C Returning?		
	AAA	
<b>(#)</b> English	<b>+ -</b>	J

Please complete the survey below.

Thank you!

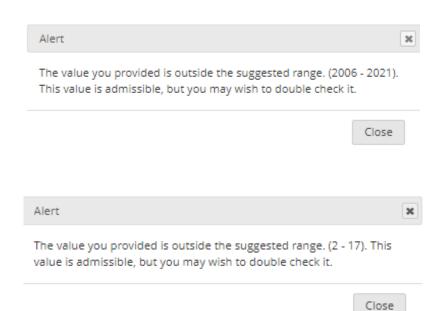
Page 1 of 20

Select your preferred language: Seleccione su idioma preferido:	<ul><li>○ English</li><li>○ Spanish (Español)</li><li>reset</li></ul>	
As explained in the letter you received with this survey, we are con show that your child was born with a heart condition. We would lik health, and your family.	,	
The survey should be completed by a parent or adult caregiver wh your child's health and health care.	o lives in this household and who is familiar with	
Please answer questions with information about your child with a heart condition only. You may choose to skip any question you do not wish to answer.		
Next Page >> Save & Return L		



Page 2 of 20

Your child's information	
In what month and year was this child born?	
Month:	O January
	O February
	O March
	O April
	O May
	O June
	O July
	O August
	O September
	O October
	ONovember
	O December
	reset
Year:	
real.	
What is this child's age in years?	
What is this time s age in years.	
ALERT: Some questions on this survey are specific to the ag child's age, the survey may take longer because it will incluyour child's age.	
Is this child Hispanic or Latino?	O Hispanic or Latino
·	Not Hispanic or Latino
	reset
What is this shildle was 2 (Salast all that apply)	
What is this child's race? (Select all that apply)	☐ American Indian or Alaska Native
	Asian
	☐ Black or African-American
	Native Hawaiian or other Pacific Islander
	White
<< Previous Page	Nevt Page >>



Page 3 of 20

Your child's heart condition		
Your child's heart condition  What is the name of the heart condition 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  ✓ Don't know/not sure  ✓ No heart condition that I know of (please	
ALERT: "Don't know/not sure" was selected along with other	answer remaining questions to the best of your ability)  answers. Please review.	
ALERT: "No heart condition that I know of" was selected along with other answers. Please review.		
If other, please specify:		
ALERT: "Other" was selected, but "If other, please specify" was not answered. You may have forgotten to type your response into the text box.		

Has this child ever had surgery for the heart condition they were born with? Heart surgery will result in scars on the middle of the chest, side, or back.	<ul><li>○ Yes</li><li>○ No</li><li>○ Don't know/not sure</li><li>reset</li></ul>
What type of information or help should be available to caregivers of children born with a heart condition?	Expand
	Expand
When this child was first diagnosed with a heart condition, were you provided enough information on what this meant for their emotional, social and physical health?	<ul><li>○ Yes</li><li>○ No</li><li>○ Don't know/not sure</li><li>reset</li></ul>
<< Previous Page  Save & Return I	Next Page >>



Page 4 of 20

Your child's heart doctors	
When is the last time this child saw a heart doctor?	<ul> <li>Less than 1 year</li> <li>1-2 years</li> <li>3-5 years</li> <li>More than 5 years</li> <li>Never seen one</li> </ul>
How many health care provider visits were with a heart doctor or at a cardiology clinic (clinic that only sees patients with heart conditions) in the past 12 months?	
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 (adult congenital heart cardiologist or adult cardiologist)?	○ Yes ○ No reset
In the past 2 years, how often has this child's heart doctor:	
Spent enough time with this child?	Always     Usually     Sometimes     Never
Listened carefully to you?	Always     Usually     Sometimes     Never
Shown sensitivity to your family's values and customs?	<ul><li>Always</li><li>Usually</li><li>Sometimes</li><li>Never</li></ul>
Provided the specific information you needed concerning this child?	Always     Usually     Sometimes     Never

Helped you feel like a partner in this child's care?	○ Always
	O Usually
	O Sometimes
	O Never
	reset
Discussed with you the range of options to consider for this child's health care or treatment?	O Always
for this child's health care or treatment?	O Usually
	○ Sometimes
	○ Never
	reset
Made it easy for you to raise concerns or disagree	O there is
with recommendations for this child's health care?	Always
	O Usually
	O Sometimes
	O Never
Worked with you to decide together which health	○ Always
care and treatment choices would be best for this	O Usually
child?	O Sometimes
	O Never
	reset
If this child has not seen a heart doctor in the last 2 years or ever, why? (Select all that apply)	☐ This child felt well
,, (	Did not think this child needed to see a heart
	doctor
	Doctor told me this child no longer needed to see a heart doctor
	Changed or lost insurance
	Moved to a different city or town
	Did not like this 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-19
	☐ This child's heart doctor postponed or
	cancelled appointments due to COVID-19
	☑ Other
If other, please specify:	
ALERT: "Other" was selected, but "If other, please specify" was your response into the text box.	as not answered. You may have forgotten to type
<< Previous Page	Next Page >>
Save & Return I	Later



Page 5 of 20

Your child's general health	
What is this child's CURRENT height? (Answer in either feet	and inches or meters and centimeters)
Feet	
AND inches	
Meters	
AND centimeters	
How much does this child CURRENTLY weigh? (Answer in ei	ther pounds or kilograms)
Pounds	
Kilograms	
In general, how would you describe this child's health?	<ul><li>Excellent</li><li>Very Good</li><li>Good</li><li>Fair</li><li>Poor</li><li>reset</li></ul>
<< Previous Page  Save & Return	Next Page >> rn Later



Page 6 of 20

Your child's medical conditions		
Has a doctor or other health care provider EVER told you that	t this child has	
Anxiety problems	○ Yes	
	○ No	reset
Depression	○ Yes	
	○ No	recet
		reset
Developmental delay	○ Yes	
	○ No	reset
Behavioral or conduct problems	○ Yes	
	○ No	reset
Intellectual disability	0	
intellectual disability	O Yes	
	○ No	reset
Speech or language disorder	○ Yes	
	O No	
		reset
Learning disability	○ Yes	
	○ No	
		reset
Attention Deficit Disorder or Attention	○ Yes	
Deficit/Hyperactivity Disorder, that is, ADD or ADHD	○ No	rocot
		reset
Autism, Autism Spectrum Disorder, Asperger's	○ Yes	
Disorder, or Pervasive Developmental Disorder (PDD)	○ No	
		reset

Diabetes		
Diabetes	O Yes	
	O No	
		reset
Down syndrome	0	
Down syndrome	O Yes	
	O No	
		reset
Other genetic or inherited condition	O	
other genetic of innerfice condition	O Yes	
	O No	
		reset
Heart failure	O v	
Treate failure	O Yes	
	O No	
		reset
Other		
Other	Yes	
	O No	
		reset
lf other, please specify:		
If other, please specify:  ALERT: "Other" was selected, but "If other, please specify your response into the text box.	' was not answered. You may hav	e forgotten to type
ALERT: "Other" was selected, but "If other, please specify"	' was not answered. You may hav	e forgotten to type
ALERT: "Other" was selected, but "If other, please specify your response into the text box.  Does this child have any of the following?		e forgotten to type
ALERT: "Other" was selected, but "If other, please specify' your response into the text box.	O Yes	e forgotten to type
ALERT: "Other" was selected, but "If other, please specify your response into the text box.  Does this child have any of the following?		e forgotten to type
ALERT: "Other" was selected, but "If other, please specify your response into the text box.  Does this child have any of the following?	O Yes	
ALERT: "Other" was selected, but "If other, please specify your response into the text box.  Does this child have any of the following?	O Yes O No	
ALERT: "Other" was selected, but "If other, please specify your response into the text box.  Does this child have any of the following?  Deafness or problems with hearing	O Yes O No	
ALERT: "Other" was selected, but "If other, please specify your response into the text box.  Does this child have any of the following?  Deafness or problems with hearing  Blindness or problems with seeing, even when	O Yes O No	
ALERT: "Other" was selected, but "If other, please specify your response into the text box.  Does this child have any of the following?  Deafness or problems with hearing  Blindness or problems with seeing, even when	O Yes O No	reset
ALERT: "Other" was selected, but "If other, please specify your response into the text box.  Does this child have any of the following?  Deafness or problems with hearing  Blindness or problems with seeing, even when	O Yes O No	reset
ALERT: "Other" was selected, but "If other, please specify" your response into the text box.  Does this child have any of the following?  Deafness or problems with hearing  Blindness or problems with seeing, even when wearing eyeglasses	O Yes O No O Yes O No O Yes O Yes	reset
ALERT: "Other" was selected, but "If other, please specify" your response into the text box.  Does this child have any of the following?  Deafness or problems with hearing  Blindness or problems with seeing, even when wearing eyeglasses	O Yes O No O Yes O No	reset
ALERT: "Other" was selected, but "If other, please specify" your response into the text box.  Does this child have any of the following?  Deafness or problems with hearing  Blindness or problems with seeing, even when wearing eyeglasses	O Yes O No O Yes O No O Yes O Yes	reset
ALERT: "Other" was selected, but "If other, please specify" your response into the text box.  Does this child have any of the following?  Deafness or problems with hearing  Blindness or problems with seeing, even when wearing eyeglasses  Serious difficulty walking or climbing stairs	O Yes O No O Yes O No O Yes O No	reset
ALERT: "Other" was selected, but "If other, please specify" your response into the text box.  Does this child have any of the following?  Deafness or problems with hearing  Blindness or problems with seeing, even when wearing eyeglasses	O Yes O No O Yes O No O Yes O Yes	reset
ALERT: "Other" was selected, but "If other, please specify" your response into the text box.  Does this child have any of the following?  Deafness or problems with hearing  Blindness or problems with seeing, even when wearing eyeglasses  Serious difficulty walking or climbing stairs  <	O Yes No Yes No Yes No No Next Page >>	reset
ALERT: "Other" was selected, but "If other, please specify" your response into the text box.  Does this child have any of the following?  Deafness or problems with hearing  Blindness or problems with seeing, even when wearing eyeglasses  Serious difficulty walking or climbing stairs	O Yes No Yes No Yes No No Next Page >>	reset

Page 7 of 20

Your child's healthcare needs		
Does this child CURRENTLY need or use medicine prescribed by a doctor, other than vitamins?	○ Yes ○ No	
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	
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	
To what extent do this child's health conditions or problems affect their ability to do things?	Very little     Somewhat     A great deal     reset	
Does this child need or get special therapy, such as physical, occupational, or speech therapy?	○ Yes ○ No	
Does this child have any kind of emotional, developmental, or behavioral problem for which they need treatment or counseling?	<ul><li>Yes</li><li>No</li></ul>	
If YES to any of questions above in this Special Healthcare Needs section (Questions 19-24), is it because of ANY medical, behavioral, or other health condition that is expected to last 12 months or longer?	○ Yes ○ No	
<< Previous Page  Save & Return L	Next Page >>	

Page 8 of 20

Your child's school/learning history	
What grade is this child currently in? (If summer, what is the highest grade level this child has already completed)?	<ul> <li>Kindergarten</li> <li>1st grade</li> <li>2nd grade</li> <li>3rd grade</li> <li>4th grade</li> <li>5th grade</li> <li>6th grade</li> <li>7th grade</li> <li>8th grade</li> <li>9th grade</li> <li>10th grade</li> <li>11th grade</li> <li>12th grade</li> </ul>
Since starting kindergarten, has this child repeated any grades?	○ Yes ○ No
DURING THE PAST 12 MONTHS, about how many days did this child miss school because of their heart condition, illness, or injury?	No missed school days  1 - 3 days  4 - 6 days  7 - 10 days  11 or more days  This child was not enrolled in school reset
Has this child EVER had any of the following special education or early intervention plans? (Select all that apply)	<ul> <li>Individualized Family Service Plan or IFSP (used for early intervention services in children younger than 3)</li> <li>Individualized Education Program or IEP (used for special education services in children 3 or older)</li> <li>504 Plan (sometimes used for special education services instead of or in addition to an IEP)</li> <li>✓ Other</li> <li>No, this child has never had a plan for special education</li> </ul>
lf other, please specify:	
ALERT: "Other" was selected, but "If other, please specify" was not answered. You may have forgotten to type your response into the text box.	

How	How likely do you think it is that this child will				
	Get a regular high school diploma? A regular high	O Definitely Will			
	school diploma includes a "GED" but does not include	O Probably will			
	a certificate of completion or a special diploma for students in special education	O Probably won't			
		O Definitely won't			
		O Don't know			
		O Already has			
			reset		
	Attend school after high school? Including technical	O Definitely Will			
	or trade school	O Probably will			
		O Probably won't			
		O Definitely won't			
		O Don't know			
		Already has			
			reset		
	Attend a special training program after high school	O Definitely Will			
	for persons with intellectual disabilities?	O Probably will			
		O Probably won't			
		O Definitely won't			
		O Don't know			
		O Already has			
			reset		
	Complete a technical or trade school program?	O Definitely Will			
		O Probably will			
		O Probably won't			
		O Definitely won't			
		O Don't know			
		O Already has			
			reset		
	Graduate from a 2-year or community college?	O Definitely Will			
		O Probably will			
		O Probably won't			
		O Definitely won't			
		O Don't know			
		O Already has			
			reset		
	Graduate from a 4-year college?	O Definitely Will			
		O Probably will			
		O Probably won't			
		O Definitely won't			
		O Don't know			
		Already has			

Get a driver's license?	O Definitely Will	
	O Probably will	
	O Probably won't	
	O Definitely won't	
	O Don't know	
	Already has	
	O 7 1222 J 1.22	reset
Eventually live away from home on his or her own without supervision?	O Definitely Will	
maiout supervision.	O Probably will	
	O Probably won't	
	O Definitely won't	
	O Don't know	
	O Already has	
		reset
Eventually live away on his or her own with	O Definitely Will	
supervision?	O Probably will	
	Probably won't	
	O Definitely won't	
	O Don't know	
	Already has	reset
Eventually get a paid job? This includes any paid job	O Definitely Will	
child does not need to make enough to support self.  This can include sheltered or supported employment.	Probably will	
mis can include sherered of supported employment.	O Probably won't	
	O Definitely won't	
	O Don't know	
	Already has	
		reset
Earn enough to support himself or herself without	O Definitely Will	
financial help from his or her family or government		
benefit programs?	Probably will     Probably won't	
	O Definitely won't	
	O Don't know	
	O Already has	reset
<< Previous Page	Next Page >>	
Save & Return	Later	



Page 9 of 20

Your child's activities and social environment		
DURING THE PAST WEEK, on how many days did this child exercise, play a sport, or participate in physical activity f at least 60 minutes?		
DURING THE PAST 12 MONTHS, did this child participate	in:	
A sports team or did he or she take sports lessons after school or on weekends?	<ul><li>○ Yes</li><li>○ No</li><li>reset</li></ul>	
Any clubs or organizations after school or on weekends?	<ul><li>○ Yes</li><li>○ No</li><li>reset</li></ul>	
Any other organized activities or lessons, such as music, dance, language, or other arts?	○ Yes ○ No	
Any type of community service or volunteer work a school, church, or in the community?	at O Yes O No	
Any work, including regular jobs as well as babysitting, cutting grass, or other occasional work	○ Yes ○ No reset	
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  Almost every day	
Compared to other children their age, how much difficul does this child have making or keeping friends?		
<< Previous Page  Save & Ret	Next Page >> urn Later	

AAA



Page 10 of 20

Your child's readiness to learn		
How often does this child share toys or games with other children?	Always     Most of the time     About half of the time     Sometimes     Never	reset
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	reset
How often does this child play well with other children?	<ul><li>Always</li><li>Most of the time</li><li>About half of the time</li><li>Sometimes</li><li>Never</li></ul>	reset
How often can this child recognize and name their own emotions?	Always     Most of the time     About half of the time     Sometimes     Never	reset
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	reset
How often does this child lose their temper?	Always     Most of the time     About half of the time     Sometimes     Never	reset
How often does this child have trouble calming down?	Always     Most of the time     About half of the time	

How often does this child have difficulty waiting for the turn?	- 1110/2	
	Most of the time	
	About half of the time	
	O Sometimes	
	○ Never	reset
		reset
How often does this child get easily distracted?	○ Always	
	Most of the time	
	About half of the time	
	O Sometimes	
	○ Never	
		reset
How often can this child focus on a task you have given	2 0 11	
them for at least a few minutes? For example, simple	O Amoys	
chores?	O Most of the time	
	About half of the time	
	O Sometimes	
	O Never	reset
How often does this child keep working at a task even	O Always	
when it is hard for them?	Most of the time	
	About half of the time	
	O Sometimes	
	○ Never	
		reset
<< Previous Page	Next Page >>	
Save & Ro	eturn Later	



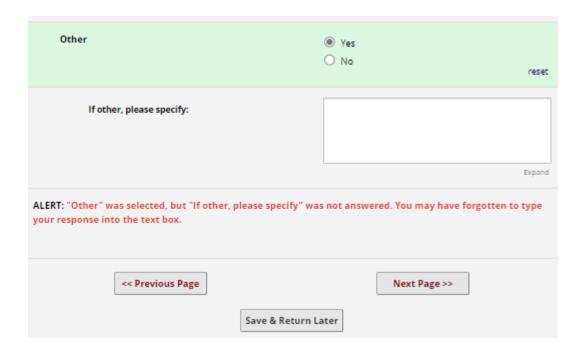
Page 11 of 20

	_
Your child's health care	
Where does this child usually go when they are sick or you need advice about their health?	This child does not have a usual place for health care or advice when sick
	O Doctor's Office
	O Hospital Emergency Room
	O Hospital Outpatient Department
	O Urgent Care Center
	O Clinic or Health Center
	Retail Store Clinic or "Minute Clinic"
	School (Nurse's Office, Athletic Trainer's Office)
	O Some other place
DURING THE PAST 12 MONTHS, how many times did this	O visits
child visit a doctor, nurse, or other health care professional to receive a PREVENTIVE check-up? A preventive check-up	○ 1 visit
is when this child was not sick or injured, such as an	O 2 or more visits
annual or sports physical, or well-child visit.	reset
DURING THE PAST 12 MONTHS, how many times did this	○ None
child visit a hospital emergency room?	O 1 time
	O 2 or more times
	reset
DURING THE PAST 12 MONTHS, was this child admitted to	○ Yes
the hospital to stay for at least one night?	O No
	reset
<< Previous Page	Next Page >>
Save & Return L	ater

Page 12 of 20

Your child's unmet needs		
DURING THE PAST 12 MONTHS, did this child need any of the following health care but it was not received? (Select all that apply)	<ul> <li>Heart care</li> <li>Other medical care</li> <li>Dental care</li> <li>Vision care</li> <li>Hearing care</li> <li>Mental health services</li> <li>✓ Other</li> <li>✓ This child has received all the healthcare they needed in the past 12 months&gt; Go to next page</li> </ul>	
Alert: "Received all healthcare" is checked with other choices.		
If other, please specify:		
ALERT: "Other" was selected, but "If other, please specify" was not answered. You may have forgotten to type your response into the text box.		

l any of the following reasons contribute to this child not i	eceiving needed nearth servic	esr
This child did not have health insurance that covered the services needed	○ Yes ○ No	reset
This child was not eligible for the services	○ Yes ○ No	reset
The services this child needed were not available in your area	○ Yes ○ No	reset
There were problems getting an appointment when this child needed one	○ Yes ○ No	reset
There were problems with getting transportation or child care	○ Yes ○ No	reset
I had too many other things going on	○ Yes ○ No	reset
The clinic or doctor's office wasn't open when this child needed care	○ Yes ○ No	reset
There were issues related to cost	○ Yes ○ No	reset
l chose to postpone or cancel appointments due to COVID-19	○ Yes ○ No	reset
The clinic or doctor's office postponed or cancelled appointments due to COVID-19	○ Yes ○ No	reset





Page 13 of 20

Your child's insurance			
Is this child CURRENTLY covered by ANY kind insurance or health coverage plan?	of health Yes  No> Go to next page reset		
Is this child CURRENTLY covered by any of the	following types of health insurance or health coverage plans?		
Insurance through a current or former union	employer or Yes No reset		
Insurance purchased directly from an ir company, including the Health Insuran Marketplace from the Affordable Care A	re O No		
Medicaid (including MassHealth, Minne PeachCare, or Georgia Families), Medica or any kind of government assistance p with low incomes or a disability	al Assistance, O No		
TRICARE or other military health care	○ Yes ○ No		
Indian Health Service	○ Yes ○ No		
Other	Ves  No reset		
If other, please specify:			
ALERT: "Other" was selected, but "If other, please specify" was not answered. You may have forgotten to type your response into the text box.			
<< Previous Page	Next Page >>		
	Save & Return Later		

Page 14 of 20

Transition to adult healthcare		
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	reset
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	reset
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	reset
Has this child's doctor or other health care provider actively v	worked with the child to:	
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	Yes No Don't Know	reset
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	Yes No Don't Know	reset
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	○ Yes ○ No ○ Don't Know	reset
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	reset
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	reset
Please rate how concerned you are about this child's future health	Very concerned Somewhat concerned Not very concerned Not at all concerned	reset
<< Previous Page  Save & Return L	Next Page >>	

Page 15 of 20

Immunizations			
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.	O Yes		reset
<< Previous Page		Next Page >>	
Save & Retu	ırn Later		

#### Page 16 of 20

COVID-19		
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)?	O Yes O No O Did not receive results	
Please select the statement that best describes this child regarding the COVID-19 vaccine:	This child has received all recommended doses of vaccine for COVID-19> Go to next page This child has received some but not all recommended doses of vaccine, and I intend for them to receive all recommended doses> Go to next page This child has received some but not all recommended doses of vaccine, and I do not intend for them to receive all recommended doses This child has not received any vaccine for COVID-19 Other reset	
What are your reasons for choosing not to get this child fully vaccinated? (Select all that apply)	<ul> <li>I'm concerned about the potential side effects of the vaccine</li> <li>I feel the vaccines were created too quickly</li> <li>I don't believe the vaccines are effective at preventing the spread of COVID-19</li> <li>I'm not concerned about this child contracting COVID-19</li> <li>I'm generally opposed to vaccinations</li> <li>A friend or family member had a bad reaction to the vaccine</li> <li>I don't think that a vaccine is necessary because COVID-19 is not a serious threat</li> <li>This child's doctor advised me not to get this child vaccinated</li> <li>✓ Other</li> <li>I prefer not to say</li> </ul>	
If other, please specify:		
ALERT: "Other" was selected, but "If other, please specify" was not answered. You may have forgotten to type your response into the text box.		
<< Previous Page  Save & Return	Next Page >> n Later	

	1080170120
About you	
How are you related to this child?	Biological or adoptive parent  Step-parent  Grandparent  Foster parent  Other: Relative  Other: Non-relative
What is your age in years?	
What is your marital status?	Married Not married, but living with partner Never married Divorced Separated Widowed reset
What is the highest grade or level of school you have completed?	Sth 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)
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 reset
In general, how is your mental or emotional health?	Excellent Very Good Good Fair Poor
How well do you feel that you are handling the day-to-day demands of raising a child with a heart condition?	Very well Somewhat well Not very well Not well at all reset

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 condition?	○ Yes ○ No	reset
If yes, did you receive support from:		
Spouse or domestic partner?	○ Yes ○ No	reset
Other family member or close friend?	○ Yes ○ No	reset
Health care provider?	○ Yes ○ No	reset
Place of worship or religious leader?	○ Yes ○ No	reset
Support or advocacy group related to specific health condition?	○ Yes ○ No	reset
Peer support group?	○ Yes ○ No	reset
Counselor or other mental health professional?	○ Yes ○ No	reset
Other person	Yes No	reset
If other person, please specify:		
ALERT: "Other person" was selected, but "If other person, please specify" was not answered. You may have forgotten to type your response into the text box.		
DURING THE PAST 12 MONTHS, did your family have problems paying for any of this child's medical or health care bills?	○ Yes ○ No	reset

DURING THE PAST 12 MONTHS, have you or other family members	
Left a job or taken a leave of absence because of this child's health or health conditions?	○ Yes
	○ No reset
Cut down on the hours you work because of this	○ Yes
child's health or health conditions?	○ No
Avoided changing jobs because of concerns about maintaining health insurance for this child?	○ Yes
maintaining nearth insurance for this child:	○ No
	reset
IN AN AVERAGE WEEK, how many hours do you or other family members spend providing health care at home for	O This child does not need health care provided
this child? Care might include changing bandages or giving	at home on a weekly basis
medication and therapies when needed.	O Less than 1 hour per week
	O 1-4 hours per week
	O 5-10 hours per week
	11 or more hours per week reset
At any time DURING THE PAST 12 MONTHS, even for one mon	ith, did anyone in your family receive:
Cash assistance from a government welfare	○ Yes
program?	○ No
	reset
Food stamps or Supplemental Nutrition Assistance	○ Yes
Program (SNAP) benefits?	○ No
	reset
Free or reduced-cost breakfast or lunches at school?	○ Yes
	○ No
	reset
Benefits from the Women, Infants, and Children (WIC)	○ Yes
program?	○ No
	reset
SINCE THIS CHILD WAS BORN, how often has it been very	O Never
hard to cover the basics, like food or housing, on your	O Rarely
family's income?	O Somewhat Often
	O Very often
	reset
<< Previous Page	Next Page >>
Save & Return I	Later



Page 18 of 20

Household information	
Does this child have another parent or adult caregiver who lives in this household?	○ Yes ○ No reset
How is this other caregiver related to this child?	Biological or adoptive parent     Step-parent     Grandparent     Foster parent     Other: Relative     Other: Non-relative
What is the highest grade or level of school this caregiver has completed?	<ul> <li>8th grade or less</li> <li>9th-12th grade; No diploma</li> <li>High School Graduate or GED Completed</li> <li>Completed a vocational, trade, or business school program</li> <li>Some College Credit, but no Degree</li> <li>Associate Degree (AA, AS)</li> <li>Bachelor's Degree (BA, BS, AB)</li> <li>Master's Degree (MA, MS, MSW, MBA)</li> <li>Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)</li> </ul>
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     reset
How many children under the age of 18 are now living in the household, not including this child?	

What is the primary language spoken in the household?	English     Spanish     Somali	
	Other     reset	
If other, please specify:		
	Expand	
ALERT: "Other" was selected, but "If other, please specify" was not answered. You may have forgotten to type your response into the text box.		
<< Previous Page  Save & Return L	Next Page >> ater	

	Page 19 of 20
Childhood experiences	
The next questions are about events that may have happened during this child's life. These things can happen in any family, but some people may feel uncomfortable with these questions. As a reminder, you may skip any questions you do not want to answer.	
To the best of your knowledge, has this child EVER experience	ed any of the following?
Parent or guardian divorced or separated	○ Yes
	O No
	reset
Parent or guardian died	○ Yes
	○ No
	reset
Parent or guardian served time in jail or prison	○ Yes
	○ No
	reset
Saw or heard parents or adults slap, hit, kick, or	○ Yes
punch one another in the home	○ No
	reset
Was a victim of violence or witnessed violence in	○ Yes
their neighborhood	○ No
	reset
Lived with anyone who was mentally ill, suicidal, or	○ Yes
severely depressed	O No
	reset
Lived with anyone who had a problem with alcohol or	○ Yes
drugs	O No
	reset
Treated or judged unfairly because of his or her race	○ Yes
or ethnic group	O No
	reset
Treated or judged unfairly because of a health	○ Yes
condition or disability	○ No
	reset
Treated or judged unfairly because of their sexual	○ Yes
orientation or gender identity	○ No
	reset
As Describer 2	New Person
<< Previous Page	Next Page >>
Save & Return I	Later

Page 20 of 20

Future needs		
What expectations do you have for this child in the future?	Expand	
What concerns do you have for this child in the future?	Expand	
Thank you for completing our survey!		
Public reporting burden for this collection of information is estimated to average 20 minutes, including completing and reviewing the collection of information. An agency may not conduct or sponsor and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road NE, MS D-74, Atlanta, GA 30333: ATTN: PRA (0920-22CL).		
<< Previous Page  Save & Return La	Submit	