

Appendix B.

Open-ended

Responses



Open-ended Responses to Question C13d: Reasons for Rating Assistance Received in Locating and Setting up Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

Male	4	when ever I've gone its been hard.
Male	11	not a whole lot of contact except by mail
Male	14	because, um, prior to the last worker he had a lot of assistance, but with the new worker it has not been there for him like the other now has been.
Male	14	I don't know what choices I have with whom.
Female	14	The school is where her problems are and they don't have any helpful programs.
Female	14	They used to be good and now they're only fair. The health care insurance we had was really Good but then we had to switch and it's not as good as we used to have.

Open-ended Responses to Question C14b: Reasons for Rating Coordination Among Different Providers and Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

Male 3 because they are not coordinated at all

Male 3 I think that there is not a very good communication system

Male 4 when we take him to the ear, nose and throat, the doctor at the regular clinic has no record of his visit with the specialist

Male 4 our insurance restricts us

Male 4 cause a lot of times they don't know what they are doing.

Male 5 they don't coordinate n the office in general

Male 6 Because there's not really any coordination between the two. The speech therapy doesn't send any information to [child's doctor] and the doctor didn't send any information to the clinic before we started.

Male 6 The are good about referring him, but their not good about following up.

Male 8 She doesn't think that the communication between the different providers are sufficient.

Male 8 don't think they communicate well with each other, they don't follow through with calling each other and reporting to each other.

Male 8 His condition has always been a emergency condition and use different doctors so it is hard because they don't have access to other doctor records

Male 8 because they don't know each other they don't do anything to each other.

Male 9 Most of the questions I want answered are not answered. There is no solution. No other options or a lot of options.

Male 9 They hurry you. Quick Diagnosis

Male 9 Basically the cost, and I feel that they could do more. I feel that he should have been to specialists

Male 9 there no communication between the speech therapist and the dr.

Male 10 same as other two sons. they are in different places

Male 10 Because we've been to doctors and they keep shifting us around, and they make wrong diagnoses. And not really informative.

Male 10 [Child] was seeing a psychologist and wasn't working well with family doctor

Male 10 because Primary Children's does not coordinate with any one, I had to beg.

Male 10 He felt like they were put on the back burner and he had to light a fire under their butts to get them to do something.

Male 10 it is the responsibility of the parent

Male 11 Because of the insurance and getting the referral and the lack of communication and a lack of effort from the staff

Male 11 Insurance company doesn't want to pay

Male 11 They don't tell you what you need to know. They don't take the time.

Male 11 the specialist deals with his disease and not his physician so there hasn't been much contact between the two.

Male 12 well neither place has access to the others records (one is medical and one is mental)...they could have if requested

Male 12 They are just too busy to follow up with information

Open-ended Responses to Question C14b: Reasons for Rating Coordination Among Different Providers and Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Male	12	lean towards school as much as to doctor
Male	12	we have tried three times and can't get the records over there and keep blaming each the other for losing them
Male	12	they don't communicate, his doctor does not know him so they don't know what to watch for
Male	12	because they do not really communicate together back and forth about what is going on with his physical and mental health
Male	12	if I want things coordinated I have to do it
Male	12	Because its seems that sometimes they do not have all the info
Male	12	some work together good, others don't
Male	13	They don't coordinate at all
Male	13	They don't talk
Male	13	Some times you have to go out of your way
Male	14	they are different places (or for mental health the other for physical)
Male	14	Well, because the doctor that we go to doesn't have hospital privileges because I have to get the records and take them to the hospital if there is a problem.
Male	14	we are fairly new in the area and he has only seen the doc at central Utah medical clinic once and that was when he got in an accident so they do not have his records yet
Male	14	They are not very coordinated.
Male	14	because sometimes like when you take them to just a regular doctor they have a different idea of what is going on so you get different diagnoses so I never know what to believe.
Male	14	I don't know, if it is just the military that made me think that or what.
Male	14	she would like to get him to see a physiatrist but insurance makes it hard
Male	14	Each doctor feels as if the others a quack, nobody want to work together
Male	14	well all of them work fairly well together, I just had problem working with the school, we've put him on home school now.
Male	15	IT IS HARD FOR THE COUNSELOR AT THE MIDDLE SCHOOL TO COMMUNICATE WITH THE DOCTOR, I HAVE TO BE THE MEDIATOR
Male	15	I got the runaround last time, one said I should call this person and the other said to call there and I want to know what to do to help him at home
Male	15	It's kind of unfair to say these schools are not good because he is all grown up now.
Male	16	I have to coordinate the services, so fair.
Male	16	I don't think that they communicate very well
Male	16	They really haven't coordinated them yet, they might but not yet
Male	17	well I don't think that the medical doctor has dealt worth the school
Male	17	because we moved and it was very hard and I tried to contact the public office and the treatment was not the best for him
Male	17	they don't even communicate at all

Open-ended Responses to Question C14b: Reasons for Rating Coordination Among Different Providers and Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Female 2 she does not have a primary care provider so there is no one to coordinate with. We have tried to get one the provider that sees the rest of our kids won't see her because of her special needs. She...

Female 2 there was issue in terms of what our insurance would cover. A referral was not covered by the insurance, so we are stuck with the bill

Female 3 Because the promptness of the specialists Dr office

Female 6 She only has a primary care, dentist and ophthalmologist and there is not really a need for much communication

Female 6 No one knows how to treat her asthma. The health care providers argue among themselves.

Female 8 Her doctors just handle the medical part they don't have good communication.

Female 9 he could be more understanding of a child who doesn't get sick that much

Female 9 the only way they know is if I take them reports. She was born with a congenital health disorder and that is why she sees a specialist. Her orthopedic surgeon sees her for the growth problem also

Female 9 We have to fight with them to pay with the bills, and it seems like they don't care about her mental health as much as her physical.

Female 10 Her last visits have been for step and they just treated it. She never really had been to a specialist.

Female 10 I'm the one who has to do everything

Female 11 the services is really poor, but they are excellent on prescriptions.

Female 12 I don't think that her specialist and her pediatrician talk at all

Female 12 Some are not trying at all and some are trying too much

Female 13 they don't communicate well

Female 13 sometimes I think that they overlook the condition or just not give them what they need until it's really BAD

Female 13 Well I say that because I think that the doctor, her regular doctor focuses a lot on the depression and her specialist views her depression as related to her hypothyroidism so they prescribe different

Female 14 Health Providers have no clue what her problem is.

Female 14 I hate that about our medical system, we can only go to providers our insurance covers and it really affects the care we can get

Female 14 Most of the time they aren't "on the ball".

Female 15 I'm trying to find records of an eye exam for her school. My primary physician can't find the records.

Female 15 due to available DR's some poorly trained DR's, only one or two good ones, good one's must not get paid enough to come out here, they just don't seem to know what they are talking about, to get good c

Female 15 Referral problems

Female 15 One insurance company doesn't like to pay so I have to argue with them

Female 15 The regular doctor and the mental health provider don't really coordinate, although mental and physical health are related.

Female 16 because the communication isn't that good for me as a parent

Open-ended Responses to Question C14b: Reasons for Rating Coordination Among Different Providers and Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Female 16 Because in going to them and being referred to another doctor she is supposed to report back to the primary physician and she in not able to get hold of them (primary).

Female 16 when she had her stroke no doctor knew what the other doctor was doing and what was going on, and my insurance was against me going a specific special ist

Female 16 Because the doctors don't usually listen

Female 17 Well, I have to coordinate it they don't communicate with each other and communicate to me.

Female 17 There is no system set up for communication between businesses and most of the time they follow up on it. the overall health system working for her health is fair

Female 17 Lack of communication dr. not having sufficient time

Female 17 There has been trouble transferring files, they have lost a lot of records, There computers are always down and we can barely ever get the medication that we need when we need it.

Female 17 They don't put forth effort unless we push them.

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 With Special Health Care Needs, Age 0-17, 2000.

SEX AGE RESPONSE

Male 1 She hasn't received any information from doctors about [child]'s allergies.

Male 1 the pediatricians in Utah rush through all the patients and are too busy

Male 4 the insurance restrictions of who we can see.

Male 7 They don't tell me what is wrong with him half of the time

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

Male 8 because there are not any clear cut answers

Male 8 dislike of the communication between each other

Male 8 having to use different providers all the time

Male 9 needs more time

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

Male 10 I feel frustrated because I have to give the information. Doctors that have the training could care less.

Male 10 Well, because I've found out more on my own than the doctors about what's going on him.

Male 10 because I feel that he isn't getting all the help he needs.

Male 11 Just for the fact that in a situation with behavioral problems they label the children

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.

Male 11 the same reasons I gave for [child]

Male 11 They are too busy, it is almost mechanical, and there is not the human touch.

Male 12 one doc tells you one thing but one doctor knows more about it than that doctor

Male 12 conflicting answers

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.

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

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.

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

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

Male 15 Professionals requiring too much money for their services

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

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 With Special Health Care Needs, Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Male	17	Because I feel like I'm out in left field and I don't know what's going on.
Female	3	getting the paper work from the specialist clinic and I am not getting what I need from the insurance company
Female	5	sometimes I feel I don't get enough info. no written material and some suggestion on research.
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
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.
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.
Female	11	insurance
Female	12	There is no cure for what [child] has and nobody knows how to help her
Female	12	they don't care
Female	13	Haven't been able to find a reason for her seizures.
Female	13	when she goes she goes to the doctor and he gives her medicine and she still hurts.
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
Female	16	The number of times that she has had strep and that her treatments aren't working.
Female	16	you get the runabout
Female	16	Because they always change their mind or lose the test results
Female	17	hard to get medical records
Female	17	everybody we go to has a different treatment plan and it gets very frustrating and we do not know who to believe in English, and I don't understand half the stuff they are doing. It seems like nobody cares about your health

Open-ended Responses to Question C18a: Cause of Dissatisfaction With Health Care Child Received, Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

Male	1	They rush and don't follow up on things
Male	8	The same reasons
Male	10	I am satisfied with the pediatrician, but very dissatisfied with the mental health care [child] is receiving.
Male	10	I don't think they're informative enough with medications they're like lets try this, lets try that. When we have reactions to things they give him then they just pass it off and we'll try something else
Male	11	Same as before.
Male	12	not being able to get a provider in our area
Male	12	Well because I don't think that they are really giving all that he needs it is just kind of a hit and miss.
Male	14	There has been no follow through.
Male	14	With the pediatric she very happy but not with the specialist.
Male	15	I'm satisfied in some ways, but I can't receive some of the health care needed because of the expenses
Male	17	Because I don't know what's going on
Male	17	We keep getting reports from school that he needs help but know one can ever find a place to go.
Female	3	She went in for a fever and the doctor wouldn't prescribe any antibiotic
Female	10	The dentist is turning her down cause she doesn't have insurance
Female	16	Same reasons.
Female	16	because of the lack of communication
Female	16	She wasn't diagnosed that fast and it could have helped
Female	16	the doctors were great but the hospital staff was very uncommunicative

Open-ended Responses to Question E10a: “Has [child] needed any health, dental, educational, mental health, behavioral, or any other services that have been hard to get?,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

Male	1	occupational therapists, home health, a nurse through TLC
Male	3	early intervention
Male	3	speech therapy
Male	5	mental health, as far as getting testing and stuff done
Male	6	Medical
Male	7	dental
Male	8	dental
Male	8	Mental services.
Male	8	tried to get him in a special school for problem child and there was a long waiting list
Male	9	Just with his learning I've had to fight for that all the way.
Male	9	optical
Male	9	for family counseling
Male	9	Behavioral
Male	9	medical and dental
Male	9	Dental
Male	10	mental health and behavioral.
Male	10	specialized mental health
Male	10	Educational
Male	11	dental
Male	11	dental. He's not covered
Male	11	mental health behavioral
Male	11	Educational, it was reading
Male	11	changing mental health programs
Male	11	services for ADD
Male	11	mental health services... no children's facility in the area and can't find one to help a child. [Child] has psychotic attacks and goes crazy and no one will help. my insurance won't keep covering it
Male	12	educational
Male	12	Educational
Male	12	psychiatric
Male	12	insurance coverage
Male	12	well we have a hard time getting the education throughout the school and it is really hard to convince the school those children with autism need differ of education. Mental health is also hard
Male	12	Braces, medical stuff,
Male	12	Educational
Male	12	mental health and medical
Male	13	behavioral health

Open-ended Responses to Question E10a: “Has [child] needed any health, dental, educational, mental health, behavioral, or any other services that have been hard to get?,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Male	13	mental health behavioral
Male	13	educational
Male	13	Dental.
Male	13	SSI took a while to get. Getting him on Medicare was very difficult.
Male	13	His studying habits. She is trying to find out if he has a learning disability and it is difficult to get to see anyone.
Male	14	to be able to get the same counselor. Schools counselor, wasn't as good enough the first counselor he had a special relationship
Male	14	Counseling services
Male	14	sometimes I've wondered if maybe he should have counseling or maybe I need it
Male	14	Neurologists.
Male	14	well we tried to get mental health for him but it was not covered
Male	14	Medication management.
Male	14	the same that is above
Male	14	For his eyes/eye doctor
Male	14	physical and occupational therapy
Male	14	The mental services
Male	15	dental
Male	15	he was struggling in school, it was obvious to the teacher he was having problems but the school won't pay attention until they are 2 to 3 ears behind so you have to go out and get a tutor and pay a
Male	15	educational
Male	16	we don't have a lot of accessibility as far as pediatric gastrointestinologist (sic) was not available in our area.
Male	16	mental health, dental, and medical
Male	16	I felt he could of used a qualified counselor in his youth and couldn't find one, now he's in a youth group.
Male	16	It was a counselor that what provided by the county to see him at school.
Male	16	metal health
Male	17	dental even just getting him into school was a fight.
Male	17	dental,
Male	17	mental health
Male	17	educational services
Male	17	The medical for his knee
Male	17	We have to drive two hours into Salt Lake to get counseling services.
Male	17	Medical insurance.
Male	17	counselor
Male	17	mental health
Female	1	health care

Open-ended Responses to Question E10a: “Has [child] needed any health, dental, educational, mental health, behavioral, or any other services that have been hard to get?,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Female 1 Specialist’s services.

Female 2 can’t find a primary care provider for her, well I probably could if I started calling around but I don’t think of it until she has a crisis

Female 2 respiratory pediatric care at primary children’s.

Female 3 they have been trying to apply for Medicaid and it’s been a joke. They give them a different thousand reasons why they can’t get it.

Female 4 Medical and dental have been hard to get because she doesn’t have insurance right now.

Female 5 dental services

Female 6 Preventive medical equipment for her asthma is hard to get.

Female 6 when she was diagnosed with her condition

Female 6 dental.

Female 7 treatment for ADHD

Female 7 Physical therapy and dental

Female 8 educational services , same frustrations that I have experienced with [child]

Female 8 Finding speech specialists that would take her problem.

Female 9 Medical and Dental are hard to get and because she doesn’t have either type of insurance.

Female 9 We’ve had trouble getting the insurance to cover mental health care costs.

Female 10 Medical services

Female 11 medical

Female 11 Dental

Female 12 extra help at school...educational, behavioral kind of stuff

Female 12 She is home schooled and that has been hard to get sometimes.

Female 12 medical

Female 13 Just to let her stay in the main stream education instead of going into a special class

Female 13 mental health , she had become suicidal and it took 6 weeks to get her into a place, I got the run around every time I called a place

Female 14 Resource services

Female 14 mental health and educational health.

Female 14 treatment for ADD, insurance only covers a few providers

Female 14 The school has been difficult to communicate with about her special needs.

Female 14 mental health and behavioral

Female 15 Help working with her disabilities. The schools are good. In the community, it is hard to find help for learning disabilities. Private schools don’t take students with learning disabilities.

Female 15 medical

Female 15 Educational

Open-ended Responses to Question E10a: “Has [child] needed any health, dental, educational, mental health, behavioral, or any other services that have been hard to get?,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Female 15 Dental. Insurance don't cover it

Female 15 Medical and dental have been hard to get because of the insurance situation.

Female 15 Rehab,

Female 15 mental health counseling

Female 15 the mental health again

Female 15 getting her counselor was very hard for us to get.

Female 15 medical and dental, uninsured

Female 15 Behavioral, trying to work with the schools.

Female 16 It was hard to get an appt for a neurologist.

Female 16 dental

Female 16 The mental health it has been hard

Female 16 physical therapy

Female 16 dental and mental

Female 16 mental services

Female 17 Behavioral services, yes, the counseling, lack of insurance coverage.

Female 17 if your child is having problems with drugs it hard to find help, especially for behavioral problems

Female 17 She needs some counseling, but I don't know how to and the price, cost is a big issue because as a foster child she has no o insurance, we pay out of pocket.

Female 17 Physical therapy, the insurance wouldn't cover it.

Open-ended Responses to Question E11a: Reasons for Rating Respite Care Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

Male	6	If it's not family, I feel that I don't have anywhere to get help. I can't afford daycare. I have cancel appointments
Male	9	They promised to find a weekend retreat for him and it never came to pass.
Male	9	don't use respite care
Male	9	Because of I don't know of any available respite.
Male	12	because they were supposed to be there when you needed them and they weren't always there
Male	12	The way they count the hours is weird, especially when you have more than one child with health care needs, the program's good, there is not enough there to take what we really need.
Male	14	I have to compare with
Male	14	when I checked into it they told me flat out that he didn't qualify.
Female	4	same reason as for the other
Female	6	because I have no help and the state won't help
Female	9	I'm a single parent and it's harder to get the respite care. Sometimes I need to just leave because I can't deal with the girls.
Female	17	They are unavailable.

Open-ended Responses to Question 9a: Reasons for Rating Child Care Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

Male	0	With him he can't be around other babies
Male	0	Because there isn't any and what is here is very expensive.
Male	0	I almost died with him, and IHC never had the same nurse with him and the child needed consistency. The child care didn't know how to take care when I was trying to get rest.
Male	1	too many kids too expensive
Male	2	it is hard to find a good day care
Male	2	I read in magazines about other states and Utah doesn't have as many services providing daycare in the work places.
Male	3	it's too expensive
Male	4	It is very expensive.
Male	4	most of the things offered are during the day when I work
Male	5	waiting list for a year and a half, not a lot of options for child care
Male	5	it's hard to find someone that will take him in because sometimes his behavior is less than positive
Male	5	because the prices are so unaffordable
Male	6	The state licensed providers in my area take too many kids and there are not enough providers. I feel better paying someone not qualified by the state and paying them more because they are better qua
Male	7	I don t feel there are any options out there
Male	8	not enough info
Male	8	don't trust anyone with my kids
Male	8	because in Utah they don't have that good of services
Male	9	Can't support the child care that is available. -Too expensive.
Male	9	there should me more care
Male	9	I have put him in so many and some I don't like and they teach him anything
Male	9	I am a single mother with five kids, and can't afford care, I have to feed them
Male	9	Because he's older and there's a lot of places that won't take him, because he's an older child and he's difficult.
Male	10	Due to the cost to put 3 children is too much
Male	10	I had left him so I could go to work, he left the pro- care and came home. and the workers didn't know he had left.
Male	10	same
Male	11	Because I don't trust anyone with my kids
Male	11	his behavioral needs he is very hard to be placed and he has to be supervised
Male	11	I have an odd schedule and he is in year around school, so it was kind of hard
Male	12	Because lot of times there may be places available but the people who give care are undesirable.
Male	12	doesn't coordinate with her
Male	14	because there is none for that age group

Open-ended Responses to Question 9a: Reasons for Rating Child Care Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Male 14 his pediatrician had normal hours but when they had an emergency the problem was always the specialist and sometimes he get there so late (the specialist), and sometimes they don't even show up

Male 15 Because Tooele is limited on their providers and services so I have to go into salt lake.

Male 16 Well because when he was younger they put him on the drugs (ADD) and when he developed the ticks and had to stop the drugs they sort of brushed it off and forgot us and we had to work through it ourselves

Male 17 I can't even find babysitters around here so I can take some of the other kids to the doctor

Female 1 the prices are pretty outrageous

Female 2 I guess I do work at home and try to find people to cover, I guess I live in a neighborhood full of stay at home moms that aren't interested. I live in a rural area and it would take about twenty min

Female 3 too many kids

Female 3 Once people find out about her condition they don't want to be responsible for her period. Or they want to charge me An arm and a leg for her.

Female 4 because they didn't look at the fact that she was pre-me they only went off financial records. They wouldn't even look at her because we made to much money. I finally found someone on the school board

Female 5 hard to find reliable care services and it was expensive.

Female 5 you have to be in a certain income line, will give it to you for a couple of months and then cut you off.

Female 6 Most of it goes back to the public schools. The schedules for kindergarten don't accommodate for a parent to work. The upper grades also have inconsistent scheduling.

Female 6 not much of anything to rely on

Female 6 Because I needed state assistance at try to go to school to try and better myself and I couldn't

Female 8 because we live out in the middle of nowhere and there are about 5 families that live in town so when one kid gets sick you can't find a babysitter

Female 9 It depends if she has outburst and I'm at work. Since she's been medicated it less difficult but she still as outburst while I'm at work.

Female 10 don't like child care

Female 11 Because there is not services for older children

Female 11 it is expensive

Female 12 the day cares won't take her at her age

Female 12 during the school year we don't need it. During the summer we can't get it.

Female 13 as a provider there are always people calling her and wanting it but she can't give it. And there aren't enough people licensed

Female 15 I've had past experiences with people caring for my children -I don't trust anyone with my children.

Female 16 hard to juggle time

Female 16 they certainly aren't open in the evenings

Open-ended Responses to Question 9a: Reasons for Rating Child Care Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Female 17 There are no resources available, what I'd really like is some respite but there aren't any resources. I haven't been able to find any respite services for her.

Female 17 personal decision and that she needed a parent available sometime and because of my personal health. Conflict with my life and decision to have someone available at all time for the children if there were

Female 17 just have to be with [child]

Open-ended Responses to Question F5a: Reasons for Rating Their Health Insurance as “Fair” or “Poor” in Covering Health Care Costs for Their Child, Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

Male	1	they haven't covered some things. They had to purchase his nebulizer, and they didn't cover it all. They don't cover out of state visits as well as if you were in the provider network.
Male	3	because we use alternative medic and the insurance does not cover it
Male	3	one of A's problems is dental work the insurance won't cover
Male	3	developmental delay and speech therapy are not covered by my health insurance
Male	4	doesn't cover his special needs, like speech therapy
Male	4	the restrictions
Male	4	Because I think they should cover more
Male	6	Same reason as before
Male	6	Because co pay to see the dr. and prescriptions are not covered very well
Male	7	they could always be better
Male	8	because we pay so much money every year for insurance
Male	8	insurance doesn't want to pay
Male	8	they don't always want me to pick the one I want
Male	9	the psychiatrist won't see him
Male	9	Everything's good except the therapy and medication
Male	9	because they are not paying any bills
Male	9	it is new coverage and I have not used it yet but you have to pay a very large copay
Male	9	Because they had such a high deductible I have to pay to much
Male	10	They don't pay hardly anything for dental or optical
Male	10	Delay and lies
Male	10	it's stupid they don't cover preventive care, like check-ups, immunizations, and etc..
Male	10	because they don't pay for any of the mental health, they only take a small percentage of the cost.
Male	10	copay went up and the cost my husband has to pay out every two weeks is kind of high, there is \$25 copay for medical care and the copay on prescriptions is \$25
Male	10	there is just a lot of things that they do not want to pay for, and they are slow on what they do pay for
Male	10	since the governor opened it to Medicaid patients, the way were treated, and the coverage that we receive.
Male	11	they only pay about 80%
Male	11	in dispute, they don't want to pay , they don't seem to want to pay for meds, it may or may not be on their list, he needs a common med but it is not on the list
Male	11	because the deductible is \$1000
Male	11	it don't cover glasses, immunizations, ER visits are 50 dollars and no dental

Open-ended Responses to Question F5a: Reasons for Rating Their Health Insurance as “Fair” or “Poor” in Covering Health Care Costs for Their Child, Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Male 11 They randomly pick stuff to not pay for. Sometimes they pay for services and sometimes they don't pay for those same services.

Male 11 they don't cover the behavioral and mental health issues that he has

Male 11 see response for [child]

Male 11 Prices keep going up

Male 11 Cigna you have to pre-approve, You have to go to a certain doctor, and they don't pay for even half.

Male 11 it's a debate between the doctors and the pre-authorization

Male 12 there are things that it doesn't cover and if you have a secondary insurance it doesn't cover it all anyway

Male 12 It is major medical and he hasn't had any major medical only little injuries so it hasn't been any good for him

Male 12 their coverage is too limited

Male 12 They are very expensive and they don't cover very much.

Male 12 they won't cover his hearing aids and he has a heart murmur and they don't cover either

Male 12 It costs a lot of money to get insurance for health and dental

Male 13 they do ok I just am not totally satisfied and I don't have access to expended mental health

Male 13 you get what you pay for on the managed care

Male 13 some do not cover because of asthma.

Male 14 It doesn't cover what he needs.

Male 14 well because they do not want to pay for anything anymore

Male 14 We are so far away from a military base and my husband is retiring and we don't know if we will be covered.

Male 14 Because of the mental health benefits.

Male 14 really slow

Male 14 Because they don't cover most of the things he needs like the mental health, there is a thousand dollar deductible on that, and eye things, we obviously need that.

Male 16 Delay in payment. Claiming they didn't get the claims.

Male 16 Same reasons as with D's.

Male 16 They don't provide dental, Change prescriptions

Male 16 poor deductibles

Male 16 Because of where we live we can't get it out here, everything we do is cash even though they are full covered.

Male 16 There is some thing that they don't cover fully.

Male 16 one is paying and one isn't

Male 16 they don't cover office visits

Male 16 because they just suck...

Open-ended Responses to Question F5a: Reasons for Rating Their Health Insurance as “Fair” or “Poor” in Covering Health Care Costs for Their Child, Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Male	17	Due to getting mixed up on social security numbers (she is married to her ex-husband’s brother).
Male	17	because heath insurance is a catastrophe. 90% I’m the one who is responsible and has to pay
Male	17	some doctors don’t want to accept medical card
Male	17	because they don’t pay for provider I will take my child to
Male	17	The deductibles are quite high. I have quite a bit of out of pocket.
Male	17	they don’t make exceptions with children that are critically ill
Male	17	they declined what the specialized had prescribed to him for his care
Male	17	just for his condition, mental health, they have very limited coverage
Female	0	there are still a lot of unknowns, so they don’t know what is being paid for by the insurance
Female	1	we just had to fight with them to get them to do anything
Female	1	because she has to get a referral for everything and when everything that is required is done then they can still reject the claim and not pay the bill.
Female	2	doesn’t cover enough
Female	3	the out of pocket deductible and it is very expensive for everything
Female	3	they have a huge deductible and even after they pay the deductible, the insurance company still does not pay the rest of the amount
Female	3	Keep changing her prescriptions and the need for referrals for her medicine and their really disorganized and process papers wrong
Female	6	they only pay a % and to see a specialist it gets pretty expensive
Female	7	on the mental health side they are not good plus the doc we go to is not on the panel so they only pay a little bit
Female	7	They have a high co-payment and premiums and it is expensive.
Female	8	It doesn’t cover well child visits after one year and it only covers 80% of all other visits.
Female	8	Well the cost of insurance, what the premiums are and what they cover.
Female	8	I’m not really sure what her health care coverage, it has been difficult to work with her father to get that info
Female	8	Rates keep going up and more keeps getting shifted to us.
Female	9	I don’t think it’s great insurance, I don’t think it’s bad insurance. I don’t know that there’s any great insurance’s out there. No.
Female	9	poor deductibles
Female	9	Because they cover, like I said before , they’ll cover her physical fine, but when it comes to mental they’ll only cover half.
Female	10	I have to pay 20%
Female	10	they have poor coverage and high deductibles
Female	11	they do cover a very good percentage of the care that I need
Female	11	restrictions

Open-ended Responses to Question F5a: Reasons for Rating Their Health Insurance as “Fair” or “Poor” in Covering Health Care Costs for Their Child, Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Female 12 That should be fair on "A" too. 'Cause it doesn't pay for preventive medicine.

Female 12 It's a lot lower than most charge, you pay.

Female 12 because it is a private plan we have a high deductible so we end up paying for it all before we get to the deductible

Female 12 too expensive

Female 12 because they don't care about the people they care about the money

Female 13 Again, they don't pay for prescription, dental, or eye.

Female 13 we have had to call and talk with them about bills they have sent us before and every time they end up paying it after we talk with them

Female 13 there is some stuff that they don't cover so you have to get creative to have her needs covered, like she needs a nutritionist that Medicaid won't cover so you have to go to a health educator and p...

Female 14 I have to pay at least 20%

Female 14 because they won't pay for a provider I want to use

Female 14 She needs therapy and the insurance company won't cover it.

Female 15 We can only afford major medical. We aren't covered for glasses, dental etc. With major, there are certain stipulations.

Female 15 Because of mental health clause

Female 15 for one they overcharge for the initial insurance, then what you have to co-pay and stuff

Female 15 don't like it

Female 15 they don't cover the alt. therapies that I use but when we go to the regular doctor they are fine.

Female 16 Bad policy coverage

Female 16 2000 deductible and it does not pay for prescriptions

Female 16 because they wouldn't cover the cost for the birth control pill

Female 16 because we have had trouble with ins. companies because they try to raise our rates so that they do not have to cover [child] because of her medical condition

Female 16 They have exclusions for certain doctors and we have to fight for the things she needs.

Female 17 our insurance Aetna and they make an agreement with the dr. that they get the coverage that we need at a discount but we pay a cobra of 10 and Aetna will pay the rest. the Dr are either unaware of how

Female 17 they refused a very important surgery that [child] needs to recover

Female 17 They really fight you , you have to jump through all your hoops to get their coverage and their prescription coverage has holes in it, and they're really slow to pay.