

## Appendix 10 - Family Survey Questionnaire

### 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?

### 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

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?

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)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Allergies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety Problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arthritis or Joint Problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asthma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Autism, Asperger's Disorder, Pervasive Developmental Disorder (PDD), or Autism Spectrum Disorder (ASD)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behavioral or Conduct Problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blindness or Impaired Vision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blood Problems other than Hemophilia or Sick Cell Anemia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Broken Bones	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cancer, Tumors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cerebral Palsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cleft Lip/Cleft Palate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Congenital Heart Disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cystic Fibrosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dental Problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Developmental Delay	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Down Syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Epilepsy or Seizure Disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Genetic Disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Head Injury, Concussion, or Traumatic Brain Injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing Loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

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

## 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)

Medi-Cal Managed Care Health Plans

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

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)

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)

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)

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

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

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 – None
- 1
- 2
- 3
- 4
- 5+

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

- 0 – None
- 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

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)

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

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

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

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

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

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

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

## 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	<input type="text"/>	<input type="text"/>
Medical Supplies	<input type="text"/>	<input type="text"/>
Other (please fill in the comment box below and answer across here)	<input type="text"/>	<input type="text"/>

Other (please specify)

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

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	<input type="text"/>	<input type="text"/>
Genetic Counseling	<input type="text"/>	<input type="text"/>
Mental Health Care, Emotional Support or Counseling	<input type="text"/>	<input type="text"/>
Help with Legal Issues	<input type="text"/>	<input type="text"/>
Help with Housing Issues	<input type="text"/>	<input type="text"/>
Help with Accessing Food Assistance and Other Government Benefits	<input type="text"/>	<input type="text"/>
Other (please fill in below and answer across for that service)	<input type="text"/>	<input type="text"/>

Other (please specify)

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 week 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 week 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 down 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 with 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.