

Appendix B.
Open-ended
Responses



Open-ended Responses to Question C17a: Cause of Dissatisfaction With Ability to Obtain Information Needed to Make Decisions About Meeting Child's Health Care Needs, Utah Children Age 0-17, 2000.

CSHCNSEX AGE RESPONSE

Yes	Male	1	She hasn't received any information from doctors about [his] allergies.
Yes	Male	1	the pediatricians in Utah rush through all the patients and are too busy
Yes	Male	4	the insurance restrictions of who we can see.
Yes	Male	7	They don't tell me what is wrong with him half of the time
Yes	Male	8	because I just feel like I haven't received any information and that they don't want to talk with me about him
Yes	Male	8	because there are not any clear cut answers
Yes	Male	8	dislike of the communication between each other
Yes	Male	8	having to use different providers all the time
Yes	Male	9	needs more time
Yes	Male	9	I just don't feel that everything is being done that could be done. Also the medical industry thinks of themselves more than their patients
Yes	Male	10	I feel frustrated because I have to give the information. Doctors that have the training could care less.
Yes	Male	10	Well, because I've found out more on my own than the doctors about what's going on him.
Yes	Male	10	because I feel that he isn't getting all the help he needs.
Yes	Male	11	Just for the fact that in a situation with behavioral problems they label the children
Yes	Male	11	They don't really treat her and her child like they even know them. They don't take the time to find out everything they need.
Yes	Male	11	the same reasons I gave for [other child]
Yes	Male	11	They are too busy, it is almost mechanical, and there is not the human touch.
Yes	Male	12	one doc tells you one thing but one doctor knows more about it than that doctor
Yes	Male	12	conflicting answers
Yes	Male	12	well about the same things as the other things they give me a diagnosis but they don't really give any information to pursue it any further or know how to handle it.
Yes	Male	13	because of his medication she had to go back to the doctor to get the medication approved and he had to write a letter and so on, it became a pain
Yes	Male	14	because of the case worker, he hasn't had the help he had. he had allot of threats. such as if he didn't go and volunteer or go date. threatened that his son could be put in foster homes.
Yes	Male	14	I don't feel like I have really good access to the doctor, his problems have mostly cleared up on their own but if they hadn't I would have had a lot more problem
Yes	Male	14	she's not sure because there is been a few issues with the specialist that some of the medication is been bad. diet the give to him... the problem is the specialist
Yes	Male	15	Professionals requiring too much money for their services

Open-ended Responses to Question C17a: Cause of Dissatisfaction With Ability to Obtain Information Needed to Make Decisions About Meeting Child's Health Care Needs, Utah Children Age 0-17, 2000. (continued)

CSHCNSEX AGE RESPONSE

Yes	Male	17	my biggest problem is it is difficult to get health insurance when self employed, when we go to clinic we go to clinic they schedule us for PA not dr. due to any health insurance. This is has been long
Yes	Male	17	Because I feel like I'm out in left field and I don't know what's going on.
Yes	Female	3	getting the paper work from the specialist clinic and I am not getting what I need from the insurance company
Yes	Female	5	sometimes I feel I don't get enough info. no written material and some suggestion on research.
Yes	Female	7	there is not a lot of info out there and there is not a specialist in this area for adhd , I have to travel to 110 miles to get treatment for that (1 way) once a month
Yes	Female	7	She feels like she is not understood (at the doctor). She feels like there is not enough communication and there needs to be more research into ADD. There has got to be a better way to test for ADD.
Yes	Female	8	I just feel where she's an older child, they just don't put enough time into them like they do the infants.
Yes	Female	11	insurance
Yes	Female	12	There is no cure for what [child] has and nobody knows how to help her
Yes	Female	12	they don't care
Yes	Female	13	Haven't been able to find a reason for her seizures.
Yes	Female	13	when she goes she goes to the doctor and he gives her medicine and she still hurts.
Yes	Female	15	They cant give me an exact name or reason for her learning disability. some doctor's say it is not from an accident that she had as a baby. Then I read in books that it is very likely. I'm getting
Yes	Female	16	The number of times that she has had strep and that her treatments aren't working.
Yes	Female	16	you get the runabout
Yes	Female	16	Because they always change their mind or lose the test results
Yes	Female	17	hard to get medical records
Yes	Female	17	everybody we go to has a different treatment plan and it gets very frus trating and we do not know who to believe in English, and I don't under stand half the stuff they are doing. It seems like nobody cares about your health
No	Male	0	just the fact that I ask questions and they give me technical terms that I don't understand, I wish they would be more straight forward and tell me what I want to know
No	Male	0	Because they are very narrow minded
No	Male	0	Because the child is sick now and all he gave us were drops.
No	Male	1	uh... Doctors can never give him an answer
No	Male	3	I think that they are in such a hurry and they don't explain things enough.
No	Male	3	never told her about vaccinations

Open-ended Responses to Question C17a: Cause of Dissatisfaction With Ability to Obtain Information Needed to Make Decisions About Meeting Child's Health Care Needs, Utah Children Age 0-17, 2000. (continued)

CSHCNSEX AGE RESPONSE

No	Male	4	they give you information for example about immunization that is really dumped up and not the risks just that everyone is supposed to get them and so you have an educated decision
No	Male	4	My health insurance wouldn't pay for it, because it was too expensive and eventually after about a year of searching I found I could get it through school for free, and the run around was delay
No	Male	5	there's no info
No	Male	6	she said she felt this way because when she had her new born they insisted on her signing a paper so that her child can get the hepatitis b shot and she refused because she did some research.
No	Male	6	they don't feel what you're saying at all
No	Male	7	they give everyone the same medicine ...they don t tell me nothing...I don t trust em
No	Male	8	The mental health supports from his school.
No	Male	10	because she doesn't speak English very well...they need more interpreters but I think that it is ok....
No	Male	13	even though I like dr. he doesn't take time to answer my questions and concerns
No	Male	13	test results haven't come back or they won't take the time to find them for me
No	Male	14	He had to have a throat culture and she doesn't feel that she received the information that she needed to get. She had to consult an ER doctor so that she could get some antibiotics so that he could
No	Male	16	Mostly people told me he was a teen and didn't give me answers
No	Male	16	we don't have insurance so we are not offered all the tests that should be done , if we had insurance they would at least try to run tests and be sure
No	Female	0	he just seems like he is in a hurry a lot, doesn't spend a lot of time with me
No	Female	1	they don't have enough information
No	Female	1	the general emphasis in the medical system to help after the fact instead of before
No	Female	1	they don't have good hours. closed when we needed their services
No	Female	2	there are times when I see one doctor who is not very thorough and I wind up having to come back and pay two co-pays because he was not thorough enough the first time
No	Female	2	I don't feel they're as informative as they could be, they just diagnose and leave.
No	Female	2	Dr wouldn't give us info that was needed for us to know what was fully going on
No	Female	2	She doesn't have insurance and it is difficult to get.
No	Female	3	They never offer information and they seem to take so many visits just to pinpoint something, they don't seem very motivated through education
No	Female	4	telling lies

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CSHCNSEX AGE RESPONSE

No	Female	4	because I am young they think I am stupid
No	Female	4	some things they have her on and they can't find things to fix the problem
No	Female	5	I know they are holding back information. They won't tell me the range of what she could have had.
No	Female	5	she had a knee injury and I don't think that they did enough to make it better.
No	Female	5	I choose not always to use the prescription and the doctor does not always give me an alternative
No	Female	7	an experience I had with them a few months ago, I was having a miscarriage and they just blew me off , I'm not happy with them at all
No	Female	9	I think doctors are put in a position that they shouldn't be. The government shouldn't be in our medical needs. There are to many people without health insurance
No	Female	10	all the red tape you have to go through to get help
No	Female	11	You just don't get the treatment you would get at a public clinic. They often see the PA instead of the Dr. and it is also a public.
No	Female	13	we are military with the tri care it very difficult. you have to call and get permission to go to a doctor
No	Female	15	they don't listen
No	Female	15	in general she doesn't help doctors. She hasn't found a doctor she trusts for a long time
No	Female	16	I have raised my children and did not get the help I need, don't use the medical profession
No	Female	16	she has scoliosis and we did not find out about it till last year. I think we should have known sooner. We found out because she has pain and we took her to a specialist
No	Female	16	the way they treat and deal with us

Open-ended Responses to Question F14: Other Reasons Respondent Gave for Having No Health Insurance Coverage for Child, Utah Children Age 0-17, 2000.

CSHCN SEX AGE RESPONSE

Yes	Male	1	closed Medicaid and has not done paper work yet to reapply
Yes	Male	8	Took him off so he could be on the CHIP program
Yes	Male	9	Parent is drug addict and he lost Medicaid eligibility on her fraud, we will get him on our plan later but he doesn't qualify yet.
Yes	Male	10	money
Yes	Male	11	His father won't cover it for him. He has a deadbeat dad.
Yes	Male	17	no, just that were 30 dollars over the limit
Yes	Female	6	She didn't send in the papers to renew the Medicaid coverage.
Yes	Female	7	the mothers company was bought out and the insurance wasn't very good
Yes	Female	17	We don't have legal papers yet and we can't do anything without legal papers.
No	Male	0	father felt the premiums were too high and he was not pleased with the coverage
No	Male	0	I have an interview next week
No	Male	1	IHC access through Medicaid ended after 1 yr., I had pneumonia and was too ill to reapply, and we have reapplied and are waiting for a card. Insurance through his father's employer would be between 2 and 3 hundred
No	Male	1	Just that we don't get it through our employers yet.
No	Male	1	Husband changed jobs so that they could get better health insurance
No	Male	4	quit job
No	Male	4	because my husband is self employed
No	Male	4	husband's employer doesn't offer it for family just employees
No	Male	5	no. Just because of the internship
No	Male	5	My husband has not passed the three month period to receive insurance.
No	Male	6	we are self-employed
No	Male	7	Husbands employer doesn't offer it
No	Male	8	The insurance didn't cover so we dropped it. I guess we didn't believe in it.
No	Male	10	Flat out (my husband) didn't want to pay the premiums, he wanted to go the cheap way.
No	Male	10	my husband is self-employed
No	Male	12	They are self-employed.
No	Male	12	I don't have insurance because I don't have the elements required.
No	Male	13	we are self employed and can't afford it
No	Male	13	we are self employed so the cost for our family would just be way too high
No	Male	13	drooped last insurance for some months to go on CHIP
No	Male	17	because his mother chooses to pay out of pocket, person being inter viewed is the guardian, not his parent. She does not have legal guardianship or she would cover child on her insurance
No	Female	1	Because they are self employed and they can't afford to pay the premiums.

Open-ended Responses to Question F14: Other Reasons Respondent Gave for Having No Health Insurance Coverage for Child, Utah Children Age 0-17, 2000. (continued)

CSHCN SEX AGE RESPONSE

No	Female	1	Because I haven't gotten her birth certificate yet and the insurance company needs it
No	Female	2	we are self employed and are in the process of getting CHIP for her
No	Female	2	Because she could not afford the insurance plus the deductible
No	Female	2	Her husband's employer hasn't offered the insurance for his family at this time.
No	Female	2	small business, inability to cover
No	Female	2	I just changed jobs and am not covered yet
No	Female	3	The family plan is too expensive for having just one child we will get it when we have another.
No	Female	3	just because we changed jobs...will get it next month
No	Female	3	lost his job, 3 months waiting list
No	Female	4	because she started own business and hasn't selected an insurance company yet
No	Female	4	haven't been accepted yet
No	Female	4	I don't know, I was thinking about getting her coverage, never tried it before
No	Female	6	my documents
No	Female	6	not affordable
No	Female	6	her mother didn't get her Medicaid card in the mail
No	Female	6	husband got sick and was working long enough to get insurance.
No	Female	7	My husband is self-employed
No	Female	8	it is so darn expensive.
No	Female	9	We make too much for CHIP, yet still can't afford our own.
No	Female	9	father was court ordered to provide insurance and he does not. Mother is self employed and does not make enough to pay for insurance
No	Female	9	self employed and couldn't afford the insurance
No	Female	9	no. her uncle sees her
No	Female	10	husband can't get it through employer
No	Female	10	The insurance company had a hassle with them saying they didn't pay the premiums and they own there own business
No	Female	11	To high to pay
No	Female	11	she looked into CHIP and they made too much money, but yet they can't afford the premiums to other health insurance Coverage. Her employer offers health insurance but it's expensive.
No	Female	11	Religious reasons.
No	Female	11	He doesn't have insurance coverage. He could get it through his company but he has a pre-existing back condition and it would cost too much to 3 pay the amount that he needs to.
No	Female	12	Just money
No	Female	12	Her father just died
No	Female	12	it was too expensive through my employer

Open-ended Responses to Question F14: Other Reasons Respondent Gave for Having No Health Insurance Coverage for Child, Utah Children Age 0-17, 2000. (continued)

CSHCN SEX AGE RESPONSE

No	Female	13	mother is self employed and just found out about CHIP
No	Female	14	my dad just pays cash for everything and does not want to take anything from the state
No	Female	15	Just the money
No	Female	16	the cost
No	Female	16	we're self-employed
No	Female	16	Just the economics of it
No	Female	17	they haven't be eligible
No	Female	17	because her dad died
No	Female	17	would rather take care of it herself