[To Survey Administrator: Please see bolded instructions in brackets where they apply. Instructions are listed *below* questions]

[Please note: the Family Health Outcomes Project will not be accepting written surveys, any survey that you fill out on paper MUST be entered into the survey online via the Survey Monkey Link.

Here is how you can enter it into your browser: https://www.surveymonkey.com/r/CYSHCNSurvey19-ENG or click the link above]

Title V Children with Special Health Care Needs - Family Survey

Family Survey - Introduction

Please fill out this survey if you have a child with one or more special health care needs, and you get health care for this child in California. Some questions are about California Children's Services, also known as CCS. California Children's Services (CCS) is a state program for children with certain diseases or health problems. Through this program, children up to 21 years old can get the health care and services they need. CCS can connect you with doctors and trained health care people who know how to care for children with special health care needs. If your child does not have CCS or if you are unsure, you can skip these questions.

If you have more than one child with special health care needs, please fill out the survey for the child that has CCS. If none of your children has CCS, or more than one child has CCS, please fill out the survey for your child who has the most health care needs.

The California Department of Health Care Services wants to know what you think about CCS, and other health care programs, and how they meet the health needs of your child. This survey is anonymous. No answers will be linked to your name. If you do not want to answer a question, you do not have to.

If you are 18 years of age or older with a special health care need, and will answer this survey for yourself, we mean you when we say "your child." Please answer each question based on you.

1. How old is your child?

[There will be a dropdown menu to select an age, you DO NOT need to read off all of the ages, simply wait for the participant to reply and then select the answer from the drop-down list.]

Title V Children with Special Health Care Needs - Family Survey

2. Is your child with special health care needs of Hispanic, Latino, or Spanish origin?

- ◯ Yes
- ◯ No

3. Which of the following categories best describes the race of your child? (choose all that apply)

- ☐ White or Caucasian
- ☐ Black or African American
- ☐ Asian, Pacific Islander, or Southeast Asian
- ☐ Native American, American Indian, Aleut, or Eskimo
- ☐ Multiracial
- ☐

Other (please specify)

Title V Children with Special Health Care Needs - Family Survey

4. Is English the primary language spoken in your home?

- ◯ Yes
- ◯ No

[SKIP LOGIC: If the participant answers YES, skip to Q7. If they answer NO, proceed to Q5]

Title V Children with Special Health Care Needs - Family Survey

Interpretation Questions

5. How often do you need an interpreter to help you speak with doctors and nurses?

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Rarely
- ◯ Never

6. How often are interpretation services available?

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Never
- ◯ Not Sure

Title V Children with Special Health Care Needs - Family Survey

Continued Family Survey

7. What California County does your child live in?

[ ]

[There will be a dropdown menu to select a county, you DO NOT need to read off all of the counties, simply wait for the participant to reply and then select the answer from the drop-down list.]

Title V Children with Special Health Care Needs - Family Survey

Conditions

8. 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? From the table below, select all that apply:

	Ever Had Condition?	Has Condition Now?	Mild, Moderate, or Severe?
Attention Deficit Disorder or Attention Deficit Hyperactive Disorder (ADD or ADHD)			
Allergies			
Anxiety Problems			
Arthritis or Joint Problems			
Asthma			
Autism, Asperger's Disorder, Pervasive Developmental Disorder (PDD), or Autism Spectrum Disorder (ASD)			
Behavioral or Conduct Problems			
Blindness or Impaired Vision			
Blood Problems other than Hemophilia or Sick Cell Anemia			
Broken Bones			
Cancer, Tumors			
Cerebral Palsy			
Cleft Lip/Cleft Palate			
Congenital Heart Disease			
Cystic Fibrosis			
Diabetes			
Depression			
Dental Problems			
Developmental Delay			
Diabetes			
Down Syndrome			
Epilepsy or Seizure Disorder			
Genetic Disorder			
Head Injury, Concussion, or Traumatic Brain Injury			
Hearing Loss			

	Ever Had Condition?	Has Condition Now?	Mild, Moderate, or Severe?
Heart Problems			
Hemophilia			
HIV or AIDS			
Infectious Disease			
Intellectual Disability			
Intestinal or Gastrointestinal Problem			
Kidney Disease or Other Kidney Problems			
Liver Problems			
Lung Disease			
Mental Health Problem (Other than Depression)			
Migraine or Frequent Headaches			
Muscular Dystrophy			
Sickle Cell Anemia (Trait or Disease)			
Spinal Bifida			
Spinal Cord Injury			

Other (please specify for as many conditions as you need to)

[For this question, read down the list of conditions—when a participant notes that a doctor has told them their child had or has the condition, read across ONLY for those conditions (so you are not reading across for every single condition). For these drop-down menus, please read them all of the options as follows and select their choice:

Ever Had Condition?:
- **Yes**
- **No**
- **Not Sure**

Has Condition Now?:
- **Yes**
- **No**
- **Not Sure**

Mild, Moderate, Severe?:
- **Mild**
- **Moderate**
- **Severe]**

Title V Children with Special Health Care Needs - Family Survey

Health Coverage

9. Is this child covered by any of the following types of health insurance or health coverage plans? Check

all that apply:

- [ ] California Children's Services (CCS)
- [ ] Medi-Cal
- [ ] Private Insurance
- [ ] I don't know
- [ ] My child is not insured

Other (please specify)

[SKIP LOGIC: If the participant answers Medi-Cal, proceed to Q10, if they select any other option, SKIP TO Q11]

Title V Children with Special Health Care Needs - Family Survey

Medi-Cal Managed Care Health Plans

10. If you know, what is the name of your child's Medi-Cal Managed Care Health Plan?

[There will be a dropdown menu to select Medi-Cal Managed Care Health Plans, please read the following options for the participant to select from:

- **Aetna Better Health of California**
- **Alameda Alliance for Health**
- **AltaMed**
- **Anthem Blue Cross Partnership Plan**
- **Blue Shield of California Promise Health Plan**
- **California Health and Wellness**
- **CalOptima**
- **CalViva Health**
- **Central California Alliance for Health**
- **CenCal Health**
- **Contra Costa Health Plan**
- **Gold Coast Health Plan**
- **Health Net Community Solutions, Inc.**
- **Health Plan of San Mateo**
- **Health Plan of San Joaquin**
- **Inland Empire Health Plan**
- **Kaiser Permanente**
- **Kern Family Health**
- **L.A. Care Health Plan**
- **Molina Healthcare of California Partner Plan, Inc.**
- **Partnership Health Plan of California**
- **Rady Children's Hospital**
- **Santa Clara Family Health Plan**
- **San Francisco Health Plan**
- **United Healthcare Community Plan**
- **I don't know**
- **Not Applicable – My child has Medi-Cal Fee-For-Service]**

Title V Children with Special Health Care Needs - Family Survey

Continued Family Survey - Services

11. Do you need more information about what services your health insurance or Health Plan covers for your child? If yes, please select which health insurance or Health Plan you would need more information about:

- [ ] California Children's Services (CCS)
- [ ] Medi-Cal
- [ ] Private Insurance
- [ ] I don't know
- [ ] My child is not insured
- [ ] I do not need more information about services
- [ ] Other (please specify)

Title V Children with Special Health Care Needs - Family Survey

Services

12. During the past 12 months was there any time when your child needed the following services:

	Service	Received All Needed Care?
Service 1		
Service 2		
Service 3		
Service 4		
Service 5		
Service 6		
Service 7		
Service 8		
Service 9		
Service 10		
Additional Services (Other)		

Other (please specify any other services you did not get to list above)

[Please read the dropdown menus for each row at a time until the participant states that there are no additional services that were needed in the previous 12 months. Before reading the services say "Did your child need…":

Services:

- **Communication Aids or Devices**
- **Dental Checkup & Teeth Cleaning**
- **Durable Medical Equipment**
- **Eyeglasses or Vision Care**
- **Hearing Aids or Hearing Care**
- **Home Health Care**
- **Hospitalization (In-patient Stay)**
- **Mental or Behavioral Health Care or Counseling**
- **Medications**
- **Other Dental Care**
- **Pain Management**
- **Physical or Occupational Therapy**
- **Specialty Care**
- **Speech Therapy**
- **Substance Abuse Treatment or Counseling**
- **Well-Child Check-up**
- **X-Rays**

Received All Needed Care?:

- **Yes - Received all needed care**
- **Some - Received some not all**
- **No - Did not receive care**
- **Not Sure]**

13. During the past 12 months, if there was any time when your child did not receive needed services, please select the main reason why from below:

	Service	Main Reason for Not Receiving Care?
Service 1		
Service 2		
Service 3		
Service 4		
Service 5		
Service 6		
Service 7		
Service 8		
Service 9		
Service 10		
Additional Services (Other)		

Other (please specify any other services you did not get to list above)

[Go through the list of services from the previous question (Q12) and, for services that were NOT received, once you have selected the service that corresponds with the service from Q12, ask them "what was the main reason that your child did not receive care for this service?" YOU DO NOT NEED TO READ THE ANSWER CHOICES TO THEM; you can simply select the answer choice from the list (added below) that best matches their answer:

Main Reason for Not Receiving Care?:

- **Cost was too much or too high**
- **No insurance**
- **Health Plan problem**
- **CCS Problem**
- **Whole Child Model Problem**
- **Difficulty getting authorizations**
- **Can't find a provider who accepts my child's insurance**
- **Not available in my area**
- **Transportation problems**
- **Not convenient times for an appointment**
- **Could not get an appointment**
- **No translation services available**
- **Provider did not know how to treat my child's illness**
- **Dissatisfied with the provider from previous appointments**
- **Did not know where to go for treatment**
- **Child refused to go**
- **Treatment is ongoing (still happening now)**
- **No referral to this service**
- **Lack of resources at school**
- **Neglected or forgot appointment**
- **Never Explained**

- **Could not find a provider for this service**
- **Other]**

Title V Children with Special Health Care Needs - Family Survey

Experienced a delayed care

14. During the past 12 months was there any time when your child needed the services you listed in the previous questions and you experienced delays in getting those services?:

	Service	Experienced Delay in Receiving Care?
Service 1		
Service 2		
Service 3		
Service 4		
Service 5		

Additional Services

(Other)

Other (please specify)

[Go through the list of services from question 12 (two questions ago) for services that <u>WERE</u> received, ask them "Did you experience a delay in receiving this care for your child?" YOU DO NOT NEED TO READ THE ANSWER CHOICES TO THEM; you can simply select the answer choice from the list (added below) that best matches their answer:

Experienced Delay in Receiving Care?:

- **No, there was no delay**
- **Yes, there was a delay of 1 month or less**
- **Yes, there was a delay of 1-2 months**
- **Yes, there was a delay of 2-4 months**
- **Yes, there was a delay of 4-6 months**
- **Yes, there was a delay of 6-8 months**
- **Yes, there was a delay of 8-10 months**
- **Yes, there was a delay of 10 to 12 months**
- **Yes, there was a delay of a year or more]**

15. During the last 12 months, did your child need any services that their insurance did not cover? Please check all that apply:

- [ ] Communication Aids or Devices
- [ ] Dental Checkup & Teeth Cleaning
- [ ] Durable Medical Equipment (e.g., Orthotics/braces, Wheelchair, etc.)
- [ ] Eyeglasses or Vision Care
- [ ] Hearing Aids or Hearing Care
- [ ] Home Health Care
- [ ] Hospitalization (In-patient Stay)
- [ ] Mental or Behavioral Health Care or Counseling
- [ ] Medications
- [ ] Other Dental Care (e.g., braces)
- [ ] Pain Management
- [ ] Physical or Occupational Therapy
- [ ] Specialty Care
- [ ] Speech Therapy
- [ ] Substance Abuse Treatment or Counseling
- [ ] Well-Child Check-up
- [ ] X-Rays

16. Does your child's health insurance allow your child to see the health care providers that your child needs?

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Never
- ◯ Not Applicable

17. 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
- ◯ Usually
- ◯ Sometimes
- ◯ Never
- ◯ Don't Know/Not Sure
- ◯ Not Applicable

18. 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
- ◯ No
- ◯ Not Sure

Title V Children with Special Health Care Needs - Family Survey

Specialists

19. 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
- ◯ 1
- ◯ 2
- ◯ 4
- ◯ 5
- ◯ 6
- ◯ 7
- ◯ 8+

20. 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
- ◯ 1
- ◯ 2
- ◯ 3+

21. During the past 12 months, how many times did your child visit a hospital emergency room?

- ◯ 0
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4+

22. 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
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ 5+

23. How many times did your child see a specialist(s) in the last year?

- ◯ 0
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ 5+

24. In the last 12 months, how often was your child able to see a specialist when needed?

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Never
- ◯ Not Applicable

25. In the last 12 months, how often was your child able to see a specialist in a quick and timely manner? (As a quick reminder, specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who focus on one area of health care.)

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Never
- ◯ Not Applicable

[SKIP LOGIC: If the participant answers ALWAYS, USUALLY or NOT APPLICABLE, skip to Q27. If the participant answers SOMETIMES or NEVER, proceed to Q26]

Title V Children with Special Health Care Needs - Family Survey

Specialists we couldn't see in a quick and timely manner

26. What type(s) of specialist(s) were you NOT able to see in a quick and timely manner? (check all that apply)

- ☐ Allergy/Immunology (related to allergic conditions and immune system)
- ☐ Cardiology (relating to the heart)
- ☐ Dermatology (relating to skin)
- ☐ Developmental Medicine (relating to behavior and development)
- ☐ Endocrinology (relating to growth, hormones, including diabetes)
- ☐ Gastroenterology (relating to the digestive system)
- ☐ General Surgery (for procedures such as inserting feeding tubes, breathing tubes, other)
- ☐ Genetics (relating to inherited conditions)
- ☐ Gynecology (relating to the female reproductive system)
- ☐ Hematology (relating to blood)
- ☐ Nephrology (relating to the kidney)
- ☐ Neurology (relating to seizures, headaches and muscles)
- ☐ Neurosurgery (relating to brain and nerves)
- ☐ Newborn Medicine (relating to care for newborns with special needs)
- ☐ Nutrition (relating to feeding and growth)
- ☐ Ophthalmology (relating to the eyes)
- ☐ Otolaryngology (relating to ear, nose and throat)
- ☐ Plastic Surgery (relating to surgeries such as cleft lip/cleft palate procedures)
- ☐ Psychiatry (relating to behavior and mental health)
- ☐ Pulmonology (relating to lungs and breathing)
- ☐ Rheumatology (relating to joints, immune system)
- ☐ Sports Medicine/Orthopedics (relating to musculoskeletal system)
- ☐ Urology (relating to urinary tract, male reproductive system)

Title V Children with Special Health Care Needs - Family Survey

Continued Family Survey - Communication & Resources

27. 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
- ◯ No
- ◯ Not Sure
- ◯ Not Applicable

28. Do you know how to file a grievance or complaint about your child's health care?

- ◯ Yes
- ◯ No
- ◯ Not Sure
- ◯ Not Applicable

[SKIP LOGIC: If the participant answers NO, NOT SURE or NOT APPLICABLE, skip to Q30. If they answer YES, proceed to Q29]

Title V Children with Special Health Care Needs - Family Survey

Grievance Filing

29. Have you ever filed a complaint or grievance about your child's health care?

- ◯ Yes
- ◯ No

Title V Children with Special Health Care Needs - Family Survey

Continued Family Survey - Care Coordination & Case Management

***Key Definition - A Case Manager helps get appointments with special doctors and care for your child, and helps get referrals to other agencies, including public health nursing and Regional Centers.**

30. Has your child/family been assigned a case manager?

- ◯ Yes
- ◯ No
- ◯ Don't Know/Not Sure

[SKIP LOGIC: If the participant answers YES, proceed to Q31. If they answer NO or NOT SURE, then SKIP to Q33]

Title V Children with Special Health Care Needs - Family Survey

Case Manager Questions

31. Who does case management for your child? Check all that apply:

- ☐ County CCS
- ☐ My Health Plan
- ☐ Regional Center
- ☐ CCS Special Care Center

Other (please specify)

32. How satisfied have you been in the past 12 months with how your case manager helps your child connect with services?

- ◯ Always Satisfied
- ◯ Usually Satisfied
- ◯ Sometimes Satisfied
- ◯ Never Satisfied
- ◯ Not Applicable, have not had contact with the case manager in the past 12 months

Title V Children with Special Health Care Needs - Family Survey

Continued Family Survey - Care Coordination

33. In addition to yourself and your family, who helps to arrange or coordinate care for your child? Check all that apply:

- [ ] Nurse Case Manager
- [ ] Case Manager at my Health Plan
- [ ] Someone at my child's primary care doctor's office
- [ ] Someone at my child's Special Care Clinic/Center
- [ ] County CCS Case Manager
- [ ] Child's school
- [ ] Nobody helps to coordinate care for my child
- [ ] Don't Know/Not Sure

Other (please specify)

34. 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
- ◯ Usually
- ◯ Sometimes
- ◯ Never - I did not need extra help in the past twelve months
- ◯ Don't Know/Not Sure

[SKIP LOGIC: If the participant answers ALWAYS, USUALLY or SOMETIMES, proceed to Q35. If they answer NEVER or DON'T KNOW/NOT SURE, then SKIP to Q36]

Title V Children with Special Health Care Needs - Family Survey

Extra Help

35. 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
- ◯ Usually
- ◯ Sometimes
- ◯ Never
- ◯ Don't Know/Not Sure

Title V Children with Special Health Care Needs - Family Survey

Continued Family Survey - Care Coordination cont.

36. How often are your child's services coordinated in a way that makes them easy to use?

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Never
- ◯ Don't Know/Not Sure
- ◯ Not Applicable

[SKIP LOGIC: If the participant answers USUALLY, SOMETIMES or NEVER, proceed to Q37. If they answer ALWAYS or DON'T KNOW/NOT SURE, then SKIP to Q38]

Title V Children with Special Health Care Needs - Family Survey

Coordinating Services

37. Can you think of what might make your child's services more coordinated in a way that is easier for you to use? If so, please write in your suggestion:

38. How often is it easy to coordinate therapy (physical therapy, occupational therapy) for your child in the school setting?

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Never
- ◯ Don't Know/Not Sure
- ◯ Not Applicable – my child does not need therapy in the school setting

39. 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
- ◯ No
- ◯ Don't Know/Not Sure

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

- ◯ Always
- ◯ Most of the time
- ◯ Some of the time
- ◯ Never

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

- ◯ Always
- ◯ Most of the time
- ◯ Some of the time
- ◯ Never

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

- ◯ Always
- ◯ Most of the time
- ◯ Some of the time
- ◯ Never

43. 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?

- ◯ Always
- ◯ Most of the time
- ◯ Some of the time
- ◯ Never

44. In the last 12 months, have you had any problems getting special Medical Equipment or Devices (such as a walker, wheelchair, nebulizer, incontinence supplies, feeding tubes, or oxygen equipment) or Medical Supplies (such as diapers, gloves, etc.)?

	How often did you have problem getting it?	What was the main reason for the problem?
Medical Equipment or Device		
Medical Supplies		
Other (please fill in the comment box below and answer across here)		

Other (please specify)

[Please read dropdown menus for each selection across as follows:

How often did you have problems getting it?:

- **Always**
- **Usually**
- **Sometimes**
- **Never**
- **No Applicable**

What was the main reason for the problem?:

- **CCS would not authorize**

- **Health Plan would not authorize**
- **I could not afford it**
- **I could not get a hold of my insurer to ask for it**
- **I could not get a provider to write a prescription**
- **Not a Medi-Cal Benefit**
- **Problems about who would pay for it**
- **Could not find a vendor to provide the equipment or supplies**
- **No vendor available that serves my county**
- **Other**
- **Not Applicable]**

45. What equipment, device(s) or supplies did you have problems getting? Please specify below:

Title V Children with Special Health Care Needs - Family Survey

Transition to Adult Care

When your child grows up and becomes an adult, they will move from having doctors who take care of children to having doctors who take care of adults. The next questions are about this transition.

46. Is your child 14 years or older?

- ◯ Yes
- ◯ No

[SKIP LOGIC: If the participant answers NO, skip to Q53. If participant answers YES, proceed to Q47.]

Title V Children with Special Health Care Needs - Family Survey

Transition Questions

47. 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
- ◯ No
- ◯ Don't know/Not sure

48. Have any of the following people or organizations helped your child find an adult medical provider? Check all that apply:

- ☐ CCS
- ☐ Health Plan
- ☐ Our Pediatrician
- ☐ None of the above

Other (please specify)

49. If yes, were you able to find an adult doctor or provider?

- ◯ Yes
- ◯ No
- ◯ Don't Know/Not Sure

50. 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
- [ ] Brochure or other reading materials
- [ ] Letter in the mail
- [ ] Social media group
- [ ] Social media video
- [ ] At school
- [ ] At Medical Therapy Unit (MTU)
- [ ] Patient support group/services
- [ ] Workshop or info session
- [ ] More information about moving from child to adult services would NOT be helpful to me

51. What information about transition from child to adult care for your child would be helpful?

Title V Children with Special Health Care Needs - Family Survey

Family Impact & Needs

52. Does your provider ask about your family's well-being (adults and children) and their needs for support?

- ◯ Always
- ◯ Most of the time
- ◯ Some of the time
- ◯ Never

53. During the past 12 months was there any time when you or other family members needed the following services and did not receive them?:

	Family Service needed?	How often did your family get all needed care?	Reason for NOT receiving service or care:
Respite Care			
Genetic Counseling			
Mental Health Care, Emotional Support or Counseling			
Help with Legal Issues			
Help with Housing Issues			
Help with Accessing Food Assistance and Other Government Benefits			
Other (please fill in below and answer across for that service)			

Other (please specify)

[For this question, read down the list of services—when a participant notes that this is a service that they needed or their family needed, read across ONLY for those services (so you are not reading across for every single service, unless the participant says yes to every single service). For these drop-down menus, please read them all of the options as follows and select their choice:

How often did your family get all needed care?:

- **Always**
- **Usually**
- **Sometimes**
- **Never**
- **Don't Know/Not Sure**
-

PLEASE NOTE, YOU DO NOT HAVE TO READ ALL OF THESE, YOU CAN SELECT THE ANSWER THAT BEST MATCHES IF YOU ARE RUNNING LOW ON TIME. Reason for NOT receiving service or care:

- **Cost was too much or too high**
- **No insurance**
- **Health Plan problem**
- **CCS Problem**
- **Whole Child Model Problem**
- **Difficulty getting authorizations**
- **Can't find a provider who accepts my insurance**
- **Not available in my area**
- **Transportation problems**
- **Not convenient times for an appointment**

- **Too busy**
- **Could not get an appointment**
- **No translation services available**
- **Provider did not know how to treat**
- **Dissatisfied with the provider from previous appointments**
- **Did not know where to go for treatment**
- **Treatment is ongoing (still happening now)**
- **No referral to this service**
- **Lack of resources**
- **Neglected or forgot appointment**
- **Never Explained**
- **Could not find a provider for this service**
- **I feel embarrassed about needing this service**
- **I feel unsafe in seeking this service**
- **Other]**

54. What is your annual family income?

- ◯ Less than $20,000
- ◯ $20,000 to $34,999
- ◯ $35,000 to $49,999
- ◯ $50,000 to $74,999
- ◯ $75,000 to $99,999
- ◯ Over $100,000

55. What is the highest level of education that you have completed?

- ◯ Middle school
- ◯ Some high school
- ◯ High school diploma or GED
- ◯ Some college
- ◯ College bachelor's degree
- ◯ Graduate level degree or higher

56. How many hours per w eek do you or other family members spend arranging or coordinating care?

- ◯ 0 - 5 hours per week
- ◯ 6 - 10 hours per week
- ◯ 11 - 15 hours per week
- ◯ 16 - 20 hours per week
- ◯ 20 + hours per week

Other (please specify)

57. How many hours per w eek do you or other family members spend providing care for your child's medical condition at home for your child?

- ◯ 0 - 10 hours per week
- ◯ 10 - 20 hours per week
- ◯ 20 - 30 hours per week
- ◯ 30 - 40 hours per week
- ◯ 40 - 50 hours per week
- ◯ 50 - 60 hours per week
- ◯ 60 - 70 hours per week
- ◯ 70 + hours per week

Other (please specify)

58. Have you or other family members ever cut dow n on hours or had to leave a job because of your child's health?

- ◯ Yes
- ◯ No
- ◯ Not Sure

59. Has a health care provider or case manager help linked you w ith support (e.g. family support groups, parent mentors, online support groups, etc.)?

- ◯ Yes
- ◯ No
- ◯ Not Applicable (haven't had a need for support)

60. 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
- [ ] In person support group
- [ ] Parent mentor or parent partner
- [ ] Not Applicable

Other (please list other social and/or emotional supports here)

Title V Children with Special Health Care Needs - Family Survey

Overall Satisfaction with CCS

61. If your child is or has been insured with CCS, are there any additional comments about the CCS program or other services that your child has received that you would like to share? (Note: if you have never had CCS services for your child, please skip this question)

62. What is your overall satisfaction with CCS services? (Note: if you have never had CCS services for your child, please skip this question)

- ◯ 0 – Very Dissatisfied
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ 5
- ◯ 6
- ◯ 7
- ◯ 8
- ◯ 9
- ◯ 10 – Very satisfied

Title V Children with Special Health Care Needs - Family Survey

Overall Satisfaction with Health Plan or Health Insurer

63. 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 – Very Dissatisfied
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 – Very satisfied

Title V Children with Special Health Care Needs - Family Survey

End of survey questions

64. Who asked you to fill out this survey or sent this survey to you?

- County CCS
- Health Plan
- Local Family Resource Center
- Family Voices
- Children Now
- My child's doctor

Other (please specify)

65. How did you complete this survey?

- At CCS as part of annual paperwork
- At my child's specialist
- By phone (someone called me)
- By computer (went to Survey Monkey)
- By smartphone (went to Survey Monkey)
- Someone interviewed me over the phone in English
- Someone interviewed me over the phone in Spanish
- Someone interviewed me over the phone in another language

Thank you very much for taking the time to fill out this survey. The information from this survey will be used to help improve the CCS program and services for children and youth with special health care needs. If you have any questions about this survey, you can contact the Family Health Outcomes Project at (415)-476-5283.