

Survey Question Number

Survey Question

- 1 What is the name of the heart problem that this child was born with? (Select all that apply)
- Aortic valve stenosis
 - Atrial septal defect (ASD)
 - Atrioventricular septal defect (AVSD) or Atrioventricular canal (AV canal)
 - Bicuspid aortic valve
 - Coarctation of aorta
 - Ebstein Anomaly
 - Hypoplastic left heart syndrome (HLHS)
 - Patent ductus arteriosus (PDA)
 - Pulmonary atresia
 - Pulmonary valve stenosis
 - Single ventricle (double inlet left ventricle)
 - Tetralogy of Fallot (TOF)
 - Transposition of the great arteries (TGA)
 - Tricuspid atresia
 - Truncus arteriosus
 - Ventricular septal defect (VSD)
 - Other, specify
 - Don't know/not sure
 - No heart problem that I know of
- 2 Has this child ever had surgery for the heart problem they were born with?
- Yes
 - No
 - Don't know/not sure
- 3 When this child was first diagnosed with a heart problem, do you feel like you were provided enough information about what this meant for this child?
- Yes
 - No
 - Don't know/not sure
- 4 In what month and year was this child born?
- 5 Is this child Hispanic or Latino?
- Hispanic or Latino
 - Not Hispanic or Latino

What is this child's race? (Select all that apply)

- American Indian or Alaska Native alone
- Asian
- Black or African American
- Native Hawaiian and Other Pacific Islander
- White

6

What is this child's CURRENT height (Answer in either feet and inches or meters and centimeters)?

7

How much does this child CURRENTLY weigh? (Answer in either pounds or kilograms)

8

In general, how would you describe this child's health?

- Excellent
- Very good
- Good
- Fair
- Poor

9

Has a doctor or other health care provider EVER told you that this child has: (Select all that apply)

- Anxiety problems
- Depression
- Developmental delay
- Behavioral or conduct problems
- Intellectual disability (formerly known as Mental Retardation)
- Speech or other language disorder
- Learning disability
- Attention Deficit Disorder or Attention Deficit/Hyperactivity Disorder, that is, ADD or ADHD
- Autism, Autism Spectrum Disorder, Asperger's Disorder, or Pervasive Developmental Disorder (PDD)
- Diabetes
- Down Syndrome
- Other genetic or inherited condition
- Heart failure
- Cardiac dysrhythmias or irregular heartbeat
- Other (specify)
- None of the above

10

- 11 Does this child have any of the following? (Select all that apply)
-Serious difficulty walking or climbing stairs
- 11 continued Does this child have any of the following? (Select all that apply)
-Deafness or problems with hearing
-Blindness or problems with seeing, even when wearing eyeglasses
- 12 Does this child CURRENTLY need or use medicine prescribed by a doctor, other than vitamins?
Yes
No
- 13 Does this child need or use more medical care, mental health, or educational services than is usual for most children of the same age?
Yes
No
- 14 Is this child limited or prevented in any way in their ability to do the things most children of the same age can do?
Yes
No
- 15 To what extent do this child's health conditions or problems affect their ability to do things?
Very little
Somewhat
A great deal
- 16 Does this child need or get special therapy, such as physical, occupational, or speech therapy?
Yes
No
- 17 Does this child have any kind of emotional, developmental, or behavioral problem for which they need treatment or counseling?
Yes
No

If yes to any of the questions in this Special Healthcare Needs section, are any of the above because of ANY medical, behavioral, or other health condition that is expected to last 12 months or longer?

18 Yes
No

What grade is this child currently in? (If summer, what is the highest grade level this child has already completed)?

19 -Kindergarten
-1st grade
-2nd grade
-3rd grade
-4th grade
-5th grade
-6th grade
-7th grade
-8th grade
-9th grade
-10th grade
-11th grade
-12th grade

Since starting kindergarten, has this child repeated any grades?

20 -Yes
-No

DURING THE PAST 12 MONTHS, about how many days did this child miss school because of illness or injury?

21 No missed school days
1-3 days
4-6 days
7-10 days
11 or more days
This child was not enrolled in school

Has this child EVER had any of the following special education or early intervention plans? (Select all that apply)

- Individualized Family Service Plan or IFSP (used for early intervention services in children younger than 3)
- Individualized Education Plan or IEP (used for special education services in children 3 or older)
- 504 Plan (sometimes used for special education services instead of or in addition to an IEP)
- Other, specify
- No, my child has never had a plan for special education

22

How likely do you think it is that this child will...(definitely will, probably will, probably won't, definitely won't, don't know, already has)

- Get a regular high school diploma? A regular high school diploma includes a "GED" but does not include a certificate of completion or a special diploma for students in special education
- Attend school after high school? Including technical or trade school
- Attend a special training program after high school for persons with intellectual disabilities?
- Complete a technical or trade school program?
- Graduate from a 2-year or community college?
- Graduate from a 4-year college?
- Get a driver's license?
- Eventually live away from home on his or her own without supervision?
- Eventually live away on his or her own with supervision?
- Eventually get a paid job? This includes any paid job -- child does not need to make enough to support self. This can include sheltered or supported employment
- Earn enough to support himself or herself without financial help from his or her family or government benefit programs?

23

DURING THE PAST WEEK, on how many days did this child exercise, play a sport, or participate in physical activity for at least 60 minutes?

- 0 days
- 1-3 days
- 4-6 days
- Every day

24

DURING THE PAST 12 MONTHS, did this child participate in (Y/N):

A sports team or did he or she take sports lessons after school or on weekends?

Any clubs or organizations after school or on weekends?

Any other organized activities or lessons, such as music, dance, language, or other arts?

Any type of community service or volunteer work at school, church, or in the community?

25

Any work, including regular jobs as well as babysitting, cutting grass, or other occasional work?

DURING THE PAST 12 MONTHS, how often was this child bullied, picked on, or excluded by other children?

Never

1-2 times (in the past 12 months)

1-2 times per month

1-2 times per week

26

Almost every day

Compared to other children their age, how much difficulty does this child have making or keeping friends?

No difficulty

A little difficulty

A lot of difficulty

27

How often does this child share toys or games with other children?

Always

Most of the time

About half of the time

Sometimes

28

Never

How often does this child show concern when they see others who are hurt or unhappy?

Always

Most of the time

About half of the time

Sometimes

29

Never

- 30 How often does this child play well with other children?
Always
Most of the time
About half of the time
Sometimes
Never
- 31 How often can this child recognize and name their own emotions?
Always
Most of the time
About half of the time
Sometimes
Never
- 32 How often does this child have difficulty when asked to end one activity and start a new activity?
Always
Most of the time
About half of the time
Sometimes
Never
- 33 How often does this child lose their temper?
Always
Most of the time
About half of the time
Sometimes
Never
- 34 How often does this child have trouble calming down?
Always
Most of the time
About half of the time
Sometimes
Never
- 35 How often does this child have difficulty waiting for their turn?
Always
Most of the time
About half of the time
Sometimes
Never

- 36 How often does this child get easily distracted?
- Always
 - Most of the time
 - About half of the time
 - Sometimes
 - Never
- 37 How often can this child focus on a task you give them for at least a few minutes? For example, simple chores?
- Always
 - Most of the time
 - About half of the time
 - Sometimes
 - Never
- 38 How often does this child keep working at a task even when it is hard for them?
- Always
 - Most of the time
 - About half of the time
 - Sometimes
 - Never
- 39 Where does this child usually go when he or she is sick or you need advice about his or her health?
- This child does not have a usual place for health care or advice when sick
- Doctor's Office
 - Hospital Emergency Room
 - Hospital Outpatient Department
 - Urgent Care Center
 - Clinic or Health Center
 - Retail Store Clinic or "Minute Clinic"
 - School (Nurse's Office, Athletic Trainer's Office)
 - Some other place

- 40 DURING THE PAST 12 MONTHS, how many times did this child visit a doctor, nurse, or other health care professional to receive a PREVENTIVE check-up? A preventive check-up is when this child was not sick or injured, such as an annual or sports physical, or well-child visit.
- 0 visits
 - 1 visit
 - 2 or more visits
- 41 DURING THE PAST 12 MONTHS, how many times did this child visit a hospital emergency room?
- None
 - 1 time
 - 2 or more times
- 42 DURING THE PAST 12 MONTHS, was this child admitted to the hospital to stay for at least one night?
- Yes
 - No
- 43 How many health care provider visits were with a heart doctor or at a cardiology clinic (clinic that only see patients with heart problems) in the past 12 months?
- 44 When is the last time this child saw a heart doctor?
- Less than 1 year
 - 1-2 years
 - 3-5 years
 - More than 5 years
 - Never seen one
- 45 Who are the majority of patients that this child's primary heart doctor usually sees?
- Children and adolescents (pediatric cardiologist)
 - Adults (adult congenital heart cardiologist or adult cardiologist)
 - Don't know/not sure

Has a doctor or other health care provider talked with you about when this child will need to see heart doctors who treat adults?

46

Yes
No

Has this child's heart doctor

Spent enough time with this child?

Listened carefully to you?

Shown sensitivity to your family's values and customs?

Provided the specific information you needed concerning this child?

Helped you feel like a partner in this child's care?

Discussed with you the range of options to consider for their health care or treatment?

Made it easy for you to raise concerns or disagree with recommendations for this child's health care?

Worked with you to decide together which health care and treatment choices would be best for this child?

47

If this child has not seen a heart doctor in the last 2 years or ever, why? (Select all that apply)

- My child felt well
- Did not think my child needed to see a heart doctor
- Doctor told me my child no longer needed to see a heart doctor
- Changed or lost insurance
- Moved to a different city or town
- Did not like my child's heart doctor
- Couldn't find a heart doctor
- I had too many other things going on
- There were issues related to cost
- I chose to postpone or cancel appointments due to COVID
- My child's heart doctor postponed or cancelled appointments due to COVID
- Other

48

DURING THE PAST 12 MONTHS, did this child need any of the following health care but it was not received? (Select all that apply)

- My child has received all the healthcare they needed in the past 12 months
- Heart care
- Other medical care
- Dental care
- Vision care
- Hearing care
- Mental health services
- Other, specify

49

Did any of the following reasons contribute to this child not receiving needed health services? (Select all that apply)

This child did not have health insurance that covered the services needed

This child was not eligible for the services

The services this child needed were not available in your area

There were problems getting an appointment when this child needed one

There were problems with getting transportation or child care

I had too many other things going on

The clinic or doctor's office wasn't open when this child needed care

There were issues related to cost

I chose to postpone or cancel appointments due to COVID

The clinic or doctor's office postponed or cancelled appointments due to COVID

50

Other, specify

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

Not covered by any insurance or health coverage plan

Insurance through a current or former employer or union

Insurance purchased directly from an insurance company

Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or a disability

TRICARE or other military health care

Indian Health Service

51

Other, specify:

Eligibility for health insurance often changes in young adulthood. Do you know how this child will be insured as he/she becomes an adult?

52

Yes

No

- 53 If no, has anyone discussed with you how to obtain or keep some type of health insurance coverage as this child becomes an adult?
- Yes
No
- 54 Has a doctor or other health care provider ever discussed with you this child's need to see a heart doctor throughout their life?
- Yes
No
- 55 Has this child's doctor or other health care provider actively worked with the child to: (Yes, No, Unsure)
- Make positive choices about his/her health? For example, by eating healthy, getting regular exercise, not using tobacco, alcohol or other drugs, or delaying sexual activity
Gain skills to manage his/her health and health care? For example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications he/she may need
Understand the changes in health care that happen at age 18? For example, by understanding changes in privacy, consent, access to information, or decision-making
- 56 How prepared do you feel this child is to make positive choices about his/her health, manage his/her own health and health care, and handle changes in health care that happen at age 18?
- Very prepared
Somewhat prepared
Not very prepared
Not at all prepared
- 57 Have this child's doctors or other health care providers worked with you and this child to create a plan of care to meet their health goals and needs?
- Yes
No
- 58 Please rate how concerned you are about your child's future health
- Very concerned
Somewhat concerned
Not very concerned
Not at all concerned

DURING THE PAST 12 MONTHS, has this child had a flu vaccination?
A flu vaccination is usually given in the fall and protects against influenza for the flu season.

59 Yes
No

Has this child ever had coronavirus or COVID-19 (based on a positive test for COVID-19 or a health professional telling you the child had COVID-19)?

60 Yes
No
Did not receive results

Please select the statement that best describes your child regarding the COVID-19 vaccine:

61 My child has received at least two doses of vaccine for COVID-19
My child has received one dose of vaccine, and I intend for them to receive a second dose
My child has received one dose of vaccine, and I do not intend for them to receive a second dose
My child has not received any vaccine for COVID-19
Other

What are your reasons for choosing not to get your child vaccinated?
(Select all that apply)

62 I'm concerned about the potential side effects of the vaccine
I feel the vaccines were created too quickly
I don't believe the vaccines are effective at preventing the spread of COVID-19
I'm not concerned about my child contracting COVID-19
I'm generally opposed to vaccinations
A friend or family member had a bad reaction to the vaccine
I don't think that a vaccine is necessary because COVID-19 is not a serious threat
My child's doctor advised me not to get my child vaccinated
I prefer not to say
Other, specify

How are you related to this child?

63 Biological or adoptive parent
Step-parent
Grandparent
Foster parent
Other: Relative
Other: Non-relative

64

What is your age in years?

What is your marital status?

Married
Not married, but living with partner
Never married
Divorced
Separated
Widowed

65

What is the highest grade or level of school you have completed?

8th grade or less
9th-12th grade; No diploma
High School Graduate or GED Completed
Completed a vocational, trade, or business school program
Some College Credit, but no Degree
Associate Degree (AA, AS)
Bachelor's Degree (BA, BS, AB)
Master's Degree (MA, MS, MSW, MBA)
Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)

66

Which of the following best describes your current employment status?

Employed full time
Employed part-time
Working WITHOUT pay
Not employed but looking for work
Not employed and not looking for work

67

Does this child have another parent or adult caregiver who lives in this household?

Yes
No

68

How is this other caregiver related to this child?

Biological or adoptive parent
Step-parent
Grandparent
Foster parent
Other: Relative
Other: Non-relative

69

- 70 What is the highest grade or level of school this caregiver has completed?
- 8th grade or less
 - 9th-12th grade; No diploma
 - High School Graduate or GED Completed
 - Completed a vocational, trade, or business school program
 - Some College Credit, but no Degree
 - Associate Degree (AA, AS)
 - Bachelor's Degree (BA, BS, AB)
 - Master's Degree (MA, MS, MSW, MBA)
 - Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)
- 71 Which of the following best describes this caregiver's current employment status?
- Employed full-time
 - Employed part-time
 - Working WITHOUT pay
 - Not employed but looking for work
 - Not employed and not looking for work
- 72 How many children under the age of 18 are now living in the household, not including this child?
- 73 In general, how is your mental or emotional health?
- Excellent
 - Very good
 - Good
 - Fair
 - Poor
- 74 How well do you feel that you are handling the day-to-day demands of raising a child with a heart problem?
- Very well
 - Somewhat well
 - Not very well
 - Not well at all
- 75 DURING THE PAST 12 MONTHS, was there someone that you could turn to for day-to-day emotional support with parenting or raising a child with a heart problem?
- Yes
 - No

- If yes, did you receive support from (Yes, No):
- Spouse or domestic partner?
 - Other family member or close friend?
 - Health care provider?
 - Place of worship or religious leader?
 - Support or advocacy group related to specific health condition?
 - Peer support group?
 - Counselor or other mental health professional?
 - Other person, specify: _____
- 76
- DURING THE PAST 12 MONTHS, did your family have problems paying for any of this child's medical or health care bills?
- Yes
 - No
- 77
- DURING THE PAST 12 MONTHS, have you or other family members... (Y/N)
- Left a job or taken a leave of absence because of this child's health or health conditions?
 - Cut down on the hours you work because of this child's health or health conditions?
 - Avoided changing jobs because of concerns about maintaining health insurance for this child?
- 78
- IN AN AVERAGE WEEK, how many hours do you or other family members spend providing health care at home for this child? Care might include changing bandages, or giving medication and therapies when needed.
- This child does not need health care provided at home on a weekly basis
 - Less than 1 hour per week
 - 1-4 hours per week
 - 5-10 hours per week
 - 11 or more hours per week
- 79
- At any time DURING THE PAST 12 MONTHS, even for one month, did anyone in your family receive (Yes/No):
- Cash assistance from a government welfare program?
 - Food stamps or Supplemental Nutrition Assistance Program (SNAP) benefits?
 - Free or reduced-cost breakfast or lunches at school?
 - Benefits from the Women, Infants, and Children (WIC) program?
- 80

SINCE THIS CHILD WAS BORN, how often has it been very hard to cover the basics, like food or housing, on your family's income?

- 81
- Never
 - Rarely
 - Somewhat often
 - Very often

To the best of your knowledge, has this child EVER experienced any of the following? (Select all that apply)

- 82
- Parent or guardian divorced or separated
 - Parent or guardian died
 - Parent or guardian served time in jail or prison
 - Saw or heard parents or adults slap, hit, kick, or punch one another in the home
 - Was a victim of violence or witnessed violence in their neighborhood
 - Lived with anyone who was mentally ill, suicidal, or severely depressed
 - Lived with anyone who had a problem with alcohol or drugs
 - Treated or judged unfairly because of their sexual orientation or gender identity
 - Treated or judged unfairly because of his or her race or ethnic group
- 83
- Treated or judged unfairly because of a health condition or disability
 - What is the biggest concern you have about this child's future?

84

What type of information or help do you think should be available to children born with heart problems and their caregivers?

85

If you would like to receive periodic updates on the progress and results of this survey, please provide your email address

Source

Source OMB information

CH STRONG

OMB No. 0920-1122, exp. 05/31/2021

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None - new question

None - new question

OMB

OMB

NSCH

OMB No. 0607-0990, exp. 04/30/2024

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SEED Teen

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Exp. Date 03/31/2021

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None - new question

NSCH

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St Jude LIFE Study

N/A

NHIS OMB NO. 0920-0214, exp. 12/31/2023

NHIS OMB NO. 0920-0214, exp. 12/31/2023

University of South Florida
COVID-19 Vaccine Survey N/A

University of South Florida
COVID-19 Vaccine Survey N/A

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None - new question

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Source Question

Age group

What is the name of the heart problem that you were born with? (Mark all that apply)

- Aortic valve stenosis
- Atrial septal defect (ASD)
- Atrioventricular septal defect (AVSD) or Atrioventricular canal (AV canal)
- Bicuspid aortic valve
- Coarctation of aorta
- Hypoplastic left heart syndrome (HLHS)
- Patent ductus arteriosus (PDA)
- Pulmonary atresia
- Pulmonary valve stenosis
- Single ventricle (double inlet left ventricle)
- Tetralogy of Fallot (TOF)
- Transposition of the great arteries (TGA)
- Tricuspid atresia
- Truncus arteriosus
- Ventricular septal defect (VSD)
- Other (please provide name)
- Don't know/not sure
- No heart problem that I know of (please answer remaining questions to the best of your ability)

All ages (2-17)

Have you ever had surgery for the heart problem you were born with?

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

All ages (2-17)

All ages (2-17)

All ages (2-17)

All ages (2-17)

All ages (2-17)

What is this child's CURRENT height? *Your best estimate is fine.*

Ages 6-17

How much does this child CURRENTLY weigh? *Your best estimate is fine.*

Ages 6-17

In general, how would you describe this child's health (the one named above)?

Excellent

Very good

Good

Fair

Poor

All ages (2-17)

Asthma

Cerebral Palsy

Diabetes

Epilepsy or Seizure Disorder?

Heart Condition?

Frequent or severe headaches, including migraine?

Tourette Syndrome?

Anxiety problems?

Depression?

Down Syndrome?

Blood Disorders (such as Sickle Cell Disease, Thalassemia, or

Hemophilia)?

Cystic Fibrosis?

Other genetic or inherited condition?

Has a doctor, other health care provider, or educator EVER told you that this child has...

Behavioral or Conduct problems?

Developmental Delay?

Intellectual Disability?

Speech or other language disorder?

Learning Disability?

After each condition, participants were asked about the severity and whether they still have the condition.

Has a doctor or other health care provider EVER told you that this child has Autism or Autism Spectrum Disorder (ASD)? Include diagnoses of Asperger's Disorder or Pervasive Developmental Disorder (PDD).

Has a doctor or other health care provider EVER told you that this child has Attention Deficit Disorder or Attention Deficit/Hyperactivity Disorder, that is, ADD or ADHD?

All ages (2-17)

Does this child have any of the following?
-Serious difficulty walking or climbing stairs

Ages 6-17

Does this child have any of the following?
-Deafness or problems with hearing
-Blindness or problems with seeing, even when wearing glasses

All ages (2-17)

Does this child CURRENTLY need or use medicine prescribed by a doctor, other than vitamins?

Yes
No

All ages (2-17)

Does this child need or use more medical care, mental health, or educational services than is usual for most children of the same age?

Yes
No

All ages (2-17)

Is this child limited or prevented in any way in his or her ability to do the things most children of the same age can do?

Yes
No

All ages (2-17)

To what extent do this child's health conditions or problems affect their ability to do things?

Very little
Somewhat
A great deal

All ages (2-17)

Does this child need or get special therapy, such as physical, occupational, or speech therapy?

Yes
No

All ages (2-17)

Does this child have any kind of emotional, developmental, or behavioral problem for which he or she needs treatment or counseling?

Yes
No

All ages (2-17)

If yes, is this a condition that has lasted or is expected to last 12 months or longer?

Yes
No

All ages (2-17)

What grade is this child currently in? (If summer, what is the highest grade level this child has already completed)?

Ages 6-17

SINCE STARTING KINDERGARTEN, has this child repeated any grades?

Yes
No

Ages 6-17

DURING THE PAST 12 MONTHS, about how many days did this child miss school because of an illness or injury? *Include days missed from any formal home schooling.*

- No missed school days
- 1-3 days
- 4-6 days
- 7-10 days
- 11 or more days
- This child was not enrolled in school

Ages 6-17

Has this child EVER had a special education or early intervention plan?...Children receiving these services often have an Individualized Family Service Plan or Individualized Education Plan.

Yes
No

Ages 6-17

How likely do you think it is that this child will...(definitely will, probably will, probably won't, definitely won't, don't know, already has)

-Get a regular high school diploma? A regular high school diploma includes a "GED" but does not include a certificate of completion or a special diploma for students in special education

-Attend school after high school? Including technical or trade school

-Attend a special training program after high school for persons with intellectual disabilities?

-Complete a technical or trade school program?

-Graduate from a 2-year or community college?

-Graduate from a 4-year college?

-Get a driver's license?

-Eventually live away from home on his or her own without supervision?

-Eventually live away on his or her own with supervision?

-Eventually get a paid job? This includes any paid job -- child does not need to make enough to support self. This can include sheltered or supported employment

-Earn enough to support himself or herself without financial help from his or her family or government benefit programs? 12-17 years

DURING THE PAST WEEK, on how many days did this child exercise, play a sport, or participate in physical activity for at least 60 minutes?

0 days
1-3 days
4-6 days
Every day

Ages 6-17

During THE PAST 12 MONTHS, did this child participate in...

A sports team or did they take sports lessons after school or on weekends?

Any clubs or organizations after school or on weekends?

Any other organized activities or lessons, such as music, dance, language, or other arts?

Any type of community service or volunteer work at school, place of worship, or in the community?

Any paid work, including regular jobs as well as babysitting, cutting grass, or other occasional work?

Ages 6-17

DURING THE PAST 12 MONTHS, how often was this child bullied, picked on, or excluded by other children?

If the frequency changed throughout the year, report the highest frequency

Never (in the past 12 months)

1-2 times (in the past 12 months)

1-2 times per month

1-2 times per week

Almost every day

Ages 6-17

Compared to other children their age, how much difficulty does this child have making or keeping friends?

No difficulty

A little difficulty

A lot of difficulty

Ages 3-17

How often does this child share toys or games with other children?

Always

Most of the time

About half of the time

Sometimes

Never

Ages 3-5

How often does this child show concern when they see others who are hurt or unhappy?

Always

Most of the time

About half of the time

Sometimes

Never

Ages 3-5

How often does this child play well with other children?

- Always
- Most of the time
- About half of the time
- Sometimes
- Never

Ages 3-5

How often can this child recognize and name their own emotions?

- Always
- Most of the time
- About half of the time
- Sometimes
- Never

Ages 3-5

How often does this child have difficulty when asked to end one activity and start a new activity?

- Always
- Most of the time
- About half of the time
- Sometimes
- Never

Ages 3-5

How often does this child lose their temper?

- Always
- Most of the time
- About half of the time
- Sometimes
- Never

Ages 3-5

How often does this child have trouble calming down?

- Always
- Most of the time
- About half of the time
- Sometimes
- Never

Ages 3-5

How often does this child have difficulty waiting for their turn?

- Always
- Most of the time
- About half of the time
- Sometimes
- Never

Ages 3-5

How often does this child get easily distracted?

- Always
- Most of the time
- About half of the time
- Sometimes
- Never

Ages 3-5

How often can this child focus on a task you give them for at least a few minutes? For example, simple chores?

- Always
- Most of the time
- About half of the time
- Sometimes
- Never

Ages 3-5

How often does this child keep working at a task even when it is hard for them?

- Always
- Most of the time
- About half of the time
- Sometimes
- Never

Ages 3-5

Is there a place you or another caregiver USUALLY take this child when they are sick or you need advice about their health?

- Yes
- NO

If yes, where does this child USUALLY go first? *Mark (X) ONE box.*

- Doctor's Office
- Hospital Emergency Room
- Hospital Outpatient Department
- Clinic or Health Center
- Retail Store Clinic or "Minute Clinic"
- School (Nurse's Office, Athletic Trainer's Office)
- Some other place

Ages 2-17

DURING THE PAST 12 MONTHS, did this child see a doctor, nurse, or other health care professional for sick-child care, well-child check-ups, physical exams, hospitalizations or any other kind of medical care?

Yes
No

If yes, DURING THE PAST 12 MONTHS, how many times did this child visit a doctor, nurse, or other health care professional to receive a PREVENTIVE check-up? A *preventive check-up is when this child was not sick or injured, such as an annual or sports physical, or well-child visit.*

0 visits
1 visit
2 or more visits

Ages 2-17

DURING THE PAST 12 MONTHS, how many times did this child visit a hospital emergency room?

None
1 time
2 or more times

Ages 2-17

DURING THE PAST 12 MONTHS, was this child admitted to the hospital to stay for at least one night?

Yes
No

Ages 2-17

How many health care provider visits were with a heart doctor or at a cardiology clinic (clinic that only see patients with heart problems) in the past 12 months?

Ages 2-17

When is the last time you saw a heart doctor?

Less than 1 year
1-2 years
3-5 years
More than 5 years
Never seen one

Ages 2-17

Who are the majority of patients that your primary heart doctor usually sees?

Children and adolescents (pediatric cardiologist)
Adults who have had their heart problem since birth (adult congenital heart cardiologist or adult cardiologist)
Adults (adult cardiologist)

Ages 2-17

Do any of this child's doctors or other health care providers treat only children?

Yes
No

If yes, have they talked with you about when this child will need to see doctors or other health care providers who treat adults?

Yes
No

Ages 12-17

DURING THE PAST 12 MONTHS, how often did this child's doctors or other health care providers...

Spend enough time with this child?
Listen carefully to you?
Show sensitivity to your family's values and customs?
Provide the specific information you needed concerning this child?
Help you feel like a partner in this child's care?

{Always, usually, sometimes, never}

DURING THE PAST 12 MONTHS, did this child need any decisions to be made regarding their health care, such as whether to get prescriptions, referrals, or procedures?

Yes
No

If yes, DURING THE PAST 12 MONTHS, how often did this child's doctors or other health care providers...

Discuss with you the range of options to consider for their health care or treatment?
Make it easy for you to raise concerns or disagree with recommendations for this child's health care?
Work with you to decide together which health care and treatment choices would be best for this child?

{Always, usually, sometimes, never}

Ages 2-17

If you have not seen a heart doctor in the last 5 years or ever, why? *Mark all that apply.*

- Felt well
- Did not think I needed to see a heart doctor
- Doctor told me I no longer needed to see a heart doctor
- My parents stopped taking me
- Changed or lost my insurance
- Moved to a different city or town
- Did not like my heart doctor
- Couldn't find a heart doctor
- Other

Ages 2-17

DURING THE PAST 12 MONTHS, was there any time when this child needed health care but it was not received? *By health care, we mean medical care as well as other kinds of care like dental care, vision care, and mental health services.*

- Yes
- No

If yes, which types of care were not received? *Mark (X) ALL that apply.*

- Medical Care
- Dental Care
- Vision Care
- Hearing Care
- Mental Health Services
- Other, specify

Ages 2-17

Did any of the following reasons contribute to this child not receiving needed health services? Mark (X) Yes or No for EACH item.

This child was not eligible for the services
The services this child needed were not available in your area
There were problems getting an appointment when this child needed one
There were problems with getting transportation or child care
The clinic or doctor's office wasn't open when this child needed care
There were issues related to cost

Ages 2-17

Is this child CURRENTLY covered by ANY kind of health insurance or health coverage plan?

Yes
No

Is this child CURRENTLY covered by any of the following types of health insurance or health coverage plans? Mark (X) Yes or No for EACH item.

Insurance through a current or former employer or union
Insurance purchased directly from an insurance company
Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or a disability
TRICARE or other military health care
Indian Health Service
Other, specify:

Ages 2-17

Eligibility for health insurance often changes in young adulthood. Do you know how this child will be insured as he/she becomes an adult?

Yes
No

Ages 12-17

If no, has anyone discussed with you how to obtain or keep some type of health insurance coverage as this child becomes an adult?

Yes
No

Ages 12-17

When you were a teenager or young adult, did a health care provider ever discuss with you the need to see a heart doctor throughout your life?

Yes
No

Ages 12-17

Has this child's doctor or other health care provider actively worked with this child to: (Yes, No, Don't Know)

Make positive choices about their health. For example, by eating healthy, getting regular exercise, not using tobacco, alcohol or other drugs, or delaying sexual activity?
Gain skills to manage their health and health care. For example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications they may need?
Understand the changes in health care that happen at age 18. For example, by understanding changes in privacy, consent, access to information, or decision-making?

Ages 12-17

Ages 12-17

Have this child's doctors or other health care providers worked with you and this child to create a plan of care to meet their health goals and needs?

Yes
No

Ages 12-17

Please rate how concerned you are about the following (Not at all concerned, not very concerned, concerned, somewhat concerned, very concerned) : Your child's future health

Ages 2-17

DURING THE PAST 12 MONTHS, has {SC name} had a flu vaccination? A flu vaccination is usually given in the fall and protects against influenza for the flu season.

Yes
No

Ages 2-17

Has a doctor or other health professional ever told you that ^SCNAME had or likely had coronavirus or COVID-19?

Has ^SCNAME ever been tested for coronavirus or COVID-19? Ages 2-17

Please select the statement that best describes you:

I have received all of my vaccine doses and am fully vaccinated.

I have received one dose of the Pfizer or Moderna vaccine, and I intend to receive the second dose.

I have received one dose of the Pfizer or Moderna vaccine, but I do not intend to receive the second dose.

Ages 5-17

What are your primary reasons for choosing not to get vaccinated? (*check all that apply*)

I'm concerned about the potential side effects of the vaccine

I feel the vaccines were created too quickly

I don't believe the vaccines are effective at preventing the spread of COVID-19

I'm not concerned about contracting COVID-19

I'm generally opposed to vaccinations

A friend or family member had a bad reaction to the vaccine

I don't think that a vaccine is necessary because COVID-19 is not a serious threat

My primary care doctor advised me not to get vaccinated

Ages 5-17

How are you related to this child?

Biological or adoptive parent

Step-parent

Grandparent

Foster parent

Other: Relative

Other: Non-relative

Ages 2-17

What is your age in years Ages 2-17

What is your marital status?

- Married
- Not married, but living with partner
- Never married
- Divorced
- Separated
- Widowed

Ages 2-17

What is the highest grade or level of school you have completed? *Mark (X) ONE box.*

- 8th grade or less
- 9th-12th grade; No diploma
- High School Graduate or GED Completed
- Completed a vocational, trade, or business school program
- Some College Credit, but no Degree
- Associate Degree (AA, AS)
- Bachelor's Degree (BA, BS, AB)
- Master's Degree (MA, MS, MSW, MBA)
- Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)

Ages 2-17

Which of the following best describes your current employment status? *Mark (X) ONE box.*

- Employed full-time
- Employed part-time
- Working WITHOUT pay
- Not employed but looking for work
- Not employed and not looking for work

Ages 2-17

Does this child have another parent or adult caregiver who lives in this household?

- Yes
- No

Ages 2-17

How is this other caregiver related to this child?

- Biological or adoptive parent
- Step-parent
- Grandparent
- Foster parent
- Other: Relative
- Other: Non-relative

Ages 2-17

What is the highest grade or level of school this caregiver has completed? *Mark (X) ONE box.*

- 8th grade or less
 - 9th-12th grade; No diploma
 - High School Graduate or GED Completed
 - Completed a vocational, trade, or business school program
 - Some College Credit, but no Degree
 - Associate Degree (AA, AS)
 - Bachelor's Degree (BA, BS, AB)
 - Master's Degree (MA, MS, MSW, MBA)
 - Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)
- Ages 2-17

Which of the following best describes this caregiver's current employment status? *Mark (X) ONE box.*

- Employed full-time
 - Employed part-time
 - Working WITHOUT pay
 - Not employed but looking for work
 - Not employed and not looking for work
- Ages 2-17

How many children under the age of 18 are now living in the household, not including this child

Ages 2-17

In general, how is your mental or emotional health?

- Excellent
 - Very good
 - Good
 - Fair
 - Poor
- Ages 2-17

How well do you think you are handling the day-to-day demands of raising children?

- Very well
 - Somewhat well
 - Not very well
 - Not well at all
- Ages 2-17

DURING THE PAST 12 MONTHS, was there someone that you could turn to for day-to-day emotional support with parenting or raising children?

- Yes
 - No
- Ages 2-17

If yes, did you receive support from (Yes, No):

- Spouse or domestic partner?
- Other family member or close friend?
- Health care provider?
- Place of worship or religious leader?
- Support or advocacy group related to specific health condition?
- Peer support group?
- Counselor or other mental health professional?
- Other person, specify: _____

Ages 2-17

DURING THE PAST 12 MONTHS, did your family have problems paying for any of this child's medical or health care bills?

- Yes
- No

Ages 2-17

DURING THE PAST 12 MONTHS, have you or other family members...(Y/N)

- Left a job or taken a leave of absence because of this child's health or health conditions?
- Cut down on the hours you work because of this child's health or health conditions?
- Avoided changing jobs because of concerns about maintaining health insurance for this child?

Ages 2-17

IN AN AVERAGE WEEK, how many hours do you or other family members spend providing health care at home for this child? *Care might include changing bandages, or giving medication and therapies when needed.*

- This child does not need health care provided at home on a weekly basis
- Less than 1 hour per week
- 1-4 hours per week
- 5-10 hours per week
- 11 or more hours per week

Ages 2-17

At any time DURING THE PAST 12 MONTHS, even for one month, did anyone in your family receive (Yes/No):

- Cash assistance from a government welfare program?
- Food stamps or Supplemental Nutrition Assistance Program (SNAP) benefits?
- Free or reduced-cost breakfasts or lunches at school?
- Benefits from the Women, Infants, and Children (WIC) program?

Ages 2-17

SINCE THIS CHILD WAS BORN, how often has it been very hard to cover the basics, like food or housing, on your family's income?

- Never
- Rarely
- Somewhat often
- Very often

Ages 2-17

To the best of your knowledge, has this child EVER experienced any of the following? (Y/N)

- Parent or guardian divorced or separated
- Parent or guardian died
- Parent or guardian served time in jail or prison
- Saw or heard parents or adults slap, hit, kick, punch one another in the home
- Was a victim of violence or witnessed violence in their neighborhood
- Lived with anyone who was mentally ill, suicidal, or severely depressed
- Lived with anyone who had a problem with alcohol or drugs
- Treated or judged unfairly because of their sexual orientation or gender identity (AGES 6-17 ONLY)
- Treated or judged unfairly because of their race or ethnic group
- Treated or judged unfairly because of a health condition or disability

Ages 2-17

Ages 2-17

For future planning, what type of information or help do you think should be available to people born with heart problems? Ages 2-17

If you would like to receive periodic updates on the progress and results of this survey, please provide your email address. Ages 2-17