorder or attention deficit hyperactive disorder (ADD or ADHD)	10.2	35.0	43.4	21.7
Allergies	25.2	46.8	36.9	16.3
Anxiety problems	15.0	39.3	43.2	17.4
Arthritis or joint problems	11.1	27.5	45.3	27.1
Asthma	15.0	51.2	34.3	14.5
Autism, Asperger's disorder, pervasive developmental disorder (PDD), or autism spectrum disorder (ASD)	8.3	35.3	32.1	32.6
Behavioral or conduct problems	13.1	33.0	45.4	21.6
Blindness or impaired vision	23.1	41.7	34.7	23.6
Blood problems other than hemophilia or sickle cell anemia	4.2	39.4	25.5	35.1
Broken bones	6.9	46.1	27.9	26.0
Cancer, tumors	5.3	27.4	30.8	41.9
Cerebral palsy	18.8	31.3	38.7	30.0

DIAGNOSES (CONT.)

Has a doctor or other health care provider ever told you that your child had or has any of the conditions in the list below? If yes, does the child currently have the condition, and is/was that condition mild, moderate, or severe? (check all that apply)

Diagnoses	Total	Mild	Mod	Sev
Cleft lip/cleft palate	3.6	38.8	38.8	22.5
Congenital heart disease	9.8	39.6	30.4	30.0
Cystic fibrosis	1.1	44.0	28.0	28.0
Diabetes	8.2	21.5	48.6	29.8
Depression	7.3	49.1	37.3	13.7
Dental problems	15.3	42.2	40.7	17.1
Developmental delay	29.5	31.9	32.1	36.0
Down syndrome	2.6	34.5	29.3	36.2
Epilepsy or seizure disorder	13.9	33.4	36.4	30.2
Genetic disorder	11.8	19.1	30.5	50.4
Head injury, concussion, or traumatic brain injury	7.5	27.1	31.9	41.0
Hearing loss	16.4	25.1	42.4	32.5
Heart problems	13.2	43.2	31.2	25.7
Hemophilia	0.8	55.6	16.7	27.8
HIV or AIDS	0.4	75.0	12.5	12.5
Infectious disease	1.7	47.4	28.9	23.7

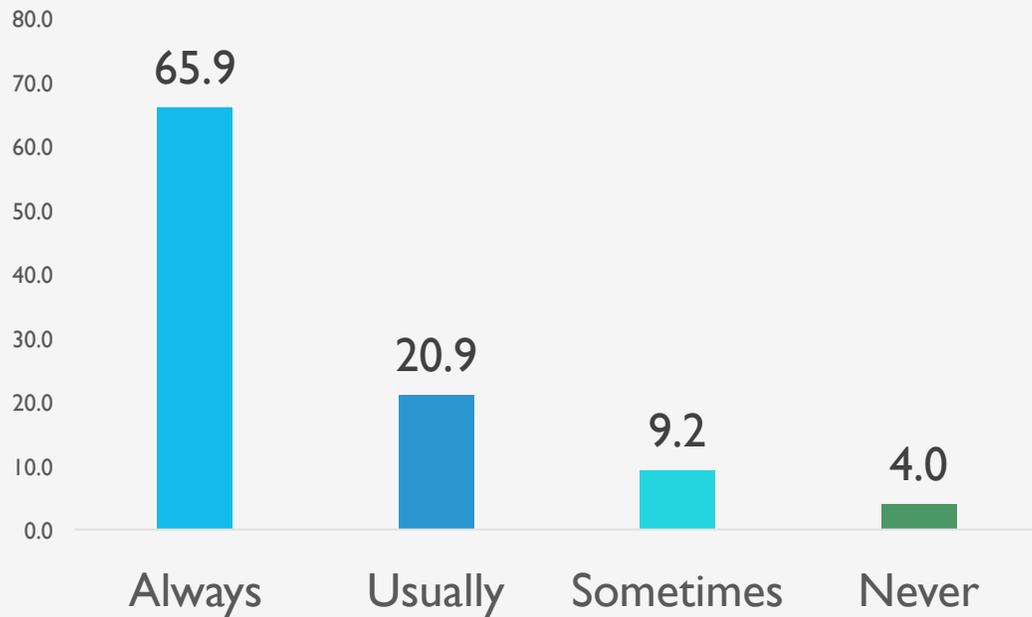
DIAGNOSES (CONT.)

Has a doctor or other health care provider ever told you that your child had or has any of the conditions in the list below? If yes, does the child currently have the condition, and is/was that condition mild, moderate, or severe? (check all that apply)

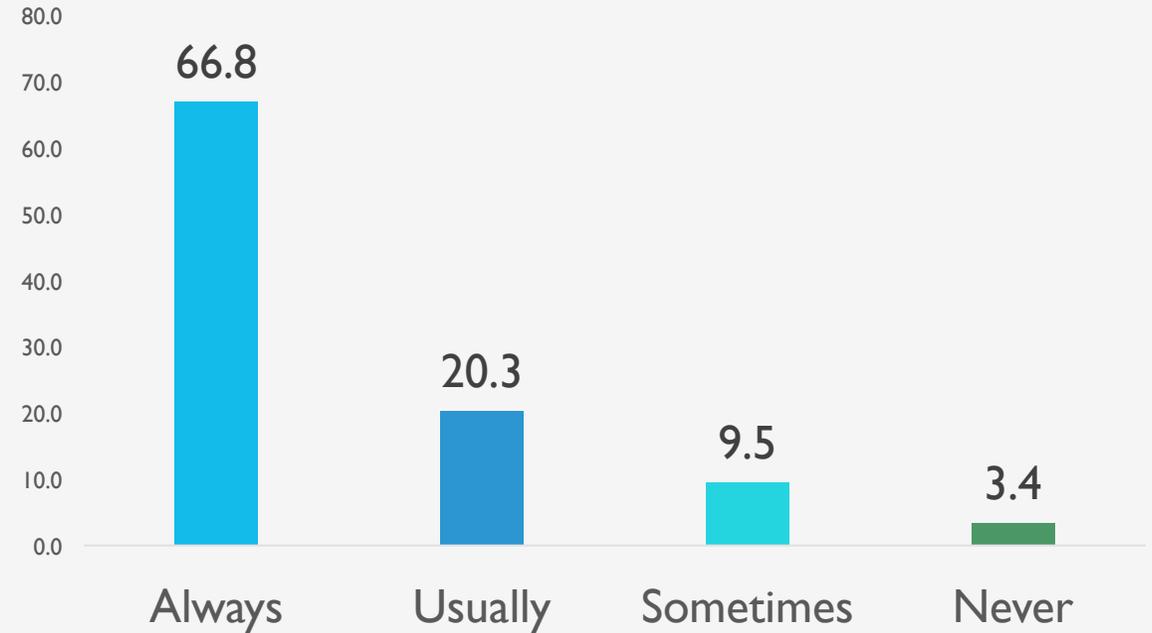
Diagnoses	Total	Mild	Mod	Sev
Intellectual disability	17.4	28.2	31.8	40.1
Intestinal or gastrointestinal problem	17.3	27.3	44.5	28.1
Kidney disease or other kidney problems	7.4	29.7	41.8	28.5
Liver problems	2.3	40.0	36.0	24.0
Lung disease	5.7	29.1	37.8	33.1
Mental health problem (Other than depression)	5.0	31.3	39.3	29.5
Migraine or frequent headaches	9.1	43.1	40.1	16.8
Muscular dystrophy	3.0	20.9	31.3	47.8
Sickle cell anemia (trait or disease)	0.9	40.0	25.0	35.0
Spinal bifida	2.8	24.6	34.4	41.0
Spinal cord injury	1.6	41.7	22.2	36.1

FAMILIES AS PARTNERS

Do you and your doctor/provider work together as partners to make health care decisions?

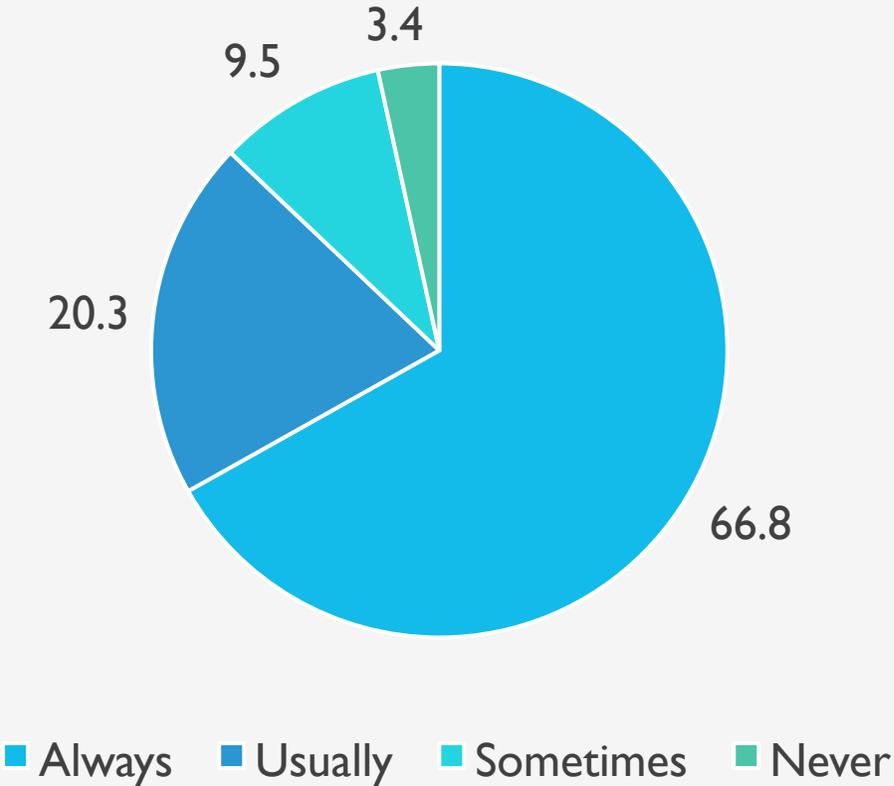


Do you and your doctor/provider talk about the range of treatment and care choices for your child/youth?

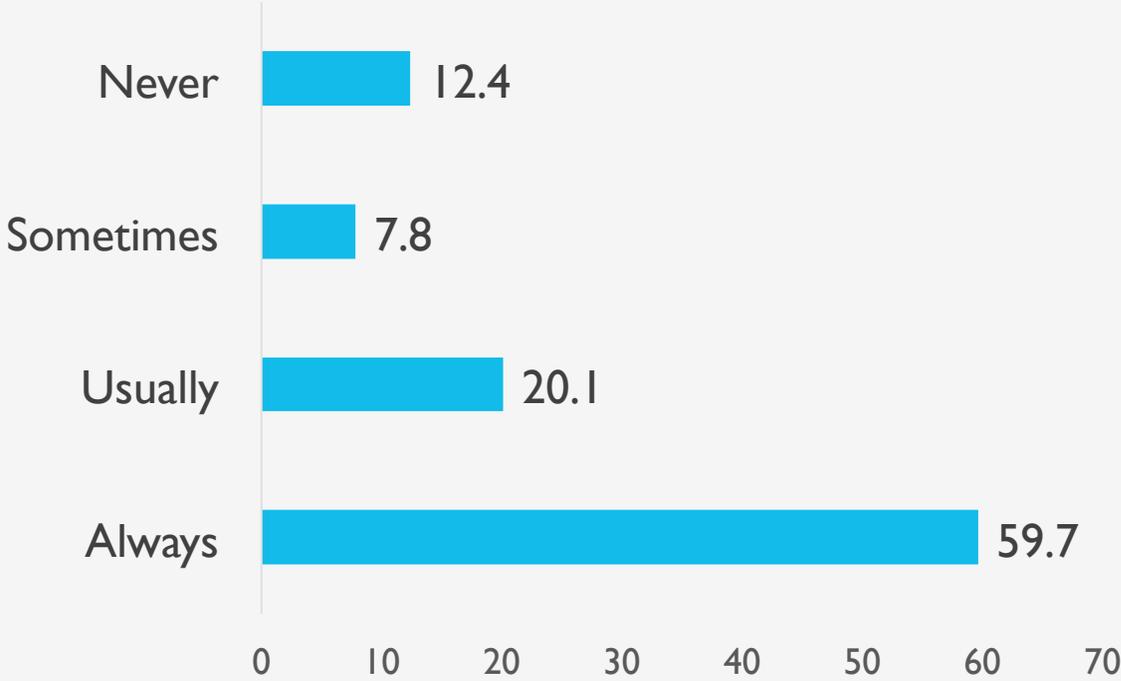


FAMILIES AS PARTNERS

How often did your child's doctor and/or other health care providers spend enough time with you and your child?



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 care?



CASE MANAGEMENT

Has your child/family been assigned a case manager?	%
Yes	46.8
No	20.6
Do not know	22.9
Missing	9.7

If case manager assigned, what agency? Check all that apply.	%
County CCS	73.7
Health Plan	6.2
Regional Center	19.6
CCS Special Care Center	18.9
Other	6.9
Missing	1.9

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	71.4
Usually	21.7
Sometimes	5.9
Never	1.0

SATISFACTION WITH CCS AND HEALTH PLAN

Overall, how satisfied are you with the CCS program on a scale of 0 (not at all) to 10 (very)?	%
0 to 5	4.8
6 to 8	24.6
9	10.8
10	59.8

What is your overall satisfaction with the services that your Health Plan provides for your child?	%
0 to 5	6.5
6 to 8	24.7
9	12.6
10	56.2

ACCESSING HEALTH CARE

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	66.9
No	18.8
Do not know	5.5
Missing	8.9

During the past 12 months, how many times did your child visit a hospital emergency room?	%
0	49.2
1	19.1
2	9.7
3	5.3
4+	7.0
Missing	9.8

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	2.9
1	9.1
2 - 3	32.6
5 - 7	17.2
8+	28.5
Missing	9.7

SERVICE NEEDS AND CARE RECEIVED

Any Services Needed	%
1	16.7
2	15.8
3	14.7
4	14.1
5-6	19.4
7+	19.4

During the past 12 months was there any time when your child needed the following services:	% Received care (%)			
	Total	All	Some	None
Communication aids or devices	5.1	80.6	8.6	10.8
Dental checkup/teeth cleaning	19.3	88.0	7.6	4.4
Durable medical equipment	13.3	85.9	7.7	6.4
Eyeglasses or vision care	13.8	87.0	8.5	4.5
Hearing aids or hearing care	4.8	83.3	9.8	6.8
Home health care	5.4	82.4	8.1	9.5
Hospitalization (in-patient stay)	10.5	90.6	6.6	2.8
Mental/behavioral health care	6.2	84.1	7.6	8.2
Medications	19.3	89.0	7.2	3.8
Other dental care	3.7	77.5	9.8	12.7
Pain management	14.2	86.1	9.5	4.4
Physical/occupational therapy	11.3	33.4	36.4	30.2
Specialty care	12.6	87.8	9.0	3.2
Speech therapy	10.1	85.8	9.8	4.4
Substance abuse treatment/counsel	0.1	50.0	0.0	50.0
Well-child check-up	18.3	90.6	7.0	2.4
X-rays	12.6	91.0	6.4	2.6

ACCESS TO SPECIALTY CARE

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	10.9
1	35.9
2	26.5
3	15.5
4+	11.2

In the last 12 months, how often was your child able to see a specialist when needed?	%
Always	74.2
Usually	19.2
Sometimes	5.5
Never	1.1

How many times did your child see a specialist(s) in the last year?	%
0	7.6
1	18.9
2	20.2
3	12.3
4	10.6
5+	30.4

In the last 12 months, how often was your child able to see a specialist in a quick and timely manner?	%
Always	59.8
Usually	26.2
Sometimes	11.2
Never	2.8

ACCESS TO SPECIALTY CARE

- What type(s) of specialist(s) were you NOT able to see in a quick and timely manner table
- 19.2% of families report not being able to see at least one type of specialist in a quick and timely manner

Specialist	%
Allergy/Immunology	4.6
Cardiology	9.3
Dermatology	5.5
Developmental Medicine	5.0
Endocrinology	9.5
Gastroenterology	14.8
General Surgery	3.0
Genetics	7.5
Gynecology	1.1
Hematology	2.4
Nephrology	3.5
Neurology	23.0
Neurosurgery	10.5
Newborn Medicine	1.2
Nutrition	4.0
Ophthalmology	16.3
Otolaryngology	10.5
Plastic Surgery	2.4
Psychiatry	5.0
Pulmonology	8.4
Rheumatology	1.4
Sports Med/Orthopedics	10.4
Urology	4.7

INSURANCE COVERAGE

Child covered by any of the following types of insurance (check all that apply)	%
Medi-Cal	90.9
Private	13.5
Do not know	0.2
Uninsured	0.1

Does your child's health insurance allow your child to see the health care providers that your child needs?	%
Always	74.5
Usually	18.6
Sometimes	4.2
Never	0.6
Not applicable	1.2
Missing	0.7

INSURANCE COVERAGE

- During the last 12 months, did your child need any services that their insurance did not cover? Please check all that apply:
 - 17.8% (609) checked at least one service

Service	%
Communication aids or devices	7.2
Dental checkup/teeth cleaning	14.3
Durable medical equipment	20.0
Eyeglasses or vision care	17.9
Hearing aids or hearing care	5.4
Home health care	3.6
Hospitalization (in-patient stay)	4.1
Mental/behavioral health care	5.1
Medications	26.8
Other dental care	12.3
Pain management	2.0
Physical/occupational therapy	11.7
Specialty care	8.7
Speech therapy	10.8
Substance abuse treatment/counsel	0.2
Well-child check-up	4.6
X-rays	2.6

WELL-CHILD VISITS

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	8.8
1	16.8
2	15.8
3+	15.0
Missing	10.2

HEALTH PLANS

Do you need more information about:	%
CCS	26.1
Medi-Cal	23.5
Private Insurance	2.0
Do not know	2.3
My child is not insured	0.1
I do not need more information	55.0

Do you know how to file a grievance or complaint about your child's health care?	%
Yes	41.9
No	30.3
Not sure	14.5
Not applicable	3.2
Missing	10.0

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	69.5
No	10.5
Not sure	9.2
Not applicable	1.2
Missing	9.6

If yes to Q28, have you ever filed a complaint?	%
Yes	38.9
No	18.1
Not sure	10.0
Not applicable	2.1
Missing	0.5

INTERPRETATION SERVICES

Is English the primary language spoken in your home?	%
Yes	70.0
No	29.5

How often do you need an interpreter to help you speak with doctors and nurses?	%
Always	39.8
Usually	11.8
Sometimes	18.3
Never	8.7

How often are interpretation services available? (for those who always, usually or sometimes need an interpreter)	%
Always	69.1
Usually	17.3
Sometimes	11.3
Never	0.8

COORDINATION OF SERVICES

How often are your child's services coordinated in a way that makes them easy to use?	%
Always	53%
Usually	29%
Sometimes	14%
Never	4%

How often is it easy to coordinate therapy (physical therapy, occupational therapy) for your child in the school setting?	%
Always	49%
Usually	21%
Sometimes	10%
Never	7%
Do not know	12%

IMPACTS ON FAMILIES – FAMILY SURVEY

How many hours per week do you or other family members spend arranging or coordinating care?	%
0 to 5	65.0
6 to 10	14.1
11 to 15	5.1
16 to 20	2.4
20 +	13.4

Have you or other family members ever cut down on hours or had to leave a job because of your child's health?	%
Yes	54.0
No	43.3
Do not know	2.6

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	50.8
10 to 20	10.4
20 to 30	6.8
30 to 40	4.1
40 to 50	3.6
50 to 60	2.2
60 to 70	2.1
70 +	20.0

SOCIAL & EMOTIONAL SUPPORT AND CARE COORDINATION

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	32.8
No	30.5
Do not know	26.1

In addition to yourself and your family, who helps to arrange or coordinate care for your child? (check all that apply)	%
Nurse Case Manager	12.3
Health Plan	8.6
Regional Center	15.3
Special Care Clinic/Center	14.1
County CCS Case Manager	20.9
Childs school	4.6
Nobody helps	34.5
Dont Know/Not Sure	7.9

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	11.8
Usually	7.0
Sometimes	17.8
Never	43.1
Not applicable	7.3
Missing	13.4

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	18.2
In person support group	22.8
Parent mentor or parent partner	11.2
Not Applicable – no additional support needed	42.1

TRANSITION TO ADULTHOOD

Is your child 14 years or older?	%
Yes	27.1
No	62.5
Missing	10.4

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	36.7
No	48.5
Do not know	11.5
Missing	3.2

Have any of the following people or organizations helped your child find an adult medical provider? Check all that apply:	%
CCS	22.2
Health Plan	13.8
Our Pediatrician	13.5
None of the above	47.2

If yes, were you able to find an adult doctor or provider?	%
Yes	59.4
No	12.1
Do not know	26.6
Missing	1.9

COMMENTS FROM PARENTS

- “My 18 year old grandchild (I am his guardian/conservator for 15+ years and have cared for him since birth) has been receiving CCS benefits since he was an infant. I honestly can say I don't know what I would have done back then without them. He has a twin with the same muscle disease and is also a CCS client. Their particular disease is known as one of the most underdiagnosed diseases due to the complexity of symptoms. It is genetic with each generation presenting more severe until finally a baby with the most severe form is diagnosed. We are so grateful to have our CCS manager who understands my grandsons' needs and helps us keep our team of doctors that care for them. And now with the new dx of leukemia, it is even more important than ever that we keep receiving our authorizations in a timely manner. It means so much to have a specialized group at CCS that truly understands complex diseases and knows the importance of keeping on top of the kids needs. We have never had a delay in a call back or authorization ever, and when you have a seriously ill child, that means a lot. We are also grateful to the Lucile Packard Childrens Hospital and Medical doctors that accept Medi-Cal/CCS.”

COMMENTS FROM PARENTS

- “A lot of it is better communication. Even sending out, what rights are in CCS , understanding of how program works. I didn't even know how my child qualified. It was a traumatic time when I signed the paperwork and I must've signed it not realizing. I'm sure someone told me because I was caught up in life.”
- “after transition to adult, we need help with services, medication, medical equipment, we don't know where to go for help sometimes.”
- “Appreciate the yearly meetings we had at MTU to talk about the transition for child to adult and what changes occur.”
- “Because of [WCM] changes this year it was difficult to continue processing RX with specialty company and supply nasal medications, caused a lot of delays/potential dangers”
- “Call people back! Get referrals approved faster or at least timely! Weeks is too long”
- “CCS provides critical services we could not manage without “

COMMENTS FROM PARENTS

- “CCS was very thorough explaining to me the process that I needed to go through to get my son's hearing aids I think that is CCS wouldn't have explained it to me I would have been upset cause the ENT Dr and Craniofacial center tried to explain it to me but I didn't understand so I'm very grateful for CCS.”
- “I have had issues with the SARRS being approved timely and it delays the main medications that he needs. I have to call the CCS Nurse Case Manager to approve it. It has been becoming an issue that I have been dealing with a lot.”
- “My CCS services have been satisfactory, but I am not allowed to use them because of the Whole Child Model. The WCM doesn't provide the same standard of care.”
- “Respite Care is a dire need in Tuolumne County. What is it going to take to establish a respite and nursing agencies in the county?”
- “Thank you so much for all the help we have received from CCS. It a blessing have this services with us. I don't think I would be able to care for my child without CCS help. Great services.

CSHCN FAMILY SURVEY

- ▶ Launched in mid-April, 2018. Some counties requested an extension and are still collecting responses for county-level analyses
- ▶ 3,419 responses from CCS families used in PRELIMINARY analyses (data collected through Sept. 4)
- ▶ Number of responses from non-CCS CSHCN to be determined
 - ▶ Challenges with missing data, primarily for non-CCS CSHCN
- ▶ Administered in English and Spanish

QUESTIONS?

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