CCS Survey for Families

Introduction

Thank you for taking the time to complete this survey. The Family Health Outcomes Project at the University of California, San Francisco is conducting this survey because we are interested in your opinions about the California Children's Services (CCS) Program and how well it is meeting the needs of your child. **This information will help determine what the priorities should be for the CCS Program for the next 5 years.** All of your answers are anonymous and you may skip any question(s) you don't want to answer.

The California Children's Services (CCS) is a state program that covers the cost of treating certain diseases, physical limitations or chronic health problems in children that are financially eligible for these services. The CCS program also runs the Medical Therapy Program, which provides medical therapy (including occupational, physical and speech therapy to children with a CCS-eligible condition. The CCS program covers children with problems like:

- congenital heart disease
- cancers, tumors
- hemophilia, sickle cell anemia
- thyroid problems, diabetes
- serious chronic kidney problems
- liver or intestine diseases
- cleft lip/palate, spina bifida
- hearing loss, cataracts
- cerebral palsy, uncontrolled seizures
- rheumatoid arthritis, muscular dystrophy
- AIDS
- severe head, brain, or spinal cord injuries, severe burns
- problems caused by premature birth
- severely crooked teeth

Si prefiere completar la encuesta en español, utilice este enlace:
http://www.surveymonkey.com/s/EncuestadeCCS o haga click aquí.

1. Do you have a child that has been covered by CCS?

- Yes
- No
- Don't know/Not sure

2. If YES, is your child currently covered by CCS?

- Yes
- No
- Don't know/Not sure

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3. Do you have any children who have received treatment or services from a CCS provider or through the CCS program?

- Yes
- No
- Don't know/Not sure

NOTE: For all of the questions on this survey, when we ask about your child, we are asking about your child that is or was covered by CCS.

4. What services for your child does the California Children Services (CCS) program pay for? Please check all that apply.

- Therapy services, such as physical therapy (PT), occupational therapy (OT), or speech therapy
- Durable medical equipment, such as crutches, walkers, ventilators, communication devices, wheelchairs, braces, etc.
- Disposable medical supplies, such as gloves, swabs, diapers, etc.
- Inpatient hospital care
- Medical appointments
- Prescription medications
- Help in getting to medical appointments and therapy
- Home health care, such as nursing care, home health aid
- Hearing aids
- Don't know/Not sure
- Other

Other (please describe)

Access to Services/ Supplies/ Equipment

In the first section, we are interested in your experiences getting services, supplies, and equipment for your child. *NOTE: For all of the questions on this survey, when we ask about your child, we are asking about your child that is or was covered by CCS.*

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5. Does your child have a primary care provider, that is, a doctor, nurse, or physician's assistant, who provides your child's ongoing medical and well-child care?

- Yes
- No
- Don't know/not sure

6. Do you think your child's primary care provider has the skill and experience that is needed to care for your child?

- Yes
- No
- Don't know/not sure
- Does not apply - My child does not have a primary care provider

7. What kind of doctor or other health care provider is most important to your child's care now? Check only one.

- Primary care doctor (such as a pediatrician, or family medicine doctor)
- Specialist doctor
- Other health care provider
- Don't know/Not sure

Medical provider that is most important to your child

8. What kind of specialist or other health care provider is most important to your child now?

Access to Services/ Supplies/ Equipment

CCS Survey for Families

9. How well is this doctor or other health care provider who is most important to your child's care doing on…

	Excellent	Good	Okay	Poor	Don't know/Not sure	Does not apply
a. Overall, providing quality care?	○	○	○	○	○	○
b. Explaining about my child's health needs in a way that I can understand?	○	○	○	○	○	○
c. Being easy to contact by phone?	○	○	○	○	○	○
d. Being available to give medical care or advice at night and on weekends?	○	○	○	○	○	○
e. Giving me reassurance and support?	○	○	○	○	○	○
f. Being easy to reach in an emergency ?	○	○	○	○	○	○
g. Including my family in decision making and Giving me updated information about medical research that might help my child?	○	○	○	○	○	○
h. Showing respect for my child?	○	○	○	○	○	○
i. Respecting our culture, ethnic identity, and religious beliefs?	○	○	○	○	○	○
j. Communicating with my child's other health care providers?	○	○	○	○	○	○
k. Communicating with my child's school or early intervention program?	○	○	○	○	○	○
l. Communicating with other systems that provide services to my child (not including school)?	○	○	○	○	○	○
m. Communicating with my child's health insurance plan staff?	○	○	○	○	○	○

Access to Services/ Supplies/ Equipment continued

NOTE: For all of the questions on this survey, when we ask about your child, we are asking about your child that is or was covered by CCS.

10. A primary care provider is a doctor (for example a pediatrician or family practice doctor) nurse, or physician's assistant, who provides your child's ongoing medical and well-child care. In the last 12 months, did you have any problems getting medical care from *primary care providers* that your child needed?

- ○ My child did not need services from primary care providers
- ○ My child needed services from primary care providers and we had **no problems** getting them
- ○ My child needed services from primary care providers and we have had **some problems** getting them.
- ○ My child needed services from primary care providers and we have had **a lot of problems** getting them.

CCS Survey for Families

Problems accessing primary care

11. If you had problems in the last 12 months getting services your child needed from primary care providers, please tell us about these problems. Check all that apply...

- Getting **appointments** with primary care providers was a problem.
- Finding primary care providers with the **skill and experience** to care for my child was a problem.
- **Coordination** between my child's primary care providers and specialty doctors and other providers was a problem.
- The **amount we had to pay** for services from primary care providers was a problem.
- The **health insurance plan would not pay** for services from primary care medical providers
- My child needed but did not get services from primary care providers
- Other problems - describe below
- Does not apply - My child did not need services from primary care providers
- Does not apply - We had no problems accessing primary care providers.

Other problems - please describe

Access to Specialty Care

12. A specialty care provider is a doctor or nurse who gets extra training and becomes an expert in one part of the body or in one disease or condition (for example a cardiologist (heart doctor), an oncologist (cancer doctor), an orthopedist (a bone doctor), a neurologist (brain doctor). In the last 12 months, did you have any problems getting medical care from *specialty doctors* that your child needed?

- My child did not need services from specialty doctors
- My child needed services from specialty doctors and we had **no problems** getting them
- My child needed services from specialty doctors and we have had **some problems** getting them.
- My child needed services from specialty doctors and we have had **a lot of problems** getting them.

Problems accessing specialty care

CCS Survey for Families

13. If you had problems in the last 12 months getting services your child needed from specialty doctors, please tell us about these problems. Check all that apply...

- Getting **referrals** to get services from specialty doctors was a problem.
- Getting **appointments** with specialty doctors was a problem.
- Finding specialty doctors with the **skill and experience** to care for my child was a problem.
- Getting the **number of visits** from specialty doctors to meet my child's needs was a problem
- **Coordination** between my child's specialty doctors and other providers was a problem.
- The **amount we had to pay** for services from specialty doctors was a problem.
- The **health insurance plan would not pay** for services from specialty doctors
- My child needed but did not get services from specialty doctors
- Other problems - describe below
- Does not apply - My child did not need services from specialty doctors
- Does not apply - We had no problems getting services from specialty doctors.

Other problems - please describe

Access and Emergency Room Use

14. In the past 12 months, have you had to take your child to the hospital emergency room for a problem or illness that you think could have been taken care of by your child's health care provider if you had been able to talk to or see the provider earlier?

- Yes
- No
- Don't know/not sure

Hospital Emergency Room Visits

15. How many times did you take your child to the hospital emergency room because you could not see or talk to your child's health care provider earlier? (please enter a number)

Interpretation Services

CCS Survey for Families

16. An interpreter is someone who repeats what one person says in a language used by another person.

During the past 12 months, did you or your child need an interpreter to help speak with your child's doctors or other health care providers?

- Yes
- No
- Don't know/not sure

Interpretation Services

17. When you or your child needed an interpreter, how often were you able to get someone other than a family member to help you speak with your child's doctors or other health care providers?

- Never
- Sometimes
- Usually
- Always
- Don't know/Not Sure

18. During the past 12 months, how often did your child's doctors or other health care providers help you feel like a partner in your child's care? Would you say never, sometimes, usually, or always?

- Never
- Sometimes
- Usually
- Always
- Don't know/Not Sure

Access to Services/ Supplies/ Equipment continued

NOTE: For all of the questions on this survey, when we ask about your child, we are asking about your child that is or was covered by CCS.

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19. In the past 12 months, did you child need...?

	Yes, we got the service and were **satisfied**	Yes, we got the service and were **NOT satisfied**	Yes, but we **did NOT GET** the service	No, my child **did not need** the service	Don't know/Not sure
Dental care	jn	jn	jn	jn	jn
Disposable medical supplies – Such as catheters, swabs, diapers, syringes, etc.	jn	jn	jn	jn	jn
Durable medical equipment and medical technology – such as hearing aids, wheelchairs, ventilators, etc.	jn	jn	jn	jn	jn
In home support services (IHSS)	jn	jn	jn	jn	jn
Respite care	jn	jn	jn	jn	jn

20. During the past 24 months, were there any delays in your child getting all the medical supplies (for example catheters, swabs, diapers, syringes, etc.), that {he/she} needed?

jn Yes

jn No

jn Don't know/Not sure

jn Does not apply - My child did not need medical supplies

21. Has your child ever had to wait to get out of the hospital because of problems getting medical equipment?

jn Yes

jn No

jn Don't know/Not sure

jn Does not apply - My child did not need medical equipment when he/she got out of the hospital

jn Does not apply – My child has not been in the hospital.

22. During the past 24 months, were there any delays in your child getting mobility aids or devices, such as canes, crutches, wheelchairs, or scooters?

jn Yes

jn No

jn Don't know/Not sure

jn Does not apply – my child did not receive mobility aids or devices

CCS Survey for Families

23. If your child had delays in getting mobility aids or devices, such as canes, crutches, wheelchairs, or scooters, were the items still the correct size when they arrived?

- Yes
- No
- Don't know/Not sure
- Does not apply – my child did not receive mobility aids or devices

Organization of Services and Treating the Whole Child

The next section asks about your views on how the services your child needs are organized. *NOTE: For all of the questions on this survey, when we ask about your child, we are asking about your child that is or was covered by CCS.*

24. Thinking about services your child needs, are those services organized in a way that makes them easy to use?

- Always
- Usually
- Sometimes
- Never
- Don't know/Not sure

25. Thinking about services your child needs, would it be easier for you and your child if CCS covered ALL of the medical and therapy services your child needs, instead of just the medical and therapy services that are related to your child's CCS-eligible condition?

- Yes
- No
- Don't know/Not sure

26. During the time your child was covered by CCS, did you ever move from one county to another county in California?

- Yes
- No

Experiences in Different Counties

CCS Survey for Families

27. Which best describes your experience with CCS services in different California counties?

- My child was eligible to get the same services in both counties.
- There were some services my child was eligible for in one county but not the other county.

28. If your child was NOT eligible for certain services after moving to a new county, did your child ever receive those services?

- YES – CCS paid for them
- YES – But I had to pay for them myself
- YES – But someone else paid
- NO – my child never got the services
- Does not apply - my child was eligible to get the same services in both counties

Case Management

Good work so far. This section asks about your experience with case management. *A case manager is a person who makes sure that your child gets all the services that are needed and that these services fit together in a way that works for you. This person may have different titles such as care coordinator or a social worker, etc.*

29. Who provides case management for your child?

- Private health insurance plan
- California Children Services (CCS)
- Specialty Care Center or Hospital
- Other state agency
- Other (specify on next page)
- Don't know/Not sure
- My child does not get case management

Case Management

*** 30. Who provides case management for your child - for other, please identify:**

CCS Survey for Families

Case Managerment

31. Does your child have a CCS case manager?

- Yes
- No
- Don't know/Not sure

32. If yes, please tell us how helpful is your child's CCS case manager is. Would you say the CCS case manger is...

- Very helpful
- Helpful
- Only a little helpful
- Not at all helpful
- My child does not have a CCS case manager

33. We would like to know about what kinds case management services you get for your child and who provides them. Please put a check in the boxes to show what service you get from which program.

	Private Health Insurance Plan	CCS	Special Care Center or Hospital	Medi-Cal Managed Care	Other
Helps coordinate your child's care among the different providers and services that help your child					
Helps you understand your child's health insurance plan benefits					
Helps you to identify and use other community based programs or services for which your child may be eligible (for example, Early Start or Regional Center programs, special education, summer camps, after school programs, etc.)					
Helps you to get other public programs such as SSI for your child?					
Helps you to find other ways to pay for needed services and equipment					
Provides a case manager that has a good understanding of my child's health care needs and services.					

Other (please specify)

Care Coordination and Medical Therapy

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34. Overall, how satisfied are you with the help you have received in coordinating your child's care?

- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied
- Don't know/Not sure

35. How important is it to have ONE person who knows your child and can help you understand what your child needs and connect your child to the services he/ she needs?

- Very important
- Somewhat important
- Only a little important
- Not important at all
- Don't know/Not sure

36. In the last 12 months, has your child received any medical therapy - such as physical therapy (PT), occupational therapy (OT), or speech therapy?

- Yes
- No
- Don't know/Not sure

Experience with medical therapy

This section is for families who have experience with medical therapy.

CCS Survey for Families

37. Please tell us about your child's experience with PHYSICAL THERAPY in the last 12 months. Please check all that apply.

	Yes	No	Don't know/not sure
a. My child needed this therapy. [If NO, please go to question #38]	○	○	○
b. My child received this therapy.	○	○	○
c. My child needed but did not get this therapy.	○	○	○
d. I was satisfied with the therapy my child received.	○	○	○
e. Having therapy available at my child's school was helpful.	○	○	○
f. Having therapy appointment times from 7:00 AM to 6:30 PM was helpful.	○	○	○
g. Getting a referral for this therapy was a problem.	○	○	○
h. Getting an appointment was a problem.	○	○	○
i. Getting dropped from the therapy schedule because we missed too many appointments was a problem.	○	○	○
j. Finding a therapist with the skill and experience to care for my child was a problem.	○	○	○
k. It was a problem getting the number of visits my child needed.	○	○	○
l. It was problem getting transportation to the therapy appointment.	○	○	○
m. Coordination between my child's therapist and other providers was a problem.	○	○	○
n. The amount we had to pay was a problem.	○	○	○
o. My child's health care coverage would not pay.	○	○	○
p. Other problems (Please explain below)	○	○	○

Other problems - please explain

CCS Survey for Families

38. Please tell us about your child's experience with OCCUPATIONAL THERAPY in the last 12 months. Please check all that apply.

	Yes	No	Don't know/not sure
a. My child needed this therapy. [If NO, please go question #39]	○	○	○
b. My child received this therapy.	○	○	○
c. My child needed but did not get this therapy.	○	○	○
d. I was satisfied with the therapy my child received.	○	○	○
e. Having therapy available at my child's school was helpful.	○	○	○
f. Having therapy appointment times from 7:00 AM to 6:30 PM was helpful.	○	○	○
g. Getting a referral for this therapy was a problem.	○	○	○
h. Getting an appointment was a problem.	○	○	○
i. Getting dropped from the therapy schedule because we missed too many appointments was a problem.	○	○	○
j. Finding a therapist with the skill and experience to care for my child was a problem.	○	○	○
k. It was a problem getting the number of visits my child needed.	○	○	○
l. It was problem getting transportation to the therapy appointment.	○	○	○
m. Coordination between my child's therapist and other providers was a problem.	○	○	○
n. The amount we had to pay was a problem.	○	○	○
o. My child's health care coverage would not pay.	○	○	○
p. Other problems (Please explain below)	○	○	○

Other problems - please explain

CCS Survey for Families

39. Please tell us about your child's experience with SPEECH THERAPY in the last 12 months. Please check all that apply.

	Yes	No	Don't know/not sure
a. My child needed this therapy. [If NO, please go question #40 - on the next page]	jn	jn	jn
b. My child received this therapy.	jn	jn	jn
c. My child needed but did not get this therapy.	jn	jn	jn
d. I was satisfied with the therapy my child received.	jn	jn	jn
e. Having therapy available at my child's school was helpful.	jn	jn	jn
f. Having therapy appointment times from 7:00 AM to 6:30 PM was helpful.	jn	jn	jn
g. Getting a referral for this therapy was a problem.	jn	jn	jn
h. Getting an appointment was a problem.	jn	jn	jn
i. Getting dropped from the therapy schedule because we missed too many appointments was a problem.	jn	jn	jn
j. Finding a therapist with the skill and experience to care for my child was a problem.	jn	jn	jn
k. It was a problem getting the number of visits my child needed.	jn	jn	jn
l. It was problem getting transportation to the therapy appointment.	jn	jn	jn
m. Coordination between my child's therapist and other providers was a problem.	jn	jn	jn
n. The amount we had to pay was a problem.	jn	jn	jn
o. My child's health care coverage would not pay.	jn	jn	jn
p. Other problems (Please explain below)	jn	jn	jn

Other problems - please explain

Social Support

Only a few more sections. In this section, we want to know about the social support you and your family have needed and have received.

40. Have you attended a family support group to help you and your family to cope with your child's health condition?

jn Yes

jn No

jn Don't know/not sure

41. If YES, how often do you attend family support group meetings?

CCS Survey for Families

42. If NO, would you be interested in attending a family support group to help you and your family to deal with issues related your child's health condition?

- Yes
- No
- Don't know/Not sure

43. Has anyone from the CCS program told you that they can help you find emotional support, community resources, and family/ individual counseling for your child and your family?

- Yes
- No
- Don't know/Not sure

44. Has anyone from the CCS program referred you to any family to family support services?

- Yes
- No
- Don't know/Not sure

Insurance

Doing great. This section asks about who pays for your child's care and your experiences with health insurance.

CCS Survey for Families

45. What kind of health coverage does your child have? Please check all that apply

- ☐ CCS
- ☐ Medi-Cal Managed Care
- ☐ Medi-Cal Fee-For-Service
- ☐ Healthy Families
- ☐ Private health insurance offered through work or that I buy for my child/family
- ☐ Other (describe below)
- ☐ Don't know/Not sure

Other type - please describe

46. If your child is covered by private insurance AND CCS, does also having private insurance make it easier or harder to get the care your child needs?

- ○ Having private insurance in addition to CCS makes it EASIER to get the care my child needs
- ○ Having private insurance in addition to CCS makes it HARDER to get the care my child needs
- ○ Don't know/Not sure
- ○ My child does not have private insurance

47. Have you had problems getting the care your child needs because of the type of insurance that covers your child?

- ○ Yes (specify below)
- ○ No
- ○ Don't know/Not sure

If Yes, Which type(s) of insurance causes the problems?

48. Have you had problems getting the care your child needs because of a lack of insurance coverage?

- ○ Yes
- ○ No
- ○ Don't know/Not sure

CCS Survey for Families

49. Have you had problems getting the care your child needs because of changes in insurance?

- Yes
- No
- Don't know/Not sure

Transition

CSS is interested in making sure young adults have a successful transition to adult life, including having a place to go to for health care. If your child is 14 years old or older, please complete the following questions.

50. My child is 14 years old or older.

- Yes
- No

Transition

CSS is interested in making sure young adults have a successful transition to adult life, including having a place to go to for health care. If your child is 14 years old or older, please complete the following questions.

51. Have your child's doctors or other health care providers talked with you or your child about how (his/ her) health care needs might change when (he/ she) becomes an adult?

- Yes
- No
- Don't know/Not sure

52. Has a plan for addressing these changing needs been developed with your child's doctors or other health care providers?

- Yes
- No
- Don't know/Not sure

CCS Survey for Families

53. Have your child's doctors or other health care providers discussed having your child eventually see a doctor who treats adults?

- Yes
- No
- Don't know/Not sure

54. Has your child received any vocational or career training to help (him/ her) prepare for a job when (he/ she) becomes an adult?

- Yes
- No
- Don't know/Not sure

55. Has your child's CCS case manager talked to you and your child about your child transition to adult providers?

- Yes
- No
- Don't know/Not sure

Overall Satisfaction

Almost done! Here we want to know your views on the CCS program.

56. All things considered, how satisfied are you overall with the CCS program?

- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied
- Don't know/Not sure

CCS Survey for Families

57. All things considered, how satisfied are you overall with the Medical Therapy Unit (MTU)?

- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied
- Don't know/Not sure
- Does Not Apply – my child does not use the MTU

58. If you have any other comments about your experience with the CCS program, please share them here:

Demographics

In this last section, please tell us a bit more about yourself and your child.

59. How would you describe the community where you live?

- City or urban
- Suburban
- Farming or rural
- Other

If Other - please describe

60. What is the name of the county where you live? (please select from the list)

CCS Survey for Families

61. Does your child have any of the following conditions? Please read the list carefully and check all that apply, even if these conditions are not covered by CCS.

- ¨ Allergies or sinus trouble
- ¨ Asthma
- ¨ Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)
- ¨ Autism
- ¨ Behavior problems
- ¨ Blood disorder (such as sickle cell anemia or hemophilia)
- ¨ Cancer or leukemia
- ¨ Cerebral palsy or other neuromuscular condition
- ¨ Chronic immune condition
- ¨ Chronic lung, or breathing trouble (such as BPD but not including asthma)
- ¨ Chronic rheumatic disease
- ¨ Cleft lip and/or palate
- ¨ Congenital disorder
- ¨ Congenital heart disease
- ¨ Cystic fibrosis
- ¨ Degenerative neurological disease
- ¨ Developmental delay
- ¨ Diabetes
- ¨ Digestive or gastrointestinal disorder
- ¨ Down syndrome
- ¨ Epilepsy/ Seizure Disorder
- ¨ Head injury complications
- ¨ Hearing impairment
- ¨ Hydrocephalus
- ¨ Kidney disease or renal failure
- ¨ Mental health problems
- ¨ Mental retardation
- ¨ Muscular dystrophy
- ¨ Orthopedic or bone problems
- ¨ Paraplegia/quadriplegia
- ¨ Respiratory distress syndrome
- ¨ Scoliosis
- ¨ Spina bifida /meningomyelocele
- ¨ Technology dependent or assisted (Some examples are central venous line, colostomy, dialysis, feeding tube, shunts, tracheostomy, ventilator and others)
- ¨ Vision impairment
- ¨ Other (describe below)
- ¨ Don't know/Not sure

If Other - please describe

62. Of the conditions you checked, which one would you consider to be your child's primary MEDICAL condition?

CCS Survey for Families

63. How old is your child?

- Newborn - Less than 1 month old
- 1 month to 12 months old
- 1 year old
- 2 years old
- 3 years old
- 4 years old
- 5 years old
- 6 years old
- 7 years old
- 8 years old
- 9 years old
- 10 years old
- 11 years old
- 12 years old
- 13 years old
- 14 years old
- 15 years old
- 16 years old
- 17 years old
- 18 years old
- 19 years old
- 20 years old
- 21 years old
- 22 years old or older

64. Which of the following categories best describes the race or ethnicity of your child?

- White or Caucasian
- Black or African American
- Asian, Pacific Islander, or Southeast Asian
- Hispanic, Latino/Latina, or Spanish
- Native American, American Indian, Aleut, or Eskimo
- Multiracial
- Other (specify below)

If Other - please specify

65. In what language did you take this survey?

- English
- Spanish

CCS Survey for Families

66. Did you complete this survey after May 1st, 2010?

- Yes
- No

67. (for administrative purposes)

number

Thank you!

Thanks again for taking this survey. If you have any questions about this project, you can contact: the Family Health Outcomes Project, 415-476-5283.